

Tolerance of food intolerance

A socio-cultural study of parents who have investigated food intolerance with
their families

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The research for this thesis received the approval of the Monash University Standing Committee for Ethical Research on Humans. (Approval reference: CF09/3566-2009001923)

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Table of Contents

Declaration	ii
Acknowledgements.....	iii
Table of Contents	iv
List of Figures	vii
List of Appendices	vii
Glossary	ix
Abstract	xi
Introduction	1
Literature Review	6
Health and Learning.....	6
Individual Nature of Food Intolerance.....	7
Elimination Diets	9
Testing Approaches and Scales	17
Parent’s Role	19
Teacher’s Role	22
Contexts for Learning.....	24
Socio-cultural Contexts	26
Conclusion.....	29
Methodology	32
Significance of this Study	34
The Procedure and Research Design	34

Analysis	36
Results	40
Food and Behaviour	41
Diet first	41
Discipline approach.....	42
Real child	43
Friendships	43
Anxiety	44
Over reactions.....	44
Sleep issues	45
Food and Learning	45
Language	46
Reading and writing	46
Concentration	47
Classroom behaviour	47
Parental Values.....	48
Feelings of happiness.....	48
Instinct	48
Guilt.....	49
Beliefs about medication	49
Autism	50
Conclusion	50
Discussion Employing Grounded Theory.....	51
Food and Behaviour	51

Diet first	51
Discipline approach	52
Real child	53
Friendships	54
Anxiety.....	55
Over reactions	55
Sleep issues.....	56
Food and Learning.....	57
Language.....	57
Reading and writing.....	59
Concentration.....	59
Classroom behaviour.....	59
Parental Values	60
Feelings of happiness	60
Instinct	60
Guilt	61
Beliefs about medication.....	61
Autism.....	62
Whole answer.....	62
Discussion Employing Planes of Focus.....	63
Personal Plane.....	63
Interpersonal Plane.....	65
Community Plane.....	69
Health system.....	69
World wide web	71

Education system	72
Conclusion	73
Justification for Using Two Discussion Approaches	75
Limitations and Implications for Further Research.....	77
Conclusion.....	82
Personal Conclusion	86
References	90
Appendices.....	98

List of Figures

Figure 1 – Gender and ages of the participants children.....	41
Figure 2 –Rogoff’s (1995) planes of analysis.....	64

List of Appendices

Appendix A Transcript of interview with Abbey.....	98
Appendix B Transcript of interview with Bernice.....	109
Appendix C Transcript of interview with Camille	120
Appendix D Transcript of interview with Donna	128

Appendix E Explanatory Statement and Consent Form.....	135
Appendix F Journal prompting questions	140
Appendix G Interview questions	141
Appendix H Interview questions based on journal responses.....	143
Appendix I Ethics approval.....	146
Appendix J Table of alternative therapies and resources used by participants	148

Glossary

Challenges - when suspect food groups are reintroduced back into the diet one at a time, following an elimination diet. The food group is introduced for a certain amount of time, if no reaction occurs then another food group can be introduced. If there is a reaction then the food group is eliminated again, and when symptoms have eased, another food group can be reintroduced.

Elimination diet – a diet which removes all suspect food groups and reintroduces them as part of a challenge process.

Failsafe diet – based on an elimination diet developed by Royal Prince Alfred Hospital (RPAH) in Melbourne, now known as The Alfred hospital. It includes foods which are low in salicylates, amines, glutamates, and artificial additives. A diet that is low in all these food chemicals is called a failsafe diet.

Feingold diet – an elimination diet developed by a pediatrician, Dr Ben Feingold, in 1975. It is low in salicylates and artificial food additives. Dr Feingold suspected that these were the main foods chemicals responsible for causing hyperactivity in children.

Few foods diet – a restricted diet which includes two sources of meat, carbohydrate, fruit, and some vegetables, which are chosen based on the tastes, cravings and suspected intolerances.

FODMAP diet – a diet low in Fermentable Oligosaccharides (eg. fructans and galactans), Disaccharides (eg. lactose), Monosaccharides (eg. fructose) And Polyols (eg. sorbitol). It is suitable for people who are not able to properly absorb these molecules and have bowel related symptoms.

Food intolerance – describes the condition of a person who has difficulty digesting certain foods or food groups causing stress to the body. This stress can manifest itself in a number of different ways including stomach problems, migraines, irritability and hyperactivity. Symptoms

may take several days or weeks to appear depending on the sensitivity of the person. A person may not be aware that their food intolerance is causing certain symptoms until they go on an elimination diet and reintroduce suspect foods through challenges.

Food allergy - can be identified soon after the offending food has been consumed or touched. Symptoms are observable and may include rashes, redness, swelling or difficulty breathing. In extreme cases of allergy, an anaphylactic response may occur, where the airways are compromised by the body's overreaction to the offending substance.

Off-diet - when a person eats food they **cannot** tolerate, they are eating 'off-diet'. A person is 'off-diet' if they are eating **lots** of foods to which they are sensitive. This is how one may describe their diet before they learned about their food intolerance.

Oligoantigenic diet – a meal plan consisting of water, several vegetables, two sources of meat, carbohydrates, and fruits, used to determine food intolerance in individuals. Initially foods eaten regularly are avoided and reintroduced as a challenge once symptoms have eased. If there is no improvement in symptoms, then different foods are substituted until improvement is achieved.

On-diet - when a person eats food they **can** tolerate, they are eating 'on-diet'. A person is 'on-diet' if they eat **less** of the foods to which they are sensitive. It is often the diet a person will choose after they learn about their food intolerance.

Abstract

This study focuses on parent perceptions about food, behaviour and the learning of their young children in a sociocultural context. It aims to provide further information to educators, parents, teachers and care providers of children, particularly in the pre-school years, about families who have investigated food intolerance and its possible role in early childhood learning.

The four participants of this study are members of the Food Intolerance Network (FIN), an online discussion forum for people investigating food intolerance issues. Participants self selected to be a part of this study. They completed a journal to record their experiences with food intolerance and then participated in a follow up interview to further expand on the arising issues. All the participants are female and are mothers of either one or two children. The families all reside in Melbourne. In two of the four families, both the parents and children investigated food intolerance. The children were the main focus of the investigation in one family and the mother investigated food intolerance for herself in the remaining family.

When the participants discovered food intolerance in their families through an elimination diet, they reported changes in a range of behaviours, including sleep, aggression and anxiety. The parents from this study believe diet can improve their child's ability to concentrate and learn. In addition to this, positive relationship changes were recognised among family members and friendship groups. Some of the parents felt that their children were less likely to over react to situations and some felt that they had discovered their "real child" through discovering the foods their child could not tolerate.

Happiness was how the participants described the feelings of themselves and their children, though there was a sense of frustration as they told stories about the teachers, child care workers and extended family members who they found unaccommodating. Participants found the FIN particularly supportive while they made changes to their family diet, as it provided them with a group of people who had an understanding of food intolerance issues.

Overall participants reported positive experiences through learning and managing food intolerance issues relevant to their family. Health, behaviour and learning were some of the

benefits perceived by parents when family members ate foods which they were able to tolerate. They found that their interpersonal relationships as a family were better and they were able to find the support they needed through the FIN. The hardships identified by the participants related to the difficulty communicating food intolerance issues with their extended families and they felt misunderstood by those responsible for the care and education of their children at schools and child care facilities.

Introduction

Healthy eating has always been a part of my life. I was raised in a family with homemade food as the norm including homemade wholemeal bread. My school lunch would consist of a homemade wholemeal salad sandwich with sprouts, homemade fruit and nut cake, and an apple. My friends would have bought white bread sandwiches with coloured sprinkles, shop bought cakes and chocolates. My lunch was unusual in the 1980's because it was the only one of its kind amongst this group. My teachers would use my lunch as an example of 'healthy' foods. Their aim seemed to be to encourage others to bring healthier foods for their school lunch. Though on this diet, I missed many days and even weeks of valuable school time due to sinusitis, tonsillitis, hayfever and asthma. I struggled to think clearly and perform at my best. Since the family diet was mostly vegetarian, in my teens I chose an exclusively vegetarian diet and my goal was to have better physical health. Despite my varied plant based diet, I continued to have many persistent health issues and frequent absences from school. I was told that I could grow out of my sensitivities which caused my hayfever and asthma, however I did not, and as an adult my symptoms seemed to worsen.

In 2005, when I was in my thirties, I found a book in the local library that connected asthma and food suggesting that asthma symptoms could be caused by certain foods. After reading it and hearing about food intolerance for the first time, I consulted a dietician in 2006. My dietician felt there was a potential that certain foods could be causing my symptoms and guided me through how to undertake an elimination diet. I was required to keep a food diary which listed all the foods I ate and a score for my symptoms in a corresponding column. I eliminated all suspect food groups from my diet for two weeks or until I had no asthma symptoms. Then each food group was reintroduced, one at a time, as a challenge. If my asthma did not reoccur, then I could continue with another challenge. If my asthma did reoccur then this food group was considered suspect to causing my food intolerance. I had to stop the challenge, wait until symptoms eased before I could go on with challenging the next food group. Once all the food groups had been challenged, I took my food diary to my dietician for a review. My level of sensitivity was determined by how long it took for my symptoms to occur after the challenge had started.

Through my research, I discovered that there were three main natural food chemicals which could

cause sensitivities, amines, salicylates and glutamates. Some people could be sensitive to one or all of these natural food chemicals. I discovered that I was sensitive to amines and glutamates. My dietician guided me through identifying the offending foods in my diet and finding appropriate alternatives. I also learned about various food additives in foods. My sensitivity was not like a food allergy where symptoms may be life threatening. I experienced persistent and sometimes severe hayfever and asthma. Through learning about foods high in amines or glutamates and avoiding certain food additives, I have been able to manage my diet to stay free of my symptoms for over six years. It was literally a life changing experience. No more medication, no more sick days and I could finally enjoy good health every day. As a result of my physical health improving, I could feel my concentration improving too. I could think more clearly, remember more easily and was generally more motivated to learn. The physical and mental health benefits that I gained, sparked my curiosity as to the experience of others who had investigated food intolerance. I began to wonder whether other people who had investigated food intolerance had noticed a difference in other aspects of their health too.

My personal experience is important to this study for several reasons. Research around food intolerance tends to be focused on behavioural outcomes, particularly hyperactivity. The personal benefits that I gained from eating a diet that my body tolerated, were not related to hyperactivity. I was not a particularly disruptive student, however I believe I could have achieved more if I had a diet that was healthy for my body. I believe that I may have been able to achieve better learning outcomes if I had been aware of my food intolerances earlier. Even though my teachers saw my diet as 'healthy', and my mother provided me with highly nutritious foods, there were some foods that my body did not tolerate and I believe that it affected my ability to learn at my best.

Becoming a parent broadened my personal experience with food intolerance. I was able to see the difference that food made to my children. I saw nappy rashes disappear and then reappear when certain foods were eaten with my son. I saw restless and sleepless nights increase and decrease which I could link to what my daughter had eaten. With my son, I tried avoiding foods that I knew I did not tolerate, thinking that they could be triggers for him with a certain amount of success. When a similar diet did not seem to help my daughter, we both avoided wheat for a day (as I was breastfeeding) and to my amazement she slept all night. I sought the expertise of my dietician to assist us in undertaking an elimination diet to determine whether she was in fact intolerant to wheat. We experienced similar reactions of painful and unsettled nights every time

wheat was reintroduced as a challenge. I also observed a similar reaction when my daughter ate rye biscuits and that is when my dietician suggested that she could be intolerant to fructans which is found in wheat, rye and garlic. This was confirmed with further challenges.

Realising the individual nature of food intolerances, I further investigated my son's diet and found through elimination diets that a low dairy and low Glycemic Index (GI) diet was best for his body. My experiences again highlighting to me that there is not one diet that could cater for all food intolerances. My son has heightened anxiety issues when he eats dairy or sugar, while my daughter has chronic stomach pains that disturb her sleep if she has fructans (found in wheat, rye and garlic) or galactans (found in legumes). My children have a similar genetic makeup as they have the same parents, yet they have different symptoms from different food intolerance issues and function at their best avoiding different foods.

As a teacher, noticing the changes that diet made to my family made me wonder about the students in my class and whether some of them might benefit from eating a diet that their body could tolerate more easily. One parent, whose son I had previously taught, spoke to me about her son's success on the Failsafe diet. I shared my story with her and soon I heard success stories from other parents at the school I was teaching at, about students who were eating foods to which they were tolerant. These parents reported a range of improvements in their child's physical health, behaviour and tolerance towards others. Many of the parents felt that their improved behaviour gave them better learning opportunities. The potential wider implications of food intolerance in learning and behaviour occupied my thinking. I began to wonder whether a decrease in artificial food additives could impact on student learning, or whether food played a role in learning and behaviour.

During 2008, some of the parents at my school organized for Additive Education to give a presentation to interested people in our school community. Additive Education runs information sessions in schools, kindergartens and other community groups about the possible negative effects of the food additives that the Royal Prince Alfred Hospital (RPAH) elimination diet excludes. They are also connected with Sue Dengate, an author and advocate for food intolerance issues. She has set up the Food Intolerance Network and the Fed Up website which gives current

information about artificial food additives and intolerance issues.

At the start of my research journey, I undertook a pilot study with six of the attendees, all of them mothers and three of them were also teachers. I conducted interviews to ascertain the values and beliefs these parents had towards food additives. I asked them what they had learned from the session and whether they had implemented any changes in the family diet.

Each participant, in this pilot study, was asked various questions about their beliefs and values in regards to food, children's behaviour and learning. All the participants expressed that they believed there was a link between food and the ability to learn. This belief seemed to come from their personal experiences. One participant talked about how her mother baked their food when she was growing up and how packaged food was not commonly used then. Another participant said that "if you have a clear body then you might be able to learn better". A mother of two said that, "I think the (children) do really well because I am conscious of what they are eating". She felt that she could see "minds wandering if they don't have a substantial diet". One teacher could see the intellectual effect of a student with celiac disease who did not follow a strict diet. A different teacher believed that too many preservatives in their students' diets influenced their concentration levels and behaviour. And another teacher felt that it was "not just what they eat but when and the quantities they eat" that influenced one's ability to learn. Several participants expressed how they felt breakfast was connected to learning. One teacher felt that she could tell the difference in the students who had breakfast and those who did not.

A finding of this pilot study was that many of the parents shielded their children from the dietary changes they had made, with some making up stories rather than explaining their choices and beliefs. One of the six participants explained that they wanted their children to learn to self-regulate how much they ate of certain foods, though they had not talked about their beliefs about food additives with them. From this, I wanted to understand more about how food intolerance is managed in families and to investigate the seemingly absent role of the child in food choices. This led to my desire to further explore the socio-cultural factors associated with families who investigate food intolerance.

My own beliefs have changed since I embarked on this research journey. I started wanting to understand more about food additives and their effects on children and then I discovered the individual nature of food intolerance and the various types of foods which can cause differing or similar symptoms in people. This led me to want to find out more around the bigger issues of food intolerance, such as how families managed food intolerance and the socio-cultural influences. Now I have a desire to understand more about the values and beliefs of parents in regards to food, behaviour and learning. This desire has led to the undertaking of this study and enabled further exploration of food intolerance issues.

Literature Review

My experience as a person with food intolerance drove my passion to learn more, read more and discover more about what had been researched in the area. The literature around the topic of food intolerance spans across several disciplines, in particular health, education and psychology. This chapter presents an overview of the beliefs, values and assumptions found in the literature within each of these disciplines, while recognising their interrelatedness.

This review will consider a range of themes which emerge from the literature as pertinent to this study including health and education, while explaining the individual nature of food intolerance. Examples of elimination diets and double-blind placebo trials are outlined. Beliefs of the governing bodies which regulate food standards both overseas and in Australia are discussed. Behaviour scales used in the research are described and various contexts are explored including the learning contexts and socio-cultural contexts.

Health and Learning

Health is a complex issue dependent on cultural, social, geographical, economical, political and individual influences. Themane et al. (2003) believed that socio-economic status and the learning environment are some of the factors which have a role in the relationship between health and educational achievement. A review of the research around nutrition and cognitive development conducted by Bryan et al. (2004) acknowledged that, “a major limitation to forming conclusions from cross-sectional and longitudinal studies is that one cannot be confident that the relationship between undernutrition and cognitive performance is an independent factor and not due to other confounding factors” (p. 296). Bryan et al. also went on to say that despite the difficulties in isolating these interrelated issues, nutrition is an important factor to investigate because it “can be modified in order to optimize cognitive development” (p. 295).

The relationship between nutrition and cognition has been established through studies which included children with poor nutrition (Bellisle, 2004; Pollitt & Matthews, 1998). A study on breakfast and cognition by Pollitt and Matthews (1998) found that children who were “nutritionally at risk” (p. 813s) showed a more pronounced effect on their cognition and learning when they skipped breakfast. Bellisle (2004) found that the effects of poor nutrition in children

are more evident and stated, “the clearest effects of nutritional manipulations on cognitive efficiency and behaviour are obtained in young people with poor nutritional status” (p. s230).

A longitudinal study, exploring the connections between health and education, was conducted in South Africa by Themane et al. (2003). They found a positive relationship between nutritional status and educational achievement in over one thousand children living in rural areas. The researchers concluded from their findings that “there is a very real and necessary place for health at the table of policy makers in education when an aim is academic improvement” (Themane, 2003, p. 642). This study established a relationship between health and education suggesting that by improving the nutrition and health status of students, better academic achievement could be attained.

Improved health can be achieved through a nutritious and balanced diet. “Good regular dietary habits are the best way to ensure optimal mental and behavioural performance at all times” (Bellisle, 2004, p. S227). Balance and moderation are key concepts in relation to health, behaviour and cognition. Bellisle states that:

“Encouraging the intake of a varied diet that includes numerous foods of good nutritional content, according to sound meal pattern (with regular intake of a hearty breakfast and perhaps nutritionally valuable snacks), seems the optimal strategy to make sure that young people will have the best possible behavioural and cognitive functioning”(p. s231).

It is widely assumed that natural foods are healthy for everybody, but this is not necessarily true in terms of food intolerance or allergies. A person may consume presumably healthy foods unaware they may have a food intolerance exacerbating their feelings of ill health. Cuthbertson (1989, p. 53) states, “all foods can contribute to health, if used as part of a mixed diet; conversely, all foods can cause ill health if consumed unwisely”. A person unaware of their food intolerance issues may consume foods which could worsen their health issues.

Individual Nature of Food Intolerance

The individual nature of food intolerance makes scientific studies difficult as one substance is not likely to produce symptoms in all participants. Egger, Stolla and McEwen (1992) had sixty two

percent of their child participants respond to the oligoantigenic diet, as their symptoms were reduced. It included water, several vegetables, two meat, two carbohydrates and two fruits. The diet was tailored according to the tastes of the child, although foods which the child particularly craved were excluded as they are likely to be suspect foods of intolerance. In an earlier study by Egger, Carter, Graham, Gumley & Soothill (1985) of 76 children who were on the oligoantigenic diet, over 80 percent of the participants improved on the diet, with 27 percent achieving a normal range of behaviour using the Conners (1980) scale. In the study “48 foods were incriminated” (p. 540) producing reactions in varying degrees. Food stuffs which caused reactions in the highest percentage of participants included colorants, preservatives, cow’s milk, chocolate, grapes, wheat and oranges. While food additives commonly provoked reactions in the participants, “no child reacted to preservatives and colorants alone” (Egger, et al., 1985, p. 544). Removing food additives alone from a child’s diet may not show a significant improvement in symptoms if there are other factors, such as foods to which they are sensitive still in their diet. As Rapp (1991) describes, “if you have ten pebbles in your shoe and you remove one, you will still limp” (p. 166).

While hyperactivity is often the focal symptom in research related to food intolerance in studies by Boris & Mendel (1993) and Conners, Goyette, Southwick, Lees & Andrulonis (1976), there are other symptoms which can often be overlooked. While some children become overactive after ingesting foods to which they are sensitive, other children become lethargic, moody, emotional, or show other conduct disorders (Egger, et al., 1992). According to Rowe (1988), children who have passive symptoms related to food intolerance are excluded from trials which include children “on the basis of ‘attention deficit’ alone” (p. 147).

Breakey (1997) suggests that by considering other symptoms of food intolerance, many of the perceived inconsistencies in the research would be eradicated. Food items which can cause significant health or behavioural issues for one individual may have no adverse effect for another. Schnoll, Burshteyn, & Cea-Aravena (2003) explain that, “food sensitivities are highly individualized in terms of the offending food and in the behavioural responses that are provoked” (p. 72). Rowe (1988) describes how the two out of eight children who reacted to colourings in her study, revealed different sensitivities in “both severity and duration of effect” (p. 147). One received a lower dose of colouring with, “more marked behaviour changes” which persisted for three and a half weeks (p. 147). The other participant responded on a higher dosage of colouring and symptoms lasted for three to four days.

“The lack of response to challenges in previous studies may have been due to an insufficient dose of dye” (Swanson & Kinsbourne, 1980, p. 1485). David (1993) explains how small quantities of food can invoke serious symptoms immediately, and in other people large quantities need to be consumed over a period of time to provoke a response. Some food intolerance symptoms are not easily observable and may not be apparent until a certain amount of the chemical has accumulated in the body (Loblay & Swain, 1986).

Elimination Diets

According to Sue Dengate (1997), an elimination diet followed by challenges is the preferred way to determine an individual’s food intolerance. An elimination diet removes all suspect food groups from the diet. Suspect foods include natural foods containing salicylates, amines, glutamates, or fructose. Challenges reintroduce suspect food groups back into the diet. Each food group is introduced separately, allowing time to see if the food is tolerated or if there is an adverse reaction.

Boris and Mandel (1993) agree that elimination diets which remove food groups are more effective than diets which avoid individual foods. Avoiding individual food items may not show an effect as other foods from the same food group may remain in the diet. The body would continue to react to the residual foods in the diet, masking any clear indication of food intolerance.

Williams, Cram, Tausig & Webster (1978) found that trials were most successful if they started with an elimination diet as an elimination diet gives the individual a baseline to compare their reactions to various foods.

Dr Ben Feingold (1975), an American pediatrician, was one of the first to suggest a link between food additives, poor behaviour and learning difficulties in children. A diet low in salicylates and artificial food additives became known as the Feingold diet, named after the founder Dr Feingold (1975). Suspecting a link between the natural food chemical salicylates, found in some fruits and vegetables, and hyperactivity in children, he treated his patients with hyperactivity and learning difficulties through eliminating salicylates and artificial food colours from their diets. Based on his investigations and clinical experience, he discovered that eliminating certain foods could improve the learning ability and behaviour in many of his pediatric patients. Connors’ (1980) reported that children who followed the Feingold diet experienced, “a steady, gradual increase in self-control

and a marked improvement in schoolwork” (p. 10).

The Feingold diet was further developed to create a Low Additive Low Salicylate (LALS) diet as used by Australian researchers Breakey, Hill, Reilly and Connell (1991). It excluded artificial additives, preservatives, natural foods high in salicylates, monosodium glutamate (MSG), chocolate, natural colours, flavours, strong aromatic smells, amines and yeast spreads. Participants in their study were referred to a Queensland clinic for diet therapy. Breakey et al. (1991) found that 132 of the 136 children in the trial of this diet reacted to at least one of the eliminated foods.

To explore Feingold’s (1975) claims that hyperactivity can be caused by certain foods, Harley, Ray, et al., (1978) undertook a study which involved 36 school aged boys with significant hyperactive tendencies. They used classroom, laboratory and parent observations. Parents observed positive changes in behaviour when their children were on the Feingold diet, whereas there was no dietary effect in the laboratory or classroom observations. Harley, Ray, et al. (1978) concluded that the cause-effect relationship between behaviour and the Feingold diet was “overstated” (p. 827). As part of this study there was a small sample of ten pre-school children. The parent observations for this age group suggested that their behaviour improved on the Feingold diet. This finding was described to be of “considerable interest and potential significance” (Harley, Ray, et al., 1978, p. 825), though it was a small sample size and lacked teacher observations used for the school aged participants.

Double-blind placebo trials have been used in several studies to substantiate Feingold’s (1975) hypothesis. Double-blind placebo trials measure the effect of substances. Participants are given an active or a non-active (placebo) substance without them knowing which they are given. In the case of artificial food additive trials, food additives are removed from the diet and then reintroduced using active and placebo substances. Active and placebo substances are disguised to look the same and are given in an order known only to the research administrator. A baseline of behaviour is recorded before the trial begins. Behaviour is then monitored and recorded by the nominated observers, after both the active and placebo substances have been consumed by the participant. The participants, observers and parents do not know when the active or the placebo has been taken so the observations are not biased by their expectations.

Thorley (1984) undertook a double blind trial to look at the effects of artificial food colours on ten intellectually challenged children. They found no convincing adverse effects of artificial food colours on the behaviour of these children. David (1987) conducted double-blind challenges of a readily used artificial colour, tartrazine, with a commonly used preservative, benzoic acid, on children whose parents claimed that they had adverse behavioural changes when these additives were consumed. Neither the parents or nurses noted any change in the behaviour of the 24 children in the study and David (1987) concluded that:

“This study does not exclude the possibility that there are rare children who have purely behavioural effects as a result of ingestion of additives such as tartrazine or benzoic acid. It does show, however, that parent’s beliefs in the behavioural effects of tartrazine or benzoic acid are often groundless and are unreliable” (p. 121).

David’s (1987) research was conducted in a hospital setting and this could give reason as to why the study was not able to objectively validate the claims of the parents. The researcher admitted that using a hospital setting was a drawback considering “it is well known that children often behave differently in new or unfamiliar situations” (David, 1987, p. 121). Children are more likely to be less inhibited in their home environment with familiar people around them. Even though certain behaviours were not observed in this study, it is possible that parents observed behavioural reactions in their home environment and their accounts need not be discredited.

Two out of a total of 24 parents from David’s (1987) study refused to resume a ‘normal’ diet that included these food additives. Most children from the study resumed a ‘normal’ diet after the trial and reportedly had no adverse reactions. Because the participants had been on low additive diets from one month to three years prior to the trial, Rowe (1988, p. 145) suggests that it would be difficult to assess if there had been any “unconscious reduction in the intake” of foods containing additives, especially as they are “readily avoidable” (Egger, et al., 1985). The parents may not have been aware of how much of the additives they avoided and it would be hard to ascertain how much or little of these additives parents actually began to include back into their ‘normal’ diet after avoiding them for this length of time.

In an earlier study, David (1985) expressed his belief that it is “essential” for parents to consult a dietician when doing an elimination diet with their children (p. 29). Other researchers also believe

in the importance of consulting with a dietician, including Dengate (1997) and Egger, et al. (1992). David (1987) states, “parents are usually but not always right about a child, and they cannot be objective. While popular belief has it that additives may have harmful behavioural effects, objective verification is required to prevent overdiagnosis” (p. 122).

Conners, et. al. (1976) conducted a double-blind crossover trial on fifteen school aged children with hyperkinetic symptoms, these manifest as high levels of activity. Teachers observed significantly less hyperactive behaviours when the children were on the elimination diet and more when they were on the control diet. Parents did not observe the same differences. The researchers felt that this could be because of the different expectations of children at school compared to home. The researchers from the Bateman, et al. (2004) study believed that “parental ratings might be more sensitive to changes in behaviour in that parents experience their child’s behaviour over a longer period of time, in more varied settings and under less optimal conditions” (p. 510).

A double-blind placebo trial was conducted by Harley, Matthews & Eichman (1978), on nine school aged boys who showed the most improvement from the elimination diet during phase one of this study. During the study all the food was provided for the entire family with challenges and placebos disguised in candy bars and cookies during phase two. The participants in the study consumed half the average daily intake of food colours as a challenge. Mothers, fathers and teachers completed observations in different settings. The aim of this study was to test Feingold’s (1975) hypothesis that fifty percent of children with hyperactive tendencies improved on his elimination diet. The hypothesis was not supported by the findings in this study (Harley, Matthews, et al., 1978). While in their study behavioural changes were not observed in school aged boys, Harley, Matthews, et al. (1978) believed that there was a need for further research in regards to preschool aged children to explain the parental reports of behavioural changes in this age group. This belief was based on the findings by Goyette, Conners, Petti and Curtis (1978).

Goyette, Conners, Petti and Curtis (1978) conducted two studies. One involved sixteen children with hyperactive tendencies who had previously responded to an elimination diet and averaged eight years of age. They found that three of the younger children in the group had more pronounced responses to the food dyes, and retested these children in the laboratory. Their performance was measured each hour for three hours and behaviour tended to worsen after the

first hour for all three participants. This finding led to a second experiment recruiting eight younger participants with an average age of five years. This study showed significant effects,

“suggesting that artificial food dyes do indeed act to impair and disrupt the behaviour of the children. The authors believe these data firmly establish that artificial colors may be particularly disruptive to younger children and that it will be important to delineate characteristics of those who are sensitive to the dyes and to examine the possible mechanisms whereby these chemicals act on the CNS (Central Nervous System)” (Goyette, et al., 1978, p. 40).

One of the earliest studies investigating the various reactions that food can have on the nervous system of children was conducted by Shannon (1922). They documented eight case studies investigating the cause of symptoms ranging from nervousness, asthma, eczema, irritability and sleep difficulties. After assessing each case the researchers performed prick tests which required the body to be exposed to various foods and proteins on areas of the skin which had been pricked. Swelling at the sight of the prick determined which foods or proteins caused a reaction and the specific offending foods for each individual were removed from the diet. Once the offending foods or proteins were avoided in the diet, symptoms abated.

While diet can improve physical symptoms, Kolata (1982) reports that there is biochemical evidence in laboratory animals that suggests diet can change behaviour through various neurotransmitters in the brain. This suggests that food can change the messages that the brain sends to the body. However, it was also reported by Kolata (1982) that “the effects on human behaviour are subtle” (p. 1209).

Setting out to “explore a method for assessing dietary interventions capable of determining each individual’s response to food additives” (p. 241), Salamy, Shucard, Alexander, Peterson & Braud (1982) designed a study to measure “autonomic and central nervous system activity” (p. 242). There were eight participants with hyperactive tendencies in the study. Their siblings without hyperactive tendencies were the control group. The participants were on the Feingold diet prior to the experiment and were challenged with an experimental and placebo drink. Only the experimental drink contained artificial colours, whereas both drinks contained sugar. An “absence” (p. 244) of physiological changes was observed in the control group of children who did

not have hyperactive tendencies and they found that there was an “abundance” (p. 244) of physiological changes in children with hyperactive tendencies after they consumed both the placebo and experimental drink. The possibility was raised by Salamy, et al. (1982) that the sugar may have caused the physiological changes, but they add, “it is also conceivable that some hyperactive and some control children will respond to dietary substances and some children in each group will not” (p. 244).

Schnoll, Burshteyn and Cea-Aravena (2003) point out other possible reasons for why participants have a positive response to the Feingold diet. They suggest that when following the Feingold diet, processed foods are reduced and this would also reduce the participants’ intake of sugar. While sugar has often been associated with hyperactivity by parents, Wolraich, Wilson & White (1995) found that sugar did not necessarily have a physiological effect as expected by parents, though it could not be ruled out that sugar could have an effect on some children. An artificial sweetener was used as a placebo in this study. Artificial sweeteners contain chemicals which can cause significant reactions common to food intolerance in some people, and are among the additives avoided in most elimination diets. This could have influenced the outcome of this study as children may have reacted to either the sugar, artificial sweetener, or both. Using a natural sweetener as a placebo in future studies may eliminate this possibility.

Further reviewing artificial food additives, paired association tests were used by Swanson & Kinsbourne (1980) on forty children, where half the participants were considered hyperactive, the other half were not. All children had an artificial food additive free diet for five days and were challenged with artificial food additives. The results suggested that “a large dose of food dye blend decreases attention span in hyperactive children” (p. 1486). The performance of the non-hyperactive group was not affected when challenged by the artificial food additives.

Bateman et al. (2004), Boris and Mandel (1993), McCann, et al. (2007), Pollock and Warner (1990), and Swanson and Kinsbourne (1980), all conducted studies which eliminated artificial food additives from the diet and then used a double-blind process to reintroduce foods to determine any adverse health and behavioural effects. McCann et al.’s (2007) study suggested that food additives exacerbate hyperactive behaviours in children, while Pollock and Warner (1990) found that a mixture of artificial food colours can produce a small yet significant negative behavioural

change in children. Bateman et al. (2004) found an adverse effect of food colourings and preservatives on the behaviour of three year olds.

In the study by Bateman, et al. (2004), 397 preschool children were selected from the general population of the Isle of Wight in the United Kingdom, to participate in a double-blind trial, challenging artificial food colourings and benzoate preservatives. Children ate a diet which eliminated these food additives from their diet for a week prior to the commencement of the three week trial. Bateman et al. (2004) concluded, “Our study has shown that the effect of food additives on behaviour occurs independently of pre-existing hyperactive behaviour or indeed atopic status” (p. 510)

Other diets which have been researched include the “few foods” diet. It was used by Carter, Urbanowicz and Hemsley (1993), and as the name suggests it limited the children’s diets to a small number of foods for several weeks. The parents of fifty-nine of the seventy-eight participants (76%) revealed a “worthwhile improvement in behaviour” (p. 566). They concluded that:

“observations of change in behaviour associated with diet made by parents and other people with a role in the child’s care can be reproduced using double blind methodology and objective assessments. Clinicians should give weight to the accounts of parents and consider this treatment in selected children with suggestive medical history” (Carter, et al., 1993, p. 564).

Three quarters of the participants in the study by Rowe and Rowe (1988), reported improvement in behaviour when artificial additives were removed from the diet and a “deterioration in behaviour” (p. 693) when artificial additives were introduced. Rowe and Rowe (1988) found that there were significantly different symptoms in the children aged between two and six, compared to the seven and fourteen year old age group. The younger participants had symptoms like constant crying, tantrums and severe sleep disturbances, while the older participants were irritable, whiney and unhappy.

Studies with children from a range of age groups found clear conclusive results in children under nine or in the preschool age group (Bateman, et al., 2004; McCann, et al., 2007). They found that food additives exacerbated hyperactive behaviours, particularly in preschool aged children. Food

additives were also found to have a significant adverse effect on the behaviour of three year old children by Breakey, Hill, Reilly & Connell (1991). They reported that “an age effect was evident” (p. 92) in their study on a low additive and low salicylate diet. In this large sample of over five hundred children, they observed that “younger children have earlier, clearer reactions” when foods were reintroduced into the diet (p. 92).

Reduced activity and inattentiveness was found in three year olds across the general population in Bateman et al.’s (2004) study after removing artificial preservatives and colourings from the diet. They stated that,

“(W)e believe that this suggests that benefit would accrue for all children if artificial food colours and benzoate preservatives were removed from their diet” (Bateman, et al., pp. 510-511).

A study on food additives conducted in the United Kingdom by McCann et al., (2007) found “strong support for the case that food additives exacerbate hyperactive behaviours (inattention, impulsivity, and overactivity) in children at least up to middle childhood” (p.1566) in the general population. Prior to this study, research that involved food additives was in the main based on clinical trials (Breakey, et al., 1991; Carter, et al., 1993; Egger, et al., 1992; Pollock & Warner, 1990; Rowe & Rowe, 1994), which meant that those who participated were already seeing a practitioner for hyperactivity or a similar behaviour disorder. The research of McCann et al. (2007) is significant as it was conducted on a representative sample of children from the general population. Participants were not previously diagnosed with hyperactivity or behavioural disorders. The research findings suggested that the adverse effects of food additives were evident in the behaviour of children from the general population.

McCann’s (2007) research was funded by the Food Standards Agency (FSA) in the United Kingdom (UK). Based on the suggested link between artificial food colours and hyperactivity in children from the general population by this research, the FSA (2008) called for manufacturers to voluntarily remove six artificial food colours from food products.

In response to this action taken in the UK, Food Standards Australia New Zealand (FSANZ) (2011) published an article stating that the studies to date, including McCann et al. (2007) provided

limited evidence that artificial food additives effect children in the general population. They stated in the article that they believed Australian children consume a smaller quantity of food additives than children in the UK based on dietary exposure assessments. FSANZ have conducted dietary exposure assessments and estimate that artificial food colours are consumed at levels which are considered safe for the general population. They acknowledge the adverse effects that some children may have to food additives. However they believe that it is a small percentage of the population. Food colours and preservatives continue to be used by Australian manufacturers in breads, yoghurts, pasta, sauces, biscuits, cakes, muffins, pastries, juices, flavoured milks, drinks, confectionery and snack foods.

The European Food Safety Authority (EFSA) has reviewed the McCann et al. (2007) study and concluded that because a mixture of additives was used for the study, that the effects could not be attributed to any of the individual additives (European Food Safety Authority, 2012). Though the Accepted Daily Intake (ADI) for three of the colours were reduced after being independently reviewed and they have begun to reassess all of the forty-five colours permitted in Europe (European Food Safety Authority, 2012). They explain that:

“EFSA is currently reviewing the safety of all food additives which have been approved for use in the EU (European Union), as many additives were initially authorized for use a long time ago and in a number of cases new scientific data have since become available” (European Food Safety Authority, 2012).

Testing Approaches and Scales

McCann, et al. (2007) measured hyperactivity in their study using three different scales to calculate a Global hyperactivity aggregate (GHA). The Conners' scale (1969) is a checklist of 39 symptoms and behaviours using a four point scale. It has been used in many studies measuring hyperactivity even though it was originally designed for teachers to assess the behaviour of children on drug trials. Egger, Carter, Graham, Gumley & Soothill (1985) used the Conners' scale (1969) to determine the change in hyperactive behaviour of participants in their research and it was used in many of the early studies looking at the effects of food intolerance in children (Harley, Matthews, et al., 1978; Swanson & Kinsbourne, 1980; Thorley, 1984). Pollock & Warner (1990) also used this scale in their study and found that food additives did have an effect on behaviour. In this study parents were given the opportunity to make comments alongside the Conners' scale

(1969) and it was found that behavioural changes were not always significant enough for the parents to detect.

Noting the limitations of the Conners' scale (1969), and that it was a tool designed for teachers to measure hyperactivity in children on drug trials, Rowe (1988) developed the Rowe Behaviour Rating Inventory (RBRI) an eight item checklist of behaviours commonly reported by parents. It was to be used in her research on food colourings and hyperactivity. The RBRI includes ratings of over-activity, restlessness, impulsiveness, distractibility, low frustration tolerance, overt aggression, short attention span and sleep disturbance. Including these behaviours in studies related to food intolerance means that children with a food intolerance which manifests as behaviour, will more easily identify the foods to which they cannot tolerate. It acknowledges a broader range of behaviours, resulting in more accurate findings.

Rowe (1988) found that parents described different "common features of behaviour associated with the ingestion of food colourings" and "emphasized extreme 'irritability', 'restlessness' and 'sleep disturbance' rather than those associated with attention deficits" (p.147). Parents of participants in the Rowe study noted an increase in these behaviours when food additives were consumed and a noticeable decrease when food additives were taken out of the diet. "Many parents commented that after the few foods diet phase that their children had become more manageable and more amenable to reasoning rather than less active or better able to concentrate" (Carter, et al., 1993, p. 568).

As the RBRI recognises a broader range of behaviours associated with food intolerance, it was used in Rowe and Rowe (1994). Twenty-four children reacted to artificial colours in the study by Rowe and Rowe (1994) and two of them scored significantly on the Conners' rating scale measuring their hyperactivity levels. "The main behaviour features described and subsequently rated by parents were irritability, restlessness, and sleep disturbance, which were constant across age and sex" (Rowe & Rowe, 1994, p. 697).

Sleep disturbance is one of the many behaviours parents associate with food intolerance (Dengate & Ruben, 2002; Rowe & Rowe, 1994). A parent's strategies for managing sleep are more than just

responses to the environment, they reflect one's beliefs about raising children (Gianotti & Cortesi, 2009).

“The immediate family environment represents the microsystem into which parents bring their own background and development. The family is, in turn, embedded within the wider community and cultural networks of a macrosystem, representing overriding norms, cultural beliefs, and societal values. Although these may vary both between and within different societies and cultures, consistencies in the beliefs, attitudes, and actions of particular social groupings can be identified and can help understand how children's sleep develops” (Gianotti & Cortesi, 2009, p. 850).

Parent's Role

Johnson & McMahon (2008) state that there is more evidence to suggest the importance of the role parents play in a child's sleep behaviour and that it is beneficial for parents to teach their child to self regulate. Another study by Sadeh, Mindell, Luedtke and Wiegand (2009) found that active parent interaction was associated with “shorter and more fragmented sleep” in infants and that interventions conducive to developing independence were associated with “extended and consolidated sleep” (p. 60). Sleep deprived parents may respond to their children so that they can have more sleep. Williams, Wright and Partridge (1999) suggest that parenting may be a response to their child's behaviour as well as having an influence on it.

Gianotti and Cortesi (2009) suggest that there is an enormous variation in expectation and interpretation of what are acceptable sleeping patterns. “Family and cultural attitudes and beliefs strongly influence whether or not sleeping behavior is perceived as problematic” (Gianotti & Cortesi, 2009, p. 851). One family may see certain sleeping patterns as normal, while another family may believe it is a problem.

The Rowe Behaviour Rating Inventory (RBRI) was used by Dengate and Ruben (2002). They found that irritability was the behaviour most observed in their study measuring the effect of a commonly used bread preservative. The trial was conducted with 27 children whose behaviour showed significant improvement on the Royal Prince Alfred Hospital elimination diet. Dengate and Ruben (2002) added how there were some effects which were suggestive of food intolerance that were not measured by the RBRI including, “loud voice, lethargy, growing pains, stomach

aches, headaches, bedwetting or urinary urgency” (p. 375).

Egger, et al., (1985) suggests that additives “have no-nutritional value” (p. 544) and can be avoided without negatively impacting on diet. It was concluded by Carter, Urbanowicz & Hemsley (1993) that parents who notice some effects of diet should be given support by medical professionals to explore exclusion diets. Pollock & Warner (1990) stated, “we feel strongly that parents of children with behavioural problems should receive a sympathetic hearing and that their ideas are not dismissed out of hand” (p. 77).

“I certainly understand why professionals are reluctant to embrace any therapy that lacks scientific documentation. But when the therapy is safe (in the case of a child on an elimination diet), such reluctance may not be in the best interest of the patient, the family, or his teachers, who are trying to cope with his hyperactivity on a day-to-day basis” (Crook, 1980, p. 53)

Arnold and Jensen (1995) list many familial, genetic and environmental factors associated with Attention Deficit and Hyperactivity Disorders (ADHD). The heritable and environmental factors which determine parent and childhood behaviour are pointed out by Williams, Wright and Partridge (1999). They also raise the importance of parental mental health on child development. It is suggested by Williams, Wright and Partridge (1999) that modeling the skills required to maintain attention on a task in the home environment can make it easier for children to learn how to attend to tasks.

Another way that a parent can influence their child’s behaviour is through the types of limits and boundaries that they use. Parenting without limits or boundaries can lead to children having behavioural difficulties. Diet can be one indicator of the limits a parent may use with their children.

“Parents who are unable to set consistent limits on behavior may allow their children to ingest more sugary snacks and drinks and also may report more hyperactive or aggressive behavior as a result of permissive parenting” (Rojas & Chan, 2005, p. 126).

While parenting may influence children’s behaviour, Barkely (1985) and Williams, Wright and Partridge (1999) suggest that parenting may also be a response to children’s behaviour. Children

with learning or behavioural difficulties can influence their parent's behaviour. The difficulties associated with parenting a child with behavioural and learning issues can involve more stress, anxiety and effort. These factors change the way a parent makes decisions and deals with their child's behaviour.

In 2009, I conducted a pilot study to look at the beliefs and values of parents towards food additives. Six parents were interviewed about their values and beliefs related to food additives. Each of the participants had attended an Additive Education session and volunteered to talk about their experiences. Most of the parents had begun to make changes to the family diet based on the information they received from the session. Analysis of these interviews, found that these parents had not discussed the dietary changes that they had made to the family diet with their children. One participant told her children that the shop had run out of BBQ chips, when in fact she did not want to buy them because of the artificial additives in them and her belief that the additives were not good for her children to eat. Other parents did not want their children to 'miss out' on things or be seen by others as the 'only one' not having something. One participant said, "I don't want to be a parent who says, "no you can't have that" but went on to say, "we do have treats and they need to learn that if you have that today then that does your quota for the day". Comments such as these suggest a conflict between parental values to provide food they considered 'good', with their need to maintain a positive relationship with their children, and for their child to feel included. Only one parent participant mentioned teaching her child about her beliefs related to diet modification and encouraging self-regulation in relation to food intolerance.

"Diet modification has great appeal for parents, as it adds to their sense of control and efficacy and aligns well with parents' desires to promote a healthy lifestyle for their child" (Rojas & Chan, 2005, p. 118). However it could be argued that many of the options available to manage behaviour disorders such as behaviour management strategies or medication could appeal to parents wanting a sense of control and efficacy. In the pilot study previously mentioned, some of the parents discussed their belief that diet modification could provide health benefits as well as improved behavioural and educational outcomes. Breakey, et al., (1991, p. 93) found that, "dietary intervention is difficult, but where there is improvement, parents report it is better than managing a difficult child".

It was suggested by Cruz and Bahna (2006) that foods without food additives appeal to parents who do not like commercially processed food.

“It also may be easier for the parents to accept the idea that their child’s behavioral problem is due to a dietary factor than to psychosocial issues that are often difficult to evaluate and tackle. The perceived favorable effect of a certain elimination diet might be attributed to the fact that it gives the family a sense of solving the problem and provides the child with substantial attention” (p. 728).

Harley, Matthews, and Eichman (1978) wrote that parents who had concerns related to synthetic substances and additives in food stuffs may be attracted to the Feingold diet because they were not satisfied with other therapies and preferred to seek alternatives to medication.

“The diet may help to reduce the parent’s feelings of guilt or other negative emotions involving their hyperactive child because an ‘outside’ causative agent has now been identified that helps to minimize any threatened experience of blame on the part of the parents” (p. 982).

Teacher’s Role

In a review of thirteen studies which looked at the relationship between diet and behaviour, Breakey (1997) suggests that “parents and teachers monitor different symptoms and that this difference can add rather than detract from results” (p. 192). This difference could be due largely because of the different settings in which they observe the children and both perspectives provide valuable insights.

Contributing factors need to be considered, including the expectation of society, schools, teachers and parents in order to gain a good understanding of why these behaviour disorders exist.

Graham (2006) asks the question, do “the disorders of society create disorders in our children?” (p.2). Individual perceptions of certain behaviours are a factor in determining a diagnosis for behaviour disorders. This makes diagnosis somewhat subjective because, as Graham (2006, p.5) states, “what is bothersome to me might not be to another”. Behaviour is “interpreted differently by different people” (Purdie, Hattie, & Carroll, 2002, p. 66). For research purposes, observers need to be trained to interpret behaviour consistently, and this is known as “inter-observer reliability” (Trochim & Donnelly, 2008, p. 87). Consistency is important when creating a

benchmark, though without training, expectations are individual and subjective, with realistic expectations for one child being unrealistic for another. Rogoff (2003) describes these as “variations in expectations” (p. 6).

There can be variations in what is expected of children by teachers and parents. This may explain why teachers are more likely to be the first to suggest an Attention Deficit Hyperactive Disorder (ADHD) diagnosis, according to a study by Sax and Kautz (2003). Teachers made the first report 46% of the time, parents 30%. Physicians, school personnel other than teachers, and other consultants like psychiatrists and psychologists make up the other 24% (Sax & Kautz, 2003). Graham (2006) believes that one reason teachers may suggest an ADHD diagnosis is so that they do not have to reassess teaching approaches. Another reason may be that some teachers do not understand how different teaching strategies can be used to engage children with attention difficulties (L. Hallowell, personal communication, February 2, 2012).

In many instances medication is used to limit the behavioural symptoms of ADHD. The use of prescription medication to treat Australian children for behaviour disorders has increased dramatically, with dexamphetamine sulfate prescriptions rising 2400% and Ritalin prescriptions rising 620% between 1991 and 1998, according to a study by Mackey & Koprass (2001), with similar figures in the United States (Sax & Kautz, 2003).

Purdie et al. (2002) found that medication does not necessarily lead to greater learning capacity or achievement even though behaviour may improve.

“Stimulants have an effect on attention, concentration, and motivation but no clear effect on academic performance or learning; that stimulants may be used as a ‘crutch’ when implemented in the short term; and that medication treatments may postpone the use of nonpharmacological intervention that may be more effective in the long term” (Purdie, et al., 2002, p. 66).

While medication may abate behavioural symptoms, it may also “result in the child never getting the support and understanding they really need” (Graham, 2006, p. 8).

Contexts for Learning

Much of the research around the treatment of ADHD measures hyperactive behaviours suggesting that, “on-task, in-seat behaviors are necessary for achievement to occur, and once these behaviours are realized then achievement does occur” (Purdie, et al., 2002, p. 72). Medication may give the child the ability to stay in their seat, though some children may still struggle to learn if this is the only strategy implemented. While academically driven curriculums may bring successful outcomes for some children, other children learn better when they are engaged in more active pedagogy. Sax (2001) reviewed the literature of early elementary curriculum in the United States of America and suggests there has been a shift from play-based learning to more academically oriented programs in kindergartens.

In later research by Sax and Kautz (2003) it is suggested that this shift has been paralleled by an increase in the diagnosis of behaviour disorders. They discuss how some children probably need “a more developmentally appropriate curriculum” (p. 173) rather than being prescribed medication to alter the child’s behaviour. They also suggest that future research could examine whether teachers in a more academically oriented kindergarten are more likely to suggest the diagnosis of ADHD than their counterparts using a play-based curriculum.

Smith (1995) researched the influence of play on learning and believes that teachers can enhance the learning in their classrooms through understanding the principles of play. Parents can also help to maximize their child’s potential through understanding the benefits of play according to Smith (1995). It is explained by Smith (1995) that play can “encourage attention to academic lessons and serve as a valued reward for participation in assigned tasks” (p. 21) and aptly states that, “play and playfulness illustrate humanness” (p. 19).

“While the spontaneous play of young children may appear to have no aim, there is often quite a definite aim and direction for the children involved” (Dockett & Fleer, 1999, p. 25). Play has an important role in a child’s development and Dockett and Fleer (1999) believe that this is not acknowledged in the surplus energy theory which suggests that children play to use up their excess energy.

Evans and Pellegrini (1997) refer to the surplus energy theory which is based on the belief that as children are cared for by adults and do not use their energy to meet their physical needs, that they have more energy to expend on play. They suggest that this theory would mean that sitting in a classroom would create a build up of energy in children and that break times are seen as opportunities to release and “use up this superfluous energy” (p. 230).

“It would follow then that at breaktimes we would see children engaged in more vigorous activity designed to gradually release this pent-up energy. It would follow that the longer they had been sitting (inactive) the more energy they would have built up and the greater the need for active play” (p. 231).

The difficulty with this theory, according to Evans and Pellegrini (1997) is that some children continue to play past the point of exhaustion.

“The intensity of activity in their play doesn’t gradually dissipate as one might expect if there is only a certain reservoir of energy to be expended. Quite the contrary. Many children seem to have an endless supply of energy when it comes to playing outdoors” (p.232).

The relevance of the surplus energy theory is discussed by Evans and Pellegrini (1997), and they describe how when children are bored they can begin to fidget or look inattentive. They refer to the “emerging research which suggests that these breaks may contribute in quite unique ways to children’s attention skills and lead to an improvement in their academic performance” (p. 243). The important role in which breaks, such as play time and lunch, provide students with opportunities for social interaction and choice is explained by Evans and Pellegrini (1997). These are potential elements to consider in framing an engaging curriculum. “A progressive politics and a progressive pedagogy transcend reductionistic modes of education that simply transfer an unproblematic body of academic knowledge to children” (Kincheloe, 2002, p. 117).

Speaking of her research into ADHD, Graham (2006) says, “conspicuously absent from the field of investigation, however, is the scene of schooling and the influence that the discourses and practices of schooling might bring to bear upon the constitution of ‘disorderly behaviour’” (p. 1). Graham believes that an ADHD diagnosis is based upon the cultural expectations of schooling

where children with an abundance of energy are expected to sit in seats and write. “If children were still working in the mines at nine years of age their energy levels would be considered a bonus” (Graham, 2006, p. 14).

High energy levels are not considered in a positive light in an educational setting. Teachers need to consider and value the activity levels of their students and accommodate them, yet they are limited with the expectations placed on them to achieve certain educational outcomes.

“Problematically the contribution of changes in schooling demands (as a result of society beliefs) – such as lowering of school entry ages (pre-school costs), increased emphasis on academic learning and seat work (parent pressure on teachers too), pressure for children to learn to read earlier and better, crowding of the curriculum, the shortening of children’s recess and lunch times – barely rate a mention in the myriad of contributing and causal factors being considered in the literature around ADHD” (Graham, 2006, p. 15) .

Graham (2006) suggests that there needs to be research to study the pressure that parents may feel from schools to medicate their children and whether parents are motivated to medicate their children by their fear of school failure. This could further ascertain the role that schools play in the diagnosis of behaviour disorders. Graham also suggests a need to research parent perspectives and the reasons they choose medication over non-medical interventions like better resources and support. This type of research would give a greater understanding of how parents perceive the issues associated with behaviour disorders and various interventions.

Socio-cultural Contexts

While parenthood is universal it is a “highly variable aspect of human behaviour” (LeVine, 1980, p. 17). LeVine (1980) recognizes that “among humans the patterns of child-rearing are not uniform” (p. 17) and states that,

“in the last forty years, anthropologists have shown, with increasingly convincing evidence, that the environments of infancy and early childhood are shaped by cultural values. These values vary widely among ethnic groups and become firmly established in the personal preferences and inner regulations of individuals who seek to reestablish them in the next generation” (p. 17).

Despite the many differences among parents, LeVine (1980) concludes that there are some common goals shared by human parents everywhere. A hierarchy of common goals among parents is described by LeVine (1980), which starts with survival and health, then behavioural capacity for economic self-maintenance, followed by the capacity to maximize other cultural values. He states,

“there is also a natural developmental sequence in this set of parental goals, in that, physical survival and health are normally of greater concern in the first years of life, while the others take precedence after the child’s survival seems assured and his capacities for learning are more conspicuous” (p. 18).

Through analyzing parental goals, motivations also become apparent. “Motives are related to the person’s goals” (Hedegaard & Lompscher, 1999, p.33), and are “generally inherent in the obvious importance and interest of the activity” (Rogoff, Paradise, Mejia-Arauz, Correa-Chavez, & Angelillo, 2003, p. 188).

Hedegaard (2002, p. 63) explains, “the central motive associated with a given activity is not necessarily the person’s motive when entering the activity, an activity is more often than not multi-motivated”. She describes a progression of childhood motives from how a baby first wants contact with caregivers, exploration, followed by play and learning, acceptance of friends, to becoming someone of consequence. It is suggested by Hedegaard (2002) that these motives may also play a part in the way in which parents make decisions about how to parent their children. Understanding parental motives provides insights as to the family values involved in making their decision to either investigate food intolerance or adopt other medical or non-medical interventions for their child.

Family values are transferred from one generation to the next, “but the exact nature of the transmission remains unexplored” (Beach, 1988, p. 210). Values are passed from parent to child in different ways. In some cultures, “young children’s integration in family and community activities allows them to become increasingly deeply involved through their intent participation” (Rogoff, et al., 2003, p. 183). Though “within middle-class families, adults often structure young children’s learning by managing children’s attention, motivation, and involvement in ways that resemble lessons”(Rogoff, et al., 2003, p. 188). The way in which families teach their children about food

preparation may lead to an understanding of how their family values are acquired by the next generation.

“Episodes of parent and child conflict and resistance demonstrates how power relations are played out on a daily basis” (Grieshaber, 2004, p. 123) , including during the common rituals and routines of mealtimes which can be “sites of resistance” (p. 144), a time of conflict, challenge, struggle, and competition. A child may choose mealtimes to express their resistance to their parent’s beliefs. Mealtimes can reveal important family values and the role of the child in food choices. They can provide an opportunity to explore the relationship between parents and children and while giving a perspective on parenting practices.

A parent’s approach to discipline may give an indication as to their beliefs and values. 1-2-3 Magic (Phelan, 2003) is a behaviour management program which encourages parents to set their children clear and consistent consequences for their behaviour. Parents are directed to use fewer words, briefly telling their children the possible consequences of their actions and enforcing them. The importance of consistency is a key characteristic of the program. The program provides tools for parents to control their personal anger as well as skills to be responsive and manage their child’s behaviour.

Maternal empathy and responsive parenting was the focus of a study by Kochanska, Friensenborg, Lange and Martell (2004). They found that mothers who frequently showed empathy towards their children were also more likely to be a responsive parent. The study looked at the role of both parents in the formation of a child’s personality and attachment. It found that the personality of parents explained the interactions they had with their children and their responsiveness to their child. “Insecure parents often fail to be warm, responsive, and affectively positive, and they in turn promote insecure attachment in their children” (Kochanska, et al., 2004, p. 755). Responsive and secure parenting can have significant positive outcomes on a child’s development, including their language development.

Parents play a role in encouraging and engaging in meaningful verbal and nonverbal exchanges by providing an “interactive environment” for their children (Pungello, Iruka, Dotterer, Mills-Koonce, & Reznick, 2009, p. 545). Many factors including age, gender, culture, and family create individual

differences which influence language development in children. There are some learning disorders which make it difficult for children to acquire language skills.

Autism is one learning disorder which can effect language development, as children with autism can find language development difficult. The experiences of people with autism who have adjusted their diet to accommodate their food intolerance have been documented in their autobiographies. Jodi Shaw, a twelve year old boy with autism, says of his gluten and casein free diet, "I have to admit that over a period of time my temperament improved, my concentration span increased and I became much more sociable"(Shaw, 2002, p104). Donna Williams (1993), a person with autism, describes in her autobiography how understanding her food intolerance helped her to function more easily in society. These autobiographies could be seen as "thin slicing" to provide an insight into the lives of people with autism, in the same way this study will be "thin slicing" those who manage food intolerance (Gladwell, 2005, p. 23).

"Thin-slicing' refers to the ability of our unconscious to find patterns in situations and behaviour based on very narrow slices of experience" (Gladwell, 2005, p. 23). This theory of "thin slicing" is based on the work of a psychologist, John Gottman of the University of Washington. Gottman has been able to mathematically analyse short interactions between married couples and predict whether the marriage will last and for how long with fairly high accuracy. It is based on the principle that we can learn a lot about a situation in a short amount of time, often without being conscious of it, and we can learn to read cues more quickly with training. Gottman talks about his fifteen minute interviews with married couples and explains that, "I don't think of this as just a slice in time. It's an indication of how they view their whole relationship"(Gladwell, 2005, p. 30).

"Thin slicing" (Gladwell, 2005, p. 23) can also capture some of the ever changing culture which influences what is perceived. Culture is multidimensional. It is dynamic, like the people in it. "Culture is not an entity that influences individuals. Instead, people contribute to the creation of cultural processes and cultural processes contribute to the creation of people" (Rogoff, 2003, p. 51).

Conclusion

A recent study in Melbourne by Prescott and Allen (2011), revealed that the incidence of food

allergy and sensitivity has risen up to 10% of the population. "Food allergy is now looming as a new epidemic with vast and significant implications" (p.155). One implication of this new epidemic is the need for more awareness of food intolerance issues, which this study will address.

Most of the research outlined in this review used clinical parent rating scales for parents to record their observations of their children's behaviour. This provided a limited opportunity for parents to share their point of view because parents were told which behaviours to observe. By listening to the parent voice, new rating scales have been devised by Rowe (1988) to include a wider range of behaviours associated with food intolerance. This study aims to give rise to the parent voice and acknowledges the experiences and knowledge they have gained from investigating food intolerance with their child. The literature supports the parent point of view (Carter, et al., 1993; Dengate & Ruben, 2002; Rowe & Rowe, 1994), though few studies feature the opinions of the parents to the extent of this study. Some of the studies in this review have suggested reasons why they believe parents chose dietary changes to modify their child's behaviour (Harley, Matthews, et al., 1978; Rojas & Chan, 2005), whereas this study will ask parents directly. Parents will not be given a list of behaviours to observe, but rather will be asked to describe what they have seen in their own words. To discover the parent voice, parents will be invited to respond to open-ended questions. They will be able to reflect upon and discuss their experiences with words of their choosing, not through the use of a scale or set questionnaire.

The research discussed here in this review, often involved a specific elimination diet, whereas this study invites parents to talk about their experiences of living with food intolerance and the elimination diets that they have implemented. The existing research suggests that the symptoms of food intolerance are more readily reported by parents of pre-school aged children, which is why this age group is of particular interest in this study. The parents in this study will not be selected on the basis of their child's hyperactive tendencies, unlike the participants selected for the clinical trials reviewed in this chapter, this may provide insights into other reasons parents may investigate food intolerances with their children.

The questions this study will explore include:

- What are the beliefs, values and assumptions of parents from the food intolerance network about how food influences their children's behaviour and learning?
- What are the beliefs, values and assumptions about the role of children in making everyday food choices?
- What are the goals of these parents in their food choices for their families?

Methodology

Considering the research reviewed in the previous chapter, this study was based from a socio-cultural perspective. This socio-cultural perspective is described in this chapter as it is a key attribute which distinguishes it from most studies. As part of this perspective, the role of the child and parents as social participants in communities is explored. How this study is significant to the field of education is outlined, followed by an explicit description of the procedure and research design of this research. The types of analysis used for this research are also explained in detail.

The literature reviewed here did not suggest any other research which viewed food intolerance from the perspective of the parents as this study does. This study aims to discover the views of parents about diet, and learning. It will explore the goals and motives of parents who make dietary changes in their children's diets to investigate food intolerance. This study was based in Melbourne, the participants were from a minority group of parents within the local community and culture, who have investigated food intolerance.

A sociocultural perspective was chosen for this study as it considers the different layers of a person's words and actions (Rogoff, 1995). It will give a framework to consider the social and cultural context which surrounds each of the participants, as they share their perspectives on the relationship between food, behaviour and learning. As Rogoff (1990) states "(t)he particular actions and skills of an individual cannot be understood out of the context of the immediate practical goals being sought and the enveloping sociocultural goals into which they fit". The body-mind dialectical approach by Vygotsky (1987) is useful in this study to understand the connection between the physiological and psychological processes.

The way that a parent perceives their child influences the role the child has in the family and how everyday food choices are made. While there are communities which encourage children to participate in skilled tasks at varying levels, other communities encourage children to learn complex tasks. Some communities protect their children by removing them from dangerous situations and others teach their children skills to manage them. Rogoff (2003) gives the example of a girl, six years old in a Mayan (Guatemalan) community, who skillfully cares for her baby cousin. Rogoff points out that this would not often happen in the United States until a child is ten

years old. Culture influences parent perceptions which influences the way that responsibilities are shared in a family.

“Segregation of children from mature community activities is common in middle-class settings” (Rogoff, 2003, p. 133), such as those in the United States and Australia. When this occurs specific child-focused activities are used to teach children and “keep them away from adult settings” (Rogoff, 2003, p. 140) resulting in overlooking “the numerous, implicit everyday opportunities for children to gain understanding and skills of the world around them” (Rogoff, 1990, p. 151). In some communities, children participate and observe in adult life at a very young age providing them with opportunities to learn through observation (Fleer & Raban, 2007; Mejia-Arauz, Rogoff, & Paradise, 2005; Rogoff, 2003). Rogoff (2003) describes how in Taira (Japan) and Juxlahuaca (Mexico) communities babies and young children are carried by their mothers or older siblings, providing continuous opportunities for observation and participation by small children. Miniature implements, like small bows and arrows, are used by children to imitate their elders in the Dani community of New Guinea (Rogoff, 2003).

“Children’s play builds on what they observe, but what they have the opportunity to observe differs greatly depending on whether they are included in the full range of their community’s activities or are segregated from many settings that are restricted to adults” (Rogoff, 2003, p. 299).

Rogoff (1998) describes observation as an active collaborative process in child development. It was noted by Mejia-Arauz, Rogoff and Paradise (2005) that as children observe and listen to adult activities, they anticipate being involved themselves. A child’s intention to participate leads to an intrinsic drive as they know that their efforts can contribute to the family’s food and money supply, giving them a sense of satisfaction and achievement (Rogoff, 2003).

Mastov (1999) and Rogoff (1994) explore in detail the idea of a community of learners . Matsov (1999) describes three models, an ‘adult-run’ model, ‘child-run’ model or a ‘community of learners’ model. The ‘adult-run’ model is when adults organize the learning which is opposed the ‘child-run’ model where the children lead the learning process. The ‘community of learners’ model is when adults and children are an active part of the learning process and “all participants are considered to be learners” (Matsov, 1999, p. 164). Rogoff (1994) distinguishes between one-

sided models of learning, where an expert passively passes on their knowledge to another, and active models, where all parties are engaged as a community of learners.

The concept of culture within the sociocultural theory is “more than an individual construction” (Fleer, 2002, p. 112). Culture has interrelated concepts that can be explained separately but are very much a part of the other. Culture is an appreciation of different perspectives and understandings. Dewey (1966) describes culture as the ability to continually extend the meanings of what we perceive. This study aims to provide parents an opportunity to contemplate and share their perceptions.

Significance of this Study

This study will explore sociocultural influences of food choices in families. It provides parents involved in the study with an opportunity to share the reasons they chose to investigate food intolerance and whether they perceive a link between learning and food. There were fifteen clinical studies including those by Bateman, et al. (2004), Carter, et al., (1993), McCann, et al., (2007) considered in the literature review for this research. In each study, participants were given doses of artificial additives and observed for changes in behaviour with results discussed by researchers. In contrast, this qualitative study will examine the perceptions of parents who will be able to openly discuss their experiences of food intolerance. Participants will be asked open-ended questions to prompt sharing, in contrast to previous studies which have used prescriptive scales and lists of behaviours to observe.

The Procedure and Research Design

Based on a qualitative theoretical framework this research will involve four case studies of parents who have tried a low food additive or elimination diet to determine food intolerance with their preschool aged children. An invitation for participants was posted on the Food Intolerance Network (FIN), an online community of 160 people with experience or an interest in food intolerance issues. People who join the network are able to participate in forums to discuss questions and ideas with each other. Those interested in participating in the study were told that they would be expected to complete a journal in their own time, followed by a forty-five minute interview. Participants self-selected to be a part of the study after they were fully informed of

what would be involved. They were given an explanatory statement and returned a signed consent form to participate in the study (Appendix E).

The personal journal involved participants recording their perceptions on food, learning and the role of their child/children in food choices. They were given the opportunity to self-reflect about their experiences and goals. Time involved depended on the amount of detail participants were willing to include. This was completed by the participants over a period of two weeks. Each journal was an exercise book with some prompting questions on the front page (Appendix F). The questions were provided to give the participants a guide as to the sorts of experiences they could include in their journals.

The research methods chosen were based on the advice of Cannold (2001) who used a combination of self reflection and unstructured interviews in her early childhood research with parents. Using a flexible interview format will mean that the interests and comments of participants will be incorporated into the interview. Cannold (2001) found that it was “important that participants had opportunities to direct and control the conversation” (p. 85). This will be important in helping the interviewee to feel comfortable in sharing their thoughts.

Interviews provided the researcher with an opportunity to return to the important issues for each participant and for the participant to clarify points of interest to them. These forty-five minute interviews were conducted several months after the journals were completed, which meant that some of the participants had new experiences to share. The unstructured nature of the interviews allowed them to become “conversations with a purpose” (Burgess, 1984, p. 102). The questioning will be designed to begin broadly and then become specific according to the responses in their journal and to draw upon points of interest. Each interview was tailored to the individual and provided the researcher with the ability to build on their relationship with each participant.

During an interview “(t)he development of trust and confidence with participants is essential” (Grieshaber, 2004, p. 86). When a researcher can make connections and build rapport during their interviews, participants are more likely to give in-depth answers and responses. Finding out more about people and their motives is achieved when a “non-hierarchical” approach to the interview is apparent (Oakley, 1981, p. 41). Developing relationships with the participants in this study will be

achieved through a number of methods. Oakley (1981, p. 49) suggests that there is “no intimacy without reciprocity”, while Lather (1986, p. 263) discusses reciprocity and how it “implies give-and-take, a mutual negotiation of meaning and power”. The interviewer in this study has experience with elimination diets and may share experiences as a method to draw further information and detail from the participants. The opportunities for participants to share their stories could result in a more intimate view of the participants’ experiences. More depth in the research data will promote further points for discussion and analysis. Grieshaber (2004, p. 85) found that it was valuable to actively listen to participants, not ask too many questions and give participants the opportunity to “direct and control the conversation . . . refer to the incident in question and pose my understanding of the event” (p.85), and allow the parent to either confirm or correct perceptions.

The researcher will ask the questions planned for each interview (Appendix G), though if the participant shares an interesting point that needs expanding, they will be prompted to elaborate further. Participants will be given the freedom to share as they choose. When participants have finished their point, the researcher will ask questions to redirect focus if needed.

Analysis

A grounded theory approach will give a firm basis of analysis for the data collected in this study. This means that analysis will be guided by the information given by the participants and the data will drive the analysis. O’Toole and Beckett (2010) suggest that it is useful to explore the data in a neutral way and then make interpretations and inferences. They also talk about letting the “data speak directly to you” to see the emerging themes and patterns (p.171).

While based in the education discipline, this study incorporates literature from health, education and psychology disciplines with a socio-cultural lens, which has not been used in any studies around food intolerance reviewed for this research. A sociocultural approach will provide the opportunity to disclose deeper insights into food intolerance issues in a way that other approaches cannot.

Culture is like individuals, dynamic and multidimensional. Rogoff (2003) describes how culture does not necessarily influence people, though people create and contribute to culture and this

culture then plays a role in the formation of people. This study uses “thin slicing” as discussed by (Gladwell, 2005) to capture some of the ever changing culture of its participants. It will take the ‘slice’ of information received from the participants in their journals and interviews, to understand their beliefs and values. This ‘slice’ also gives the cultural context in which these beliefs and values are based.

This cultural context is important along with the varied cultural factors that are part of the individual’s journey, with their family, amongst their community. This study recognizes the dynamic social aspects that contribute to cultural practices and the individual. It acknowledges the independent and interdependent role of the community, family and individual. Gauvain (1999, p. 174) suggests that “meaningful contexts” are fundamental to a sociocultural approach. It considers the individual where they are situated, “within the cultural context in which their thinking is embedded” (Rogoff, 1990, p. 42).

The data obtained in this study was analysed using Rogoff’s (1995) planes of analysis exploring the individual, interpersonal and community relationships that arise. The individual plane considers the participant on a personal level and their distinctive character and experience. The interpersonal plane considers the immediate relationships around the participant, like family members and other close associates. The community plane explores the relationships outside of the family, like those in schools and other community groups. Each plane is significant. The personal plane is relevant to this study because food intolerance is a personal experience for each individual. The interpersonal plan reveals part of the sociocultural context influencing the participants and their family’s decisions about food intolerance. The community plane provides further insight into the role of extended family members and schools in the food intolerance journey of these participants and their families. “Such a sociocultural analysis requires considering how individuals, groups and communities transform as they together constitute and are constituted by sociocultural activity”(Rogoff, 1995, p. 161).

Rogoff (1995) suggests that looking at one plane of focus includes the other planes in the background and that understanding each part, would involve consideration of the others too, arguing that “the parts making up a whole activity or event can be considered separately as foreground without losing track of their inherent interdependence in the whole” (p. 140). This

approach is important in gaining a rich understanding of the participants in this study, as it considers the various contexts of the participants' words giving them fuller meaning.

Hedegaard (2002, p. 57) states that, "human motives are culturally and socially determined". When considering the goals of participants in this research, the hot and cold paradigms used in Pintrich, Marx and Boyle (1993) will be useful. The 'cold' paradigm represents the rational process involved in the development of knowledge, whereas the 'hot' paradigm is the irrational process which involves personal interests, motivations and social and historical factors (Pintrich, et al., 1993, p. 170). These paradigms assist in identifying the types of reasons the participants' have for investigating food intolerance. Recognising whether participants have used a rational or irrational process leads to an understanding of their fundamental beliefs and values which underlie their decision making.

Analysis began by reading the participants journals with a view to gain a broad understanding of each participant and their experience with food intolerance. Differences and similarities in the participants' experiences were coded. The themes which emerged were recorded and used to develop an interview structure for all the participants. Individual points of interest to be clarified were raised with each participant towards the end of their interview. This ensured that the themes from the journals were developed further.

Interviews were transcribed verbatim with each line numbered to support analysis and referencing (Appendix A,B,C,D) They were read initially using "unmotivated looking" (Psathas, 1995, p. 45), and Hallowell (2011) describes how this is achieved by "being open to encounters rather than having preconceived notions of what may be found" (p.23). Key themes were highlighted, and then all the interviews were reread while considering each research question. These connections were recorded on mind webs, using different colours for each participant. This was so that the researcher could get a sense of what individual participants said and later connected with what other participants talked about. Different and similar wording used by the participants was visible.

Interviews were further analysed through Rogoff's (1995) planes of analysis. Issues raised by participants were grouped according to their personal, interpersonal or community nature.

Personal ideas from each of the participants were layered, with each of the interpersonal and community related comments. The many beliefs, values and assumptions held by participants, on a personal, interpersonal and community level were explored. Recurring themes were drawn from the interviews and discussed. The outcome of this study reveals the perspectives of parents investigating food intolerance.

Results

The previous chapter outlined how the data was obtained and how it was analysed. This chapter presents the findings that were most significant from this data and reveals the perceptions of these parents about food and their child's learning. It details the beliefs and values that were expressed by the participants individually and those that resonated with all four of the participants collectively. The participants discussed how they believed food influenced behaviours such as sleep, anxiety and relationships. They also revealed how they saw the connection between food and learning through their experiences with their child's language development and concentration. Parental values were also outlined in relation to their instincts and feelings of guilt.

When asked a range of questions about their beliefs and values in regards to food intolerance, all four participants spoke about the difference that food made to their lives (Appendix A7, B166, C32, D136). They suggested a contrast in various aspects of their lives after they changed their diet to accommodate theirs and their child's food intolerance. Positive changes in physical health, relationships, behaviour and learning capacity were some of the experiences shared by the participants to illustrate how eating foods that were tolerated (when they were on-diet) had influenced their lives. They also describe the contrast of the negative effect that eating food not tolerated (off-diet) could have on their lives. Donna described the disparity by saying, "it's just night and day" (Appendix D136), "completely different" (Appendix D176). Bernice said that she is still stunned by what she calls the "stark contrast" between life on and off-diet (Appendix B166). Abbey saw "Jekyll and Hyde" (Appendix A65) in her son Alan.

Two participants, Abbey and Bernice, reported that their older children could see the changes when they ate on-diet. Abbey talked about how both her children could see the differences that food made to them (Appendix A236). She said that her older son Adam, "is glad that he doesn't have those anxiety attacks anymore" (Appendix A229). Bernice said that her daughter, Bess "feels better on it" (Appendix B17).

Birth order and age of children at the time of the interview (pseudonyms used)
 circle = female square = male

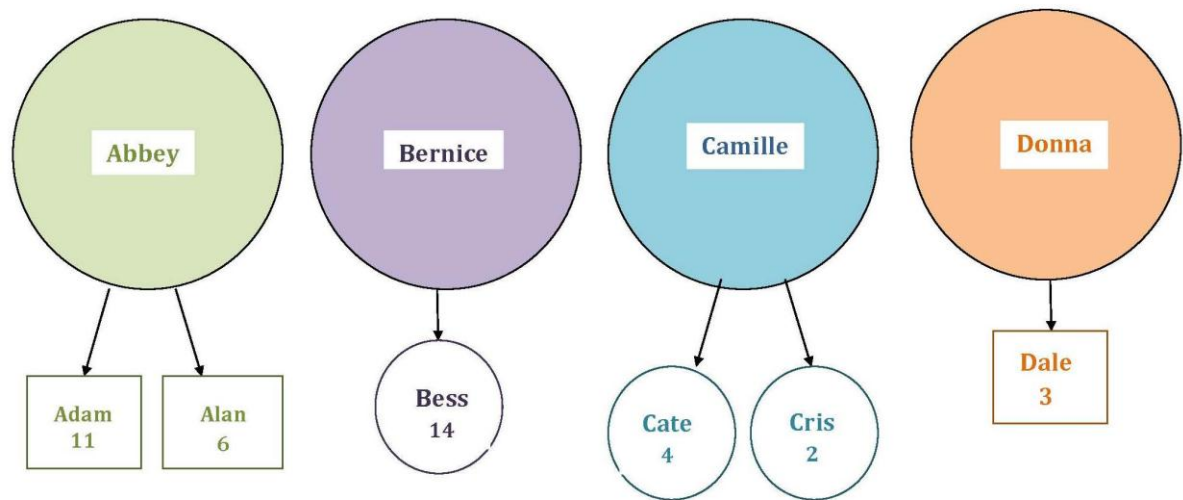


Figure 1 – Gender and ages of the participants children

Food and Behaviour

Diet first

All four participants believed that a diet which considers food intolerance had changed the behaviour in either their children or themselves. Two of the participants stated that they believed behaviour management strategies should be implemented after food intolerance is investigated with their children. Before going on an elimination diet, Bernice recollected,

171. We'd looked around at a range of different things and the psychologist at school who
172. said, "nothing wrong with you" and looked at me funny. The same with the school nurse when
173. she was a bit younger then that the school would have a social worker come in to 'teach me
174. how to parent'. And I was doing a great job she reckoned, leaving (Bess) in her room
175. screaming for hours, you know that's normal. (Appendix B171).

Bernice found a behaviour management strategy that she implemented with her child and would "recommend" (Appendix B193). It was called "one- two-three magic" (Appendix B193). She said, "but it won't work without the diet" (Appendix B195).

Donna described how her views about managing the behaviour of children had changed over the last few years and that she would now suggest to other parents to try dietary changes first. She related a conversation that she had had with her sister a few years ago, about her nephew's temper and aggression (Appendix D169). At that time, Donna did not believe that it was necessary for her sister to consult a doctor, however now she would say, "yes, absolutely go to the GP and find out if there's any issues. Try out the diet stuff first and then, yeah, you can always try new things in your parenting. No parent has got it all worked out" (Appendix D175).

Abbey did not mention behaviour management strategies and only talked about the benefits that diet made to her children's behaviour. She said, "all you need to do is change what they eat" (Appendix A11). Whereas Camille believes there is a place for both dietary changes and behaviour management approaches. She said,

200. I've seen enough in myself

201. to know that there are definitely some food things there but at the same time there is a point
202. where you are in control of your behaviour, even if it's harder when you're reacting there's still
203. a point where you can get more control or less control that I've found. So I would say that
204. behaviour issues are probably a mix of both and that while food might be some of the answer
205. it is certainly beneficial teaching children how they ought to behave and trying to work out, I
206. guess do your best to teach them how to function in a way that would work in our society,
207. because they need those skills regardless (Appendix C200).

Discipline approach

Three of the participants discussed the way they approached their child's reactions to food off-diet. Donna described explicitly how she dealt with Dale's tantrums empathetically. She began by saying some parents may disagree with her, but states her thought processes and explains her reasons for this approach.

101. Other parents might disagree with this, when I, let's say he has tantrum at night, cause I know
102. he's eaten foods that don't agree with him at childcare, I don't know exactly how that makes
103. him feel but I'm thinking that he's really upset and he's not feeling very well. His meltdown
104. might be disproportional to what has happened, so I'm making a judgment that food is making
105. him feel bad, and because of that how I'll deal with that is more with sympathy or empathy
106. rather than taking a more firmer approach I guess. I'm trying to say to him that I respect that
107. he's not having a meltdown because he's not allowed to buy something at the supermarket or
108. something like that, but because he's tired and he's not feeling great (Appendix D101).

Abbey recollected how she dealt with Adam's changed behaviour, after a party where he ate food off-diet. She said,

68. He went to the party happy, balanced, and he came home and within
69. half an hour his face changed. To having a frown on and a furrowed brow. I took one look at
70. him and I said, "you're reacting to whatever you ate at the party, you need to right now go to
71. your room and have some quiet time and I'm gonna (*sic*) tell you every single time that you start
72. to do it and you just need to walk away and do it (Appendix A68).

Bernice talked about her daughter Bess' recent difficulties with Maths and that having some food off-diet had "basically taken her from performing to standard to performing under standard now with maths" (Appendix B57). Bernice said that she believed it was "another way it's (food intolerance) impacted on her, that I feel isn't really her fault" (Appendix B64).

Real child

Three of the participants saw significant differences in their children when they were on-diet. They found that a diet which accommodated their child's food intolerance helped them to see another side of their child. Abbey talked about seeing the "real child" for the first time (Appendix A54). Changing diet gave Bernice "the child and the life that I had always known was there" (Appendix B191). Donna says, "I know he's an easy going happy little kid, sometimes he's distracted because he's not feeling well" (Appendix D80). Abbey describes Adam as "easy to get on with" when he is on-diet (Appendix A65).

Both Abbey and Bernice say that their children are "really nice" when they are on-diet (Appendix A62, B22). However they both describe their children as being 'oppositional' when off-diet (Appendix A62, B77). Donna talked about how she perceived tantrums as a symptom of food intolerance (Appendix D3).

Friendships

Both Abbey and Bernice shared how their children found peer relationships difficult before they discovered their food intolerance. Bernice stated that it was difficult for children to relate to Bess' behaviour, and it was "very upsetting" to see her only child without friends (Appendix B78). In contrast Bernice said that now, "she's got loads and loads of friends who all seem to want to be around her" (Appendix B77). Bernice, as an adult, also found that she felt more "friendly" while

on-diet (Appendix B156).

Anxiety

The participants in this study mentioned that they either personally experienced increased issues of anxiety or they observed greater anxiety in their children, when eating off-diet. They also noticed these anxiety levels diminish when on-diet. Both Abbey and Donna noted separation anxiety issues in their children (Appendix A121, D3). Donna uses the word “clingy” to describe Dale’s anxious behaviour (Appendix D30). In contrast, when on-diet Donna suggests that Dale is more relaxed (Appendix D35).

Abbey says that Alan was “crying everyday” when she was leaving him at school (Appendix A123). During a Neuro Emotional Therapy (NET - a branch of kinesiology) session she discovered that “he (Alan), in fact, felt bad that he was leaving me alone” (Appendix A124). “He got special affirmation words to say and from the very next day he never ever cried again until he had a food reaction” (Appendix A125).

Bernice and Camille, both mothers, recognized heightened anxiety in themselves when they ate off-diet (Appendix B91, C55). Camille said that when eating off-diet she would get “a bit teary and feel as though I’m losing control, not as much patience” and did not speak to the children as calmly as she would have liked (Appendix C56). Bernice felt more “calm” and “relaxed” when able to prepare food on-diet, when on their family holiday (Appendix B93).

Over reactions

All four of the participants reflected on times that had become unnecessarily emotional over seemingly small issues. Bernice describes her family’s pre-diet life as “high tension all the time” (Appendix B86). She described how her husband, Brian, and her daughter Bess, screamed at each other “over something stupid” when they had eaten off-diet (Appendix B68). Abbey talked about times when “small things were being silly” (Appendix A88). Donna recollects times when Dale had eaten off diet and he would have a “meltdown disproportional to what has happened” (Appendix A103). Camille said that when off-diet she would, “yell at the children more than I’d like to” (Appendix C56).

Sleep issues

Three of the participants recognized sleep issues associated with food intolerance. Bernice finds that she can sleep better when on-diet (Appendix B231).

Camille said, “(Cris) every other night would literally scream between six o’clock and nine o’clock at night” (Appendix C28). “So I started on the internet reading things and I came across some of the food intolerance things . . . and started to read some more about it” (Appendix C30). She said,

- 31. while I wasn’t
- 32. sure if it fitted her (Cris) it seemed to fit me. So I thought OK let’s try it. It did seem to make
- 33. quite a difference. She (Cris) sort of seemed to grow out of it, I’m sure she’s still sensitive to
- 34. something but it’s nowhere near at the level that I am at” (Appendix C31).

It was Donna’s frustration with Dale’s poor sleep patterns as a baby that initially prompted her to investigate food intolerance. Donna understands Dale’s food intolerance through his sleep patterns and says, “his sleep is a big indicator” (Appendix D139). In reflecting on her experience with the low oxalate diet for six months, she says, “there’s no waking up in the middle of the night and screaming for half an hour and yes things had improved” (Appendix D63).

Both Camille and Donna saw tiredness as a symptom of food intolerance (Appendix C122, D3). Donna said, “he’s tired because he hasn’t had as much sleep” (Appendix D29). She believes that the interrupted sleep Dale experiences when reacting to food, causes him to become grumpier and she said, “if you’re feeling grumpy you’re less likely to be adventurous” (Appendix D30, D33). Abbey also described her son Alan as being grumpy when off-diet (Appendix A52) and Camille described herself as “cranky” when off-diet (Appendix C63).

Food and Learning

It is difficult to compare the learning stages of children for a number of reasons, including differences in age, gender, family and cultural influences. Both Camille and Donna have pre-school aged children. Whereas Abbey’s children are now at primary school and Bess is in high school (Figure 1, p.40), eventhough they began to investigate food intolerance when their children

were preschoolers.

Language

Both Abbey and Donna talked about the increased use of oral language by their children when on-diet. Donna recounted how Dale is “chattier” when on-diet (Appendix D34). Abbey tells that she nearly drove off the road when Alan, aged three at the time, spoke his first ever sentence (Appendix A9). It was when Alan, who had been sick, did not eat any offending foods for three days when Abbey describes the many changes that she saw in Alan and marveled at how he “used more words” (Appendix A45). Abbey reflected how Alan (at age three) was always taught to use his manners, however it was not until he was on-diet, that ‘please’ and ‘thank-you’ were “popping out everywhere” (Appendix A46). She said, “Then he got better, and I started to feed him and the deterioration was almost instantaneous, it was like giving him drugs. It was a really amazing thing” (Appendix A48). Abbey saw Alan’s “learning ability change” and said that she decided to stay on-diet so he could “continue learning properly” (Appendix A170, A167).

Reading and writing

Bernice shared how Bess had “massive problems” with reading and writing before introducing dietary changes (Appendix B50). Bess improved by changing her diet. When Bernice reintroduced one food item back into Bess’ diet, she said, “within two and a half days, she basically lost the ability to write. So she developed it, well she was sort of low down, then it shot up in six months and then she totally lost it” (Appendix B52). She described how it was like, “the connection between her brain and her hand had gone” (Appendix B54).

Bernice has combined the Low FODMAPs (Fermentable Oligosaccharides, Disaccharides, Monosaccharides And Polyols) and Failsafe diet based on the Royal Prince Alfred hospital elimination diet. She has included some different foods with higher salicylate content. Bernice believes that including these foods higher in salicylates may have contributed to the difficulties that Bess is experiencing in maths. She said,

- 56. I think she was about 7 when that happened. The same thing again recently, these
- 57. episodes with salicylates it’s basically taken her from performing to standard to performing
- 58. under standard now with maths. She’s doing fine with most other things, more than fine. I
- 59. think it’s that reasoning thing that maths requires that is the first thing to go when she’s
- 60. reacting (Appendix B59).

Concentration

The two participants with pre-school aged children talked about how they observed better concentration for themselves and their children when on-diet. Camille noticed the deterioration in her own concentration when she was off-diet (Appendix C49) and how “it’s just so much easier to concentrate and to achieve things when your body is actually there in one piece” (Appendix C53). Donna talked about how Dale could pay attention and stick at something for longer when he was on-diet (Appendix D32, D35). She says, “he’ll play independently, he’ll get really engrossed in something, he’ll stay at it, he’ll try new things, like he might be building something and he’ll build something new” (Appendix D136).

Classroom behaviour

The two participants with school aged children felt that the teachers of their children spent too much time on behaviour management and expressed how they felt this was a concern for the learning of their children (Appendix A213, B211). Abbey said,

212. Drives me insane. Particularly this year. Just kids who can’t behave in class, they can’t sit down
213. they won’t listen, they’re defiant, the teacher spends more time with their behaviour than
214. teaching (Appendix A212).

220. And this year in particular is driving me insane, because there is
221. about 5 of them in there and I’m going Oh, you need to fix it. So I go in the classroom and I sit
222. there and I go, Oh, I know how to fix you. I feel sorry for the children themselves who are
223. causing difficulty because I think you poor things, you know you’re always getting in trouble
224. and you’re not learning what you need to learn (Appendix A220)

In her journal Bernice wrote that “the behaviour of others interferes with the whole classes learning”. When asked about this in her interview she said,

210. It’s been an ongoing issue actually. It severely impacts on her ability to learn. Basically the
211. teachers spend more than half their time attempting to bring the kids back to focus, it’s loud
212. and the kids aren’t there to learn. They’re not learning so they do other stuff. Socializing and
213. being very loud. It’s really really difficult to learn under those circumstances (Appendix B210).

Parental Values

Feelings of happiness

All participants used happiness to describe their feelings on-diet. Camille reflected on how it had made her life easier and how it's "nice to actually feel happy and stable" (Appendix C149). Bernice said, "life hums along quite happily" (Appendix B85). Donna described Dale as a "happy little kid" (Appendix D81) and Abbey expressed how Adam was "happy and balanced" (Appendix A68) and says that Alan is "more than happy" with the changes in his diet (Appendix A236). Abbey described how Alan started to smile on-diet, and off-diet he stopped smiling (Appendix A51). She also described how Alan was "sad" when he ate foods off-diet (Appendix A52).

Instinct

The four participants referred to a belief or feeling that they had, a feeling that Donna refers to as her "instincts" (Appendix D91). Donna recalls how difficult it was to find someone from the medical profession to believe her about Dale's food allergies and how "instrumental" it was that her lactation consultant took her seriously. She said from her experiences how she is now "more confident about pursuing my instincts" (Appendix D91). She said, "I knew I was right" (Appendix D90).

In reference to her pre-diet experiences, Bernice suspected problems with her daughter Bess' learning in early primary school, and says that despite being told Bess' screaming in her room for hours was normal, that "it didn't feel very normal to me" (Appendix B160, B176). She says, "I just remember feeling that constant ache that it just wasn't right, that something was very very wrong" (Appendix B196). She was not comfortable with Bess' behaviour and was relieved when on-diet she had "the child and the life that I had always known was there" (Appendix B191).

Abbey had a "slight inkling" (Appendix A164) that there was a delay in Alan's language development as a preschooler. She dismissed her instincts until she saw the difference that eating on-diet had made to Alan's language development.

Camille said in her journal that she "always believed there was a food link". She began to read books about low Glycemic Index (GI) foods in 2001 (Appendix C127) and said that she started a "food journal to see if I could make any links" (Appendix C136).

Guilt

All four of the participants in this study expressed how they felt guilt related to making dietary changes. Abbey said, “I guess it depends on what you’re feeling guilty about. I certainly felt guilty that I had been poisoning my children . . . It didn’t ease my guilt, it probably created guilt in actual fact” (Appendix A260, 264).

While Abbey felt guilty for what she had fed her children in the past, the other three participants felt guilty about how food intolerance influenced the present. Donna said, “I’m experimenting with my child, there’s increased guilt, increased worry” (Appendix D178). Camille said that, “I feel as though I’m reducing their food choices and so I guess that’s sort of guilt on the other way around” (Appendix C214). Bernice felt the same way and said, “I think there’s a huge amount of guilt there because of all the restrictions on the child” (Appendix B309). She went on to describe how the child can feel isolated and said, “to counteract that, I just acknowledge that I need to cook a certain amount more and that balances that out. I’ve taken away, I have to give back” (Appendix B317). Camille, Bernice and Donna feel guilty about depriving and isolating their children now. Whereas Abbey felt guilty about the food she had given her children in the past.

Beliefs about medication

All the participants had explored various alternative and non-medical interventions. They all talked about the many approaches they had tried, and two participants talked about their views on medication. Camille’s symptoms were inconsistent, and she would experience times where she felt better than others. She tried medication for her chronic fatigue for a period of time, and while she felt better at the time of her second appointment, she did not believe that it was because of the tablets. Camille felt that it could have just been a better time for her and she “didn’t feel right about just taking tablets for no apparent reason” (Appendix C96).

Bernice asked, “does everybody have some sort of food issue that they are just not aware of?” (Appendix B122) and said, “they ... won’t want to look” (Appendix B123). She then talked about her mother, suggesting that she does not want to look at food intolerance. Bernice says, “even my mother you know, she says ‘Oh, I’d just rather take a pill’. So she does. She eats all this stuff and takes her medication. A big box load full of it. That’s pretty common I guess” (Appendix B124).

Bernice talked about the elimination diet and admitted, “I probably didn’t do it properly, I wasn’t seeing a dietician ‘cause I’ve got this abhorrence of health professionals from my experiences with them over the years, so I tend to try and manage on my own” (Appendix B99).

Autism

Both Abbey and Donna mentioned how they had been reading about food intolerance and autism (Appendix A268, D188). Abbey talked about how Amish people do not have children with autism and how she believed it was because “they live a less chemical filled life” (Appendix A277). She explained her belief that “food intolerance is really a symptom of chemical overload in the body” (Appendix A31) and that some children displaying autistic symptoms are “displaying severe food intolerance symptoms” (Appendix A42).

Conclusion

The results suggest that the participants in this study believe that food impacts on many aspects of their children’s behaviour. Improved verbal language, reading and writing skills and classroom behaviour are believed to have resulted from following a diet in accordance with one’s food intolerance. Other benefits attributed to diet by these participants, were better sleep patterns and a greater sense of happiness. On-diet the participants perceived fewer tantrums and reduced anxiety levels. It was also expressed by participants that they felt diet was more effective than behaviour management strategies. They felt that they had become more empathetic parents and that their family’s relationships had improved. They believe that diet helped them to see a better side of their child and gave them and their family an overall sense of happiness.

In the following chapter, these results will be analysed further using a grounded theory approach with a socio-cultural lens. These findings will be discussed in these contexts to draw out the socio-cultural significance of this research.

Discussion Employing Grounded Theory

The participants in this study suggested that food intolerance was the reason for negative behaviours seen in themselves and their children, however other factors could have contributed to the differences that the participants felt they experienced on and off diet. Some may argue that the parents would know what foods had been consumed and their observations of their child's behaviour could be influenced by their expectations. Scientists use double-blind placebo trials in the hope that observers are less partial in their observations and can focus more on what they can see, rather than on what they would expect to see. These participants attributed different foods to a range of behaviours and often the results exceeded their expectations.

In this discussion, the participants' beliefs in relation to food, behaviour, their child's learning and their parental values, including instinct and guilt, are explored and related to relevant literature.

Food and Behaviour

Diet first

Bernice had tried many approaches to behaviour management before going on an elimination diet. She wanted help to manage Bess' (her daughter) behaviour and a social worker from the council came to observe their interactions at home. While Bernice did not "feel very normal" (Appendix B175) while using the behaviour management strategies suggested by the social worker, it cannot be ruled out that learning these strategies may have had an impact on her parenting and therefore the behaviour of her child. As both diet and behaviour management strategies were used, it is difficult to know which had the most influence. The behaviour management program that Bernice found useful, professes that, "one-two-three Magic is as much a control on parental anger as it is a control on children's behaviour" (Phelan, 2003, p. 20). It gives strategies to enforce consequences. Counting up to three before reacting allows time for the child to respond and the parent to think. Good consistent consequences can achieve positive behavioural changes and this program has been used to good effect with no other interventions (Phelan, 2003). Bernice used this program with dietary interventions and it is difficult to state which one had the most significant effect on behavioural change.

Donna described how her views changed over a four year period. A year after her discussion with her sister, she became a parent. It brings into question if that changed status allowed her opportunities to see food and behaviour from a different perspective. Her sister rang for advice about dealing with her nephew's aggressive behaviour. Whether her sister took him to the doctor or took a different approach is not known. If her sister did find physical reasons, like food intolerance issues related to the behaviour, then it would give further background to Donna's beliefs.

Abbey was confident in her belief that diet changes behaviour and this seems to be supported by her friends who had similar experiences (Appendix A54). Sometimes friends can influence thinking. The point of view of friends can be assimilated when spending time together and sharing experiences.

Camille related her beliefs to her own experience and her need to self-regulate her behaviour even if she is reacting to food. These beliefs may play a role in her parenting and discipline practices.

Discipline approach

Grose (1994), in his book of advice for parents, states that "all children misbehave at some stage. They're often testing the limits and wanting to know where the boundaries lie" (p. 58). Children of all ages use tantrums to get their own way or to gain attention (Grose, 1994). Children use tantrums to express their autonomy and they become less frequent with age (Barrow, 1968). More information about the types of tantrums that these participants experience would be useful in understanding what is described. As tantrums are a common part of childhood, whether the tantrums observed by these participants are more intense or frequent than tantrums observed by other parents needs to be established. Further description of what started the tantrum and the types of behavioural changes observed by the participants would be useful. It would also be interesting to know if the participants believed that changing their diet contributed to their ability to cope with the tantrums.

Tantrums usually indicate that a child is frustrated with the restrictions placed upon them (Barrow, 1968). As the participants were concerned about the restrictions imposed on their children by

their diet which considered their food intolerances (Appendix B309, C214, D181), it could be expected that tantrums would increase, yet participants reported a reduction in these types of behaviours. While this may have been due to the changes in diet, it would be interesting to know how the participants dealt with tantrums when they arose. Tantrums and similar behaviours can be reinforced when the desired outcome is achieved. “Once a child learns that throwing tantrums is effective, she repeats the behaviour more often” (Essa, 1999, p. 226).

Donna talked about feeling more empathy towards Dale (two years old) when he was having a tantrum, because she believed he was having a tantrum because he was reacting to something he ate. Donna may be making this judgment based on how food can make her feel. She said, “I’m making a judgment that food is making him feel bad, and because of that how I’ll deal with that is more with sympathy or empathy rather than taking a more firmer approach I guess” (Appendix D104).

Kochanska, Friesenborg, Lange & Martell (2004) conducted an online study about the influence a parent’s personality may have on how they form an early relationship with their child. They found that, “maternal empathy was associated with responsive parenting” (p. 751). Donna’s belief that she is more empathetic towards her son Dale may be due to a number of factors. The changes that she made to her own diet may have given her more understanding of what he is experiencing as she said, “I know how food makes me feel” (Appendix D173). It is possible that Donna’s diet may have enabled her to be more patient.

Real child

The participants with similar aged children used similar language to describe their observations, separating the older children from the younger children in the types of behaviours they believed had changed with diet. While all the children were preschool age when an elimination diet was first introduced by their parents, at the time of the interviews for this study, the children’s ages ranged from two to fourteen years of age. Abbey and Bernice’s children were aged between seven and fourteen years, whereas Camille and Donna had pre-school children aged between two and four years (Figure 1, p41). As a result this study was able to give some indication as to the types of childhood behaviours that are observed by parents over a wide range of ages, though it does not provide an indepth view of the behaviours associated with food intolerance in preschool

aged children as recognised in the literature reviewed for this study (Bateman, et al., 2004; Carter, et al., 1993; McCann, et al., 2007).

Friendships

“How children become friends is a remarkably complex process that is still only partially understood” (Parker, 1986, p. 104) and yet friendship is important for companionship, stimulation, social comparison and affection (Ginsberg, Gottman, & Parker, 1986). “Friendship provides children with a reliable, familiar partner and playmate, someone who is willing to spend time with them” (Ginsberg, et al., 1986, p. 7). Bernice and Abbey observed that their children had better friendships when on-diet, though it was not mentioned by Camille and Donna.

Camille and Donna may not have mentioned friendships because preschool children are developing their relational skills. A child understands relationships in concrete terms when they are about three and they begin to understand basic relationship concepts at around four or five years of age (Edwards & Ramsey, 1986). Children start to make reciprocal friends at around the age of three or four (Kay, 2007).

Howes (1983) found that friendships have a developmental progression. Friendships develop with the child’s verbal and cognitive skills. “Changes in friendship expectations may also reflect changes in the developmental tasks that confront children as they grow older” (Hartup & Abecassis, 2004, p. 286).

Another factor not explored in this study is the effect of aggression on friendship, though there may be a link between quality friendships and low levels of aggression. Bernice talked about how her daughter, Bess “gets really strong when angry” (Appendix B74) after describing an aggressive episode between her husband and daughter. This tendency towards aggression could also explain the difficulty that her daughter Bess had in establishing friendships. “Evidence suggests that children’s aggressive behaviour is inversely related to friendship” (Ladd, Buhs, & Troop, 2004, p. 398). Hartup and Abecassis (2004) explain that aggression is one of the main reasons used by children for not liking someone. Referring to anger and aggression, Barrow (1968), a child psychologist, states that, “naturally we expect better control in a five-year-old than in a two-year-old” (p. 44).

Anxiety

Two of the participants talked about how their child's separation anxiety levels were heightened when off-diet. Donna described how her son Dale was "clingy" (Appendix D30) when off-diet and how he was more relaxed when on-diet (Appendix D35). Even though Abbey discovered that Alan cried because he felt bad for leaving her alone, she still felt that "he never cried again until he had a food reaction" (Appendix A126). There are potentially many reasons why a child would cry when being left at school. Daniel, Wassell and Gilligan (2010) describe crying when a mother leaves as consistent with behaviours associated with secure attachment. Children may feel uncomfortable in an unfamiliar environment, or something may have happened to upset them.

"Common sense experience suggests that as they grow older, children can sustain increasingly longer periods of separation from attachment figures without distress" (Blehar, Waters, & Wall, 1978, p. 269). Kazdin (2008) describes separation anxiety as one of the behaviours considered appropriate for a young child though it would be less appropriate for an older child. "It's the same behaviour, but the different age changes it's meaning" (Kazdin, 2008, p. 245). This suggests that different expectations for each age group could explain some of the complexities in considering a child's behaviour.

Over reactions

Over reactions would look different in children of different ages. It would be reasonable to expect certain behaviours to reduce as a child grew older. "Before starting school, tantrums, fighting and destructiveness usually decline" (Daniel, et al., 2010, p. 193). It would then be difficult to determine whether maturation or diet was the main factor in the decrease of the over reactive behaviours observed by the participants and individual interpretation of behaviour is also a factor to consider. The context in which these participants spoke about over reactions relate more to the reactions they saw to specific foods rather than to maturation. Abbey spoke about how she saw her children over react after a food challenge. After her children had been on diet for a period of time she introduced a food challenge and felt that small things "were being silly" (Appendix A89). Donna's recount of her son's "meltdown" (Appendix D103) experiences also relate to what she saw as his reaction to different foods. She felt that her son Dale's reactions were more appropriate when he was on-diet. These reflections are about short term responses and do not necessarily involve the expected maturation process which would be observed over

the long term.

Camille talked about how her parenting was different when she was off-diet. It is possible that a parent's tolerance levels could have played a role in the more amenable family relationships experienced by these participants when they were on-diet. It is difficult to distinguish whether it was the children's behaviour or the parents' tolerance levels that made the most significant difference in these families.

Sleep issues

A parent's strategies for managing sleep are more than just responses to the environment, they reflect one's beliefs about raising children (Gianotti & Cortesi, 2009). An example of this was in each interview when the participants were asked to respond to this statement:

"It (also) may be easier for the parents to accept the idea that their child's behavioral problem is due to a dietary factor than to psychosocial issues that are often difficult to evaluate and tackle. (an elimination diet) gives the family a sense of solving the problem and provides the child with substantial attention"(Cruz & Bahna, 2006, p. 728).

This was Donna's response:

162. If you've got a six
163. month old whose screaming in the middle of the night. I didn't want the screaming, I didn't
164. want attention, I didn't want to be carting my 6 month old son to see anyone, I wanted him
165. to be asleep. It depends on the parent, maybe I'm just judging other parents, but I know my
166. instinct. I know my parenting choices weren't that off. With a six month old you haven't had
167. enough time to create terribly bad habits (Appendix D162).

The sleep patterns for a six month old child would vary from one parent to another. Donna expected her six month old son to sleep more than he was, though the extent of her son Dale's sleep disturbance is not clear. The variation in expectation and interpretation of what are acceptable sleeping patterns are discussed by Gianotti and Cortesi (2009). They highlight how beliefs and culture influence families' perceptions of problematic sleeping. Each family decides how and where a child sleeps and sleeping patterns are interpreted differently. The characteristics of what is normal in one family could contrast with other families' expectations.

Donna believed that her child's difficulty in sleeping was separate to her parenting choices. We do not know the types of sleep settling strategies that Donna used and why she held those beliefs. Johnson & McMahon (2008, p. 765) said that, "growing evidence suggests that parents play a pivotal role in children's sleep behaviour and that a parenting style which promotes self-regulation is beneficial". Another study by Sadeh, Mindell, Luedtke and Wiegand (2009) looked at factors that promote sleep. They found that active parent interaction was associated with "shorter and more fragmented sleep" in infants and that interventions conducive to developing independence were associated with "extended and consolidated sleep" (p. 60). It would be difficult for a sleep deprived parent to not respond to their child's sleep disturbance, especially if it is constant and persistent.

There could also be other factors which played a part in Dale's improved sleep patterns. Donna discussed using supplements and probiotics (good bacteria) and how this may have been another contributing factor in Dale's improved sleep patterns (Appendix D61, D174). There is suggestion among those with experience in food intolerance that vitamin supplements and probiotics can improve the way the stomach processes food and relieve symptoms (Chisholm, 2009). Chisholm (2009) believes that by increasing the good bacteria in the stomach it can help the body absorb nutrients more easily. There are accounts of people who have experienced a reduction in food intolerance symptoms by taking these supplements (Chisholm, 2009).

Food and Learning

The participants had different observations about their child's learning and the main reasons could be the different learning styles and age range of the children. The disparate ages of the children represented in this study, gave some indication of how food intolerance is perceived to manifest itself over a range of age groups, and provides us with an overview of the types of learning behaviours that parents observed. However, it did not provide a significant sample of children from any particular age group or learning style to draw specific conclusions.

Language

"Language development is a critical component of learning because it promotes the development of cognitive processes and allows the young child to begin to attain self-control and gradually to delay gratification impulses. It gives the child a way of expressing

his feelings other than acting them out behaviourally” (Daniel, et al., 2010, p. 162).

Language plays a vital role in learning and relationships. Fine (1971) suggests that “mastery of language and gestures is crucial for the preschool child in that it permits an understanding of and participation in interaction” (p.42). While “a responsive and emotionally supportive parent provides an interactive environment for young children to engage in reciprocal verbal and nonverbal exchanges that are stimulating and rewarding for the child” (Pungello, et al., 2009, p. 545), there are also individual differences that influence language development. Daniel et al. (2010) state that, “the sequencing of developmental milestones is much more consistent than is the actual age at which they are attained. We see great variation between different children of the same age” (p. 145).

Abbey’s older son Adam (11 years old), did not have the same language difficulties as her younger son Alan (6 years old) did, though they were raised by the same parents in a similar environment. Birth order could be considered as a contributing factor to Adam and Alan’s differences, as there is a difference in the interactions which firstborn and second born children experience, though this may not always effect language development. Oshima-Takane, Goodz and Derevensky (1996) studied the interactions of sixteen firstborn children and sixteen second born children. They found that while second born children do not have as many conversations directed towards them as children who are firstborn, they learn from the conversations that they hear around them. “The presence of an older sibling provides second born children with a varied linguistic environment that facilitates pronoun development” (Oshima-Takane, et al., 1996, p. 633).

Konig (2004) discusses the different roles that children have in the family depending on their birth order. He states from his observations that “the nature of every second child is totally different from that of the first. The second child rarely has the intention of catching up with its elder brother or sister . . . born into this special place in order to fulfill an entirely different task within the web of mankind’s life” (Konig, 2004, p. 55). This is reflected in the unique qualities that each of the participants recognized in their children and the different roles of the first and second born, as in the case of Adam and Alan.

Reading and writing

The observations reported by the participants of their child's achievements in reading and writing are of interest. This study did not employ perspectives of others, such as teachers to verify these claims. The perspective of early childhood professionals or teachers may or may not have supported those of the participants. School reports and other formal documents could be included in further studies, giving another perspective on the regression or progress observed by parents. Pre and post tests could be used to evaluate a child's achievement on and off-diet. For example children could complete writing samples before they start an elimination diet, when they are on-diet, during challenges and when a reaction is apparent. Children could also reflect on their experiences when completing each of the tasks in a journal.

Concentration

Camille talked about how personally she could concentrate better when she ate on-diet. Donna talked about how her son Dale was able to concentrate for longer when he ate on-diet. Part of Attention Deficit Hyperactivity Disorders (ADHD) is the inability to attend to a task. Bellisle (2004) suggests that considering that there has been an increased prevalence of behaviour disorders and an increased use of food additives, often in processed foods, that "the potential contribution of dietary substances to the problem deserves vigilant consideration" (S228). This was confirmed in a study by Egger, Carter, Graham, Gumley and Soothill (1985) who highlight the multifactorial nature of hyperactivity and believe that, "the suggestion that diet may contribute to behaviour disorders in children must be taken seriously" (p. 544).

Classroom behaviour

Two of the participants reported that they believed that the teachers of their children spent too much time on discipline issues (Appendix A213, B211). Abbey discussed the times when she was in the classroom to witness this firsthand. It is unclear as to how Bernice came to this conclusion, though it may have been based on what her daughter Bess had told her. This may or may not be the experience of the teachers and the other children in the class. Their perspectives of the classroom environment would have been interesting to explore and should be considered in further studies.

Parental Values

Feelings of happiness

Each of the participants attributed their heightened feelings of happiness to the changes they made in the family diet. It is possible that other factors in the lives of these participants may have contributed to this improved sense of well being. Many therapies were trialed by the participants (Appendix J) and some were considered very useful. If more than one intervention has been introduced over a period of time, it would be difficult to isolate one of them as responsible for the changes that are experienced. Further discussion with these participants would clarify why they accredited the changes in their diet as the reason for these feelings of happiness.

Instinct

Carter, et al. (1993) suggested that, “if parents notice some effects of diet, efforts should be made to support their exploration of exclusion diets”(p. 568) and that clinicians should give weight to the accounts of parents in relation to their experiences with their child’s food intolerances.

Crook (1980, p. 57) a pediatrician who wrote about his observations of his patients, who were children with hyperactive symptoms, concluded that “I am absolutely certain that what a child eats can make him dull, stupid, and hyperactive.” He also went on to state the need for more double-blind placebo trials to clarify the issue of food intolerance. He then stated, “many effective measures in treating disease and in relieving human suffering have been used by both physicians and laymen alike for decades and even centuries before the reasons for their effectiveness were scientifically explained”(Crook, 1980, p. 57).

“Parenting is a tremendous challenge, and perhaps no parenting dilemma is as difficult to handle as the question of how to respond to concerns about your child’s mental well-being. Asking for advice from friends and family members may confuse the picture further, since any parent who asks for advice will receive it in abundance, and often it will contradict what the unfortunate parent was just told by another trusted friend. Furthermore, no parenting manual will be able to cover the variety of questions that you will have about your child’s emotional well-being”(Strahan, Dixon, & Banks, 2009, p. 228).

Intuition is a useful tool in parenting. Ehrensaft (1997) writes about the difficulties of parenthood and the pitfalls they often experience. She says that parents “become even better when they listen to their own intuition and respond internally to ‘it’s crazy what we are doing’ with a

response that comes more from their 'gut' than from guilt, anxiety, or 'shoulds'"(p. 240). In her journal, Donna said that she had no hard scientific evidence for investigating food intolerance, but had learned to trust her instinct as a parent.

Guilt

Harley, Matthews & Eichman (1978, p. 982) write that, "diet may help to reduce the parents' feelings of guilt or other negative emotions involving their hyperactive child". However, this study revealed that each of the four participants felt guilt through changing diet. Abbey felt guilty for food she had given in the past and the others felt guilty for the restrictions and limitations that were imposed on their children from their food intolerance. This is an area worthy of further investigation.

According to Ehrensaft (1997) the psychological definition of guilt is "an anguished state of mind arising out of an internal conflict" (p. 74). Exactly what has caused this conflict for the participants remains unclear. Parents are not entirely responsible for either the good or the bad in their children, and they are not supposed to be perfect (Ehrensaft, 1997). Parents who love their children and demonstrate a commitment to them are "good enough" (Ehrensaft, 1997, p. 240). Most parents are good and have "no need to feel as guilty as they do" (Ehrensaft, 1997, p. 239). The participants in this study demonstrate their commitment to their children through their willingness to investigate food intolerance issues, yet they have an internal conflict which is creating feelings of guilt.

Beliefs about medication

The participants in this study used diet rather than medical intervention for health and behavioural issues. Camille, Bernice and Donna spoke of their distrust and caution of health professionals. These beliefs may have motivated their decision to investigate food intolerance, or these beliefs may have arisen as a result of their decision to explore food intolerance. It brings the question to mind as to whether their views are shared by others in the Food Intolerance Network and whether this is another reason that they were drawn to this group.

Bernice and Donna shared how their extended family often held different beliefs to them in regards to medical interventions (Appendix B124, D123). This extends the differences in beliefs

beyond food intolerance to deeper issues of health and medicine. It heightens the issue of difference on both sides, and the need for tolerance to overcome the tension that it could create.

Autism

Abbey and Donna both mentioned they had read about food intolerance relieving autistic symptoms. Reading accounts of people with autism, they learned that food could play a part in alleviating the symptoms associated with autism.

Following are examples of two autobiographies which describe the personal experiences of people with autism and food intolerance. Donna Williams (1993) describes in her book how understanding her food intolerance helped her to manage her autistic symptoms while functioning in her everyday life. Jodi Shaw (2002), a twelve year old boy with autism, attributes his improved concentration, temperament and social skills to his gluten and casein free diet. From these accounts it would seem that discovering individual food intolerance can help to improve the well being of people with autism. The participants in this study also experienced better health outcomes through managing their food intolerance.

Whole answer

“Parents are typically attracted to the diet treatment program because of dissatisfaction with other therapies that have been tried. They are frequently seeking alternatives to medication and other treatment modalities because of deeply felt negative attitudes and convictions regarding synthetic substances and positive attitudes toward natural food products” (Harley, Matthews, et al., 1978, p. 982).

Each participant shared a dynamic and individual journey with food intolerance. They all had stories of trying different approaches and achieving various results. Donna advised that “you have to keep searching” (Appendix D11) and admitted that, “we are not quite where we want to be” (Appendix D63). Bernice also talked about the adjustment that she makes to their diet and said that recently they had to “pull back” on salicylates, “hoping that’ll do it” (Appendix B29). And Camille confessed that while food made a difference, it “wasn’t the whole answer” for her (Appendix C109). Both Abbey and Camille are currently seeing a Biomedical GP (Appendix A133, C98). A biomedical approach uses blood tests to make a diagnosis, and then recommend vitamin supplements and lifestyle changes.

Discussion Employing Planes of Focus

When using Grounded theory the “data speak directly to you” (O'Toole & Beckett, 2010, p. 171), however this chapter employs Rogoff's (1995) “personal, interpersonal and community planes of focus” (p. 160). Each of these will be considered individually with reference to their intricate interrelatedness (Figure 2, p.64). Rogoff (1995, p. 140) says that “the parts making up a whole activity or event can be considered separately as foreground without losing track of their inherent interdependence in the whole”. In terms of this research it will provide a framework to consider the stories of the participants in a wholistic way.

Personal Plane

All four participants spoke about the difference that food made to their personal lives (Appendix A7, B166, C32, D136). These differences were positive and included a range of physical, mental and emotional issues. The participants believed that many parts of their life had changed for the better by eating a diet considering their food intolerance.

The participants expressed an increased feeling of happiness in their personal lives and with their families (Appendix A52, B85, C149, D81). Other words used to describe how participants felt in their life included “stable” (Appendix C149), “balanced” (Appendix B68) and “I’m much healthier” (Appendix D87). It was Bernice who summed it up by saying, “when we’re on diet it’s really amazing the way we relate to each other, so I think we have discovered a lot about how to be a family together. It has improved our relationships” (Appendix B11).

Two of the participants experienced less anxiety themselves (Appendix B91, C55) and the other two believe that their children suffered fewer anxiety issues (Appendix A121, D3). Improved sleeping behaviours were experienced by Bernice, Donna and also observed in their children (Appendix B231, D63).

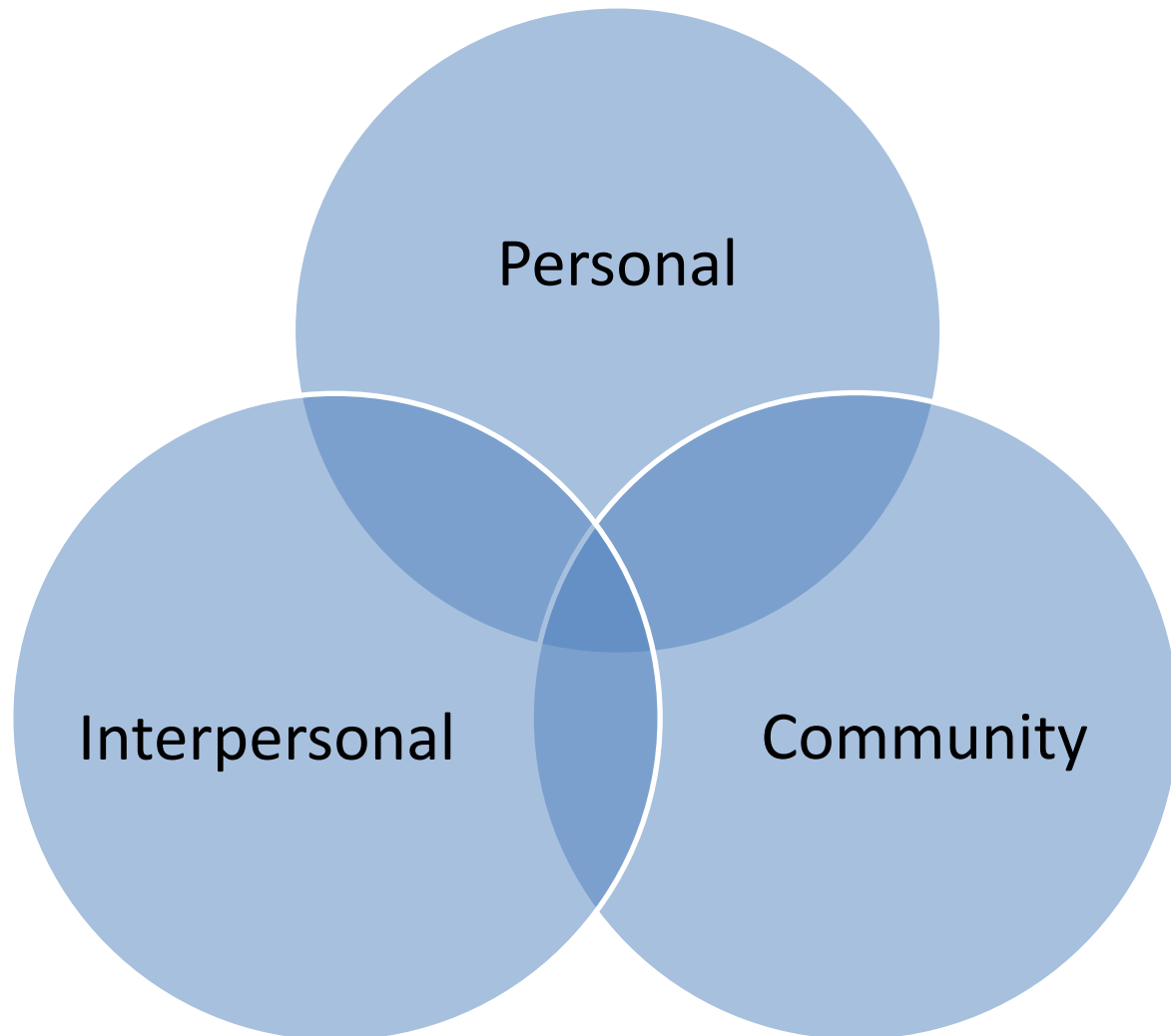


Figure 2 –Rogoff’s (1995) planes of analysis

Behaviour management strategies worked better for Donna and Bernice when they ate foods well tolerated or on-diet (D175, B195). Donna felt that this was because she was a more empathetic parent since she learned about food intolerance (Appendix D105). She empathized with her son believing that his behaviour was caused by his reaction to something he had eaten. Bernice felt that she was given “the child and the life that I had always known was there” (Appendix B191). While Abbey said that she “saw a glimpse of the real child” (Appendix A54).

Bernice felt more friendly (Appendix B156) and witnessed her daughter Bess being able to make more friends (Appendix B77). She also felt that Bess had made great improvements in her reading and writing since being on-diet (Appendix B52). Camille found it easier to concentrate and Donna believes that her son Dale stays on task longer when on-diet (Appendix C53, D136)

On a personal level, life had improved for the participants and their families. The participants reported many positive physical, mental and emotional changes in themselves and in their family. However, the participants shared the hardships associated with the changes made to accommodate food intolerances. Bernice and Camille reflected on the increased workload in thinking and preparing meals (Appendix B319, C195). Feelings of frustration were expressed by Camille (Appendix C3, C41), and Donna talked about the “increased worry” (Appendix D174) that she felt. Personally, the dietary changes required more time (Appendix B2), “limited (food) choices, lots of cooking” (Appendix C1). While Abbey did not think that dietary changes were hard, she agreed that, “it’s difficult to start” (Appendix A248).

Each of the four participants expressed an increased sense of guilt in making these dietary changes. Bernice, Camille and Donna felt responsibility for the restrictions that the diet placed on their children (Appendix B309, C214, D178), even though it resulted in so many benefits. Abbey felt guilty about the food that she had previously fed her children, not knowing that it was making them sick (Appendix A260). She was able to comfort other parents who felt they had been “poisoning” their child, by saying “you can only do what you know” (Appendix A57, A58). These participants were doing what they knew to be best yet they felt an “internal conflict” (Ehrensaft, 1997, p. 74) because their children were restricted in what they could eat. According to Ehrensaft (1997, p. 239) these participants are “good” parents because they show love and commitment to their children, so they do not need to feel guilty. She suggests that parents need to ask, “who am I doing this for, me or my child?” (Ehrensaft, 1997, p. 240), and if the answer is often one sided in either direction then parents need to correct the ratio to be more balanced. It is necessary to consider the physical, mental and emotional needs of both the parent and the child in making decisions.

Interpersonal Plane

In the interviews, participants shared their experiences to illustrate how being on-diet positively

changed aspects of their family life. Some benefits were expected and others were not. While things may have improved for these families, other aspects of the participants' lives were described as becoming more difficult. Abbey described starting the diet as difficult and explained, "it's probably difficult mentally, to be different and because it's not accepted, people probably look at you like you're some kind of psycho person" (Appendix A48).

It would seem that these difficulties do not follow a linear path as it is also difficult for the participants to deal with how others perceive them. At the outset of the interview with Bernice, when asked about the issues associated with food intolerance, she said, "socialising can be difficult, particularly with people that don't have food issues. Everything revolves around food" (Appendix B1). Bernice found it easier to socialize with people who had food issues or sensitivities to foods, and referred to an upcoming party where she would be inviting people from her online discussion group (Appendix B259). She said, "I actually prefer to do social events with these two and their families because I don't have to worry about all the guff that usually happens" (Appendix B259).

As pointed out in the interview with Bernice, socialising with family and friends often incorporates eating which becomes complicated when there are dietary restrictions to consider. This can lead to fewer social opportunities for people with a food intolerance and possible isolation.

Participants in this study were drawn to socialize with those who had experience with food intolerance. Those who have a food intolerance themselves are often more sympathetic of others with food intolerances, even if they have different sensitivities. They are more aware of the needs of those with food intolerance issues because of their personal experiences and are less likely to be skeptical as someone with no experience in food intolerance.

On several occasions Donna talked about how other parents "might disagree" (Appendix D101) with her approach to give her son Dale more "empathy" when he's having a tantrum (Appendix D105). She also said,

180. I'm not giving him certain vegetables other

181. people would argue those are very healthy vegetables and would say I'm depriving my child

182. of healthy vegetables because yeah. I'm sure other people look at what I give him on his

183. birthday, what his special treats are and say, 'you are depriving this child, it's his birthday'" (Appendix D180).

When asked to talk about her experiences in explaining these diets to people, she said, “oh, I don’t do it very often” (Appendix D123). This is a huge part of her life and she chooses not to talk about it with many people as she has found most people are not interested (Appendix D130).

While communication with those who do not understand food intolerance seems to have become less comfortable for these participants, the internet has been an integral part in their food intolerance journey. Camille first came to learn about food intolerance on the internet. All of the participants have used the internet to get information, and they all speak favourably of their experiences with the online support networks. Bernice describes them as “our life line” (Appendix B140). She said,

“I couldn’t have done it without that resource. If ever I’m having difficulty I jump onto the computer. Also I spend quite a bit of time talking to others that are having difficulties . . . It’s actually provided me with two of my closest friends who are failsafers now” (Appendix B256).

Having a forum to share experiences, questions, mistakes and successes has provided these participants with friendship, knowledge and support. It has given them opportunities to share what they have learned. Camille found comfort in the similarities she had with the people in these groups and she said, “it’s sort of interesting at least on one level you hear about other people who are struggling to have some sort of life while having a ridiculous diet. It’s quite nice” (Appendix C120). Bernice felt that, “it often lightens your load when you see others worse off” (Appendix B258).

Camille also reflected on her discussion group and said that some aspects were relevant while others were irrelevant (Appendix C118) and Donna made note of the fact that “there is so much untested on the internet” (Appendix D50). Bernice says, “oh, the crap that people come out with on these groups and you’ve got to try and keep bringing them back to focus, it’s very awkward” (Appendix B40). It seems to be easier for the participants to deal with the differences in opinions when it comes to discussion forums on the internet, as they continue to use them despite the challenges. Bernice summed it up by saying, “it’s worth the price I guess” (Appendix B137).

Bernice mentioned the difficulties she had communicating with teachers about her daughter Bess' food intolerance (Appendix B38). She also relayed a story of Bess' teachers who planned a chocolate day every Thursday (Appendix B43). "They'd have hot chocolates or bars of chocolate or whatever, it adds difficulty to things you know" (Appendix B43). Bernice had to make chocolate cupcakes at home or organize a special kind of chocolate for Bess to take each week which she would be able to tolerate with her sensitivities.

A story to illustrate the difficulty communicating about their diet with the staff at the childcare centre was told by Donna.

127. I say no tomatoes. They say, "what happens if he has tomatoes, is it
128. like an allergic reaction?" I say, it's more like food intolerance, and the eyes start to glaze over
129. and they say, "oh look at these things" and the eyes completely glaze over and they are like
130. looking around the room. And you're like right, OK, interest level zero. Then one day when the
131. normal chef was on holidays they made spaghetti bolognese. And I was asking, "oh what did
132. (Dale) have? "Yeah he had spaghetti bolognese". "Oh well what kind of sauce did he have on it,
133. did he just have meat?" "No, tomato sauce". I'm like, "isn't tomatoes on his no list?" And they're
134. like, "oh do you mean like canned tomatoes, we thought you just meant not fresh tomatoes." A
135. tomato is a tomato (Appendix D130).

She explains that,

158. really don't want him to have, but within the rest of it they have a lot of flexibility. He has a lot
159. of food at childcare that he wouldn't have at home, and that's partly because I can't think of
160. alternatives for them and partly because I don't want the look of 'you're an absolutely crazy
161. parent' (Appendix D, 158).

Bernice and Donna spoke about their values and how they related to their extended family. Donna spoke about her approach to health and it's similarity to her mother's approach. Bernice talked of a differing experience with her mother and not having similar values related to health. She reports that her mother would rather take a pill and comments on how it is common for some people to have this approach (Appendix B124).

All four participants were influenced to investigate food intolerance by non family members. Abbey heard about the elimination diet from a friend, Bernice was given a book from a friend,

Donna was told by a lactation consultant to try an elimination diet and Camille found information about food intolerance on the internet.

In talking about the discussion groups in which she participates, Bernice said, “actually now I’ve developed one that combines the two (failsafe/fructose) and there’s 40 or 50 people on that so far” (Appendix B130). This reveals another application of the internet, that new groups can be easily created to accommodate one’s changing needs.

Bernice attempts to describe her struggle by saying, “you’re fighting against what everyone is telling you that variety is healthy” (Appendix B288). Differences can divide in our society, however with these participants, there seem to be some differences that they can live with and others they cannot.

Community Plane

The Health system, the World Wide Web and the Education system are the various contexts to be discussed in the community plane of focus. The interrelatedness of the three planes becomes clearer as each of these is discussed.

Health system

The health system includes Complementary and Alternative medicines (CAM) like chiropractors or naturopaths, and conventional medical practices. Both are explored by the participants with varying outcomes (Appendix J). Donna recalls how difficult it was to find someone to believe her about Dale’s food allergies and how “instrumental” it was that her lactation consultant took her seriously (Appendix D83). Carter, Urbanowicz & Hemsley, (1993) said that clinicians should give weight to the accounts of parents in relation to their experiences with their child’s food intolerances. As mentioned earlier, Carter, et al.,(1993) suggests that, “if parents notice some effects of diet, efforts should be made to support their exploration of exclusion diets” (p. 568).

As mentioned previously William Crook (1980) a pediatrician believes that health professionals need to consider the best interests of their patients and their families. He understands the reluctance to initiate an elimination diet, though he believes it is a safe therapy to explore with families dealing with hyperactivity issues. In her journal, Donna wrote that despite the lack of

support from health professionals that she had learned to trust her instinct as a parent even though she had no hard scientific evidence to support her beliefs.

Crook (1980) suggested the need for more double-blind placebo trials to clarify the controversy around the issue of food intolerance. Mentioned formerly, he then describes how treatments without scientific explanations were used effectively for many years. Kopelman (2002, p. 41) supports this by saying, “not all conventional treatments advocated within the professional medical community are supported by rigorous testing”.

“Personal experiences of illness and healing carry significant evidentiary weight. If unacknowledged or contested by conventional medicine because of incongruities with medically accepted facts, personal experience may in fact trump medical/scientific claims and be considered the ultimate source of authoritative knowledge”(O'Connor, 2002, p. 63).

Further on this point Brody (2002, p. 82) states, “most criticisms of CAM grounded in PE (Personal Experience), turn out on further study to be quite similar to criticisms that could equally well be lodged against conventional medicine”.

Donna talked about a conversation that she had with her sister, about her nephew’s behaviour. Her nephew was “absolutely raging at home. Like he would lose his temper and he would be really quite aggressive” (Appendix D168). Her sister called her and said that she was going to take him to the doctor first. At that time, Donna reported that she did not believe that it was necessary for her sister to consult a doctor, however now she would say, “yes, absolutely go to the GP (General Practitioner) and find out if there’s any issues”(Appendix D175). However Donna also said that she would not just accept something that a General Practitioner said based on their authority (Appendix D115) and mentioned several times how she is “more confident about pursuing my instincts”(Appendix D91).

Bernice talks about how she may not have done the elimination diet properly. She said that she did not consult with a dietician because of her loathing of health professionals and explains that she would rather figure things out herself (Appendix B99). However Bernice talks about her desire for the health profession to recognize the difficulties she faces in dealing with her food

intolerances, possibly especially since she did not feel that health professionals had listened to her earlier. Bernice described her feelings about the health system in saying, “I feel like it’s a bit of a handicap (to have food intolerances) in some ways, you know and it’s not acknowledged like if I had a disability I’d get some sort of assistance or something” (Appendix B5). Bernice would like the health system to acknowledge food intolerance as a health condition with which some people may require more help or assistance.

Each participant shared a dynamic and individual journey with food intolerance. They all had stories of trying different approaches and achieving various results (Appendix J). Donna described how the journey is about continually seeking answers (Appendix D11) and admitted that there is still more that she would like to achieve (Appendix D63). Bernice also talked about recently having to make changes to their diets and reduce salicylates for her daughter’s health (Appendix B29). Camille confessed that while food made a difference that there were other things that contributed to her well being (Appendix C109). Abbey, her children, and Camille are currently seeing a Biomedical GP (Appendix A133, C98) and hope to discover more about how to manage their health issues.

“Parents are typically attracted to the diet treatment program because of dissatisfaction with other therapies that have been tried. They are frequently seeking alternatives to medication and other treatment modalities because of deeply felt negative attitudes and convictions regarding synthetic substances and positive attitudes toward natural food products” (Harley, Matthews, et al., 1978, p. 982).

All the participants had explored alternative, non-medical treatments. They all talked about the other therapies they had tried (Appendix J). Only two participants talked about their views on medication. Camille tried medication for her chronic fatigue. While she felt better she did not believe that it was because of the tablets and she did not want to take the tablets unless it was necessary (Appendix C96). Bernice made reference to how her mother chose to take medication rather than investigating food intolerance (Appendix B124).

World wide web

The World Wide Web is a rapidly developing inclusive resource, though it excludes those who do not and cannot use computers . Its inclusiveness, while positive for the participants in this study,

could also be a drawback as everyone, qualified or not, can access and contribute to these discussion groups. The content of what is written on these forums is not censored or moderated. Anybody with enough knowledge of computers can participate in these discussion groups, regardless of their qualifications, credentials or opinions. Therefore the participants found they needed to exercise discretion when reading and writing for the posts on these sites.

The participants in this study found the internet useful for information, discussions and social networking. They were able to find like minded people through these discussion groups. Participants suggested that it was easier to communicate using the internet, even though they sometimes disagreed. The reasons for this are not easy to elicit. It may be due to the fact that they are communicating electronically, or it may be their mutual understanding of food intolerance that helps them to work through other differences. It would seem that they find it easier to ignore, walk away or dismiss comments from those in these online discussion groups (L.Hallowell, personal communication, April 24, 2012).

Education system

The Education system gives rise to tension for these participants. Bernice described how she had to tell her daughter's (Bess') teachers every year about her food intolerance issues and how the information did not seem to be passed on (Appendix B38). One of Bess' teachers, to add interest to the school week, had chocolate day every Thursday and made it hard for her to feel included in the class because she was not able to participate in the same way as the other students (Appendix B43). While this could possibly be an isolated incident with Bess and this particular teacher, the education system may also play a role in how they prepare teachers to be inclusive of their students. The education system may need to consider promoting strategies to gather information about their students to help them plan learning experiences which would include each member of the class. Through considering the dietary needs of the students in their class, teachers can avoid potentially alienating experiences.

The two participants with school aged children believed that teachers spent too much time on behaviour management and expressed how they felt this was a concern for the learning of their children (Appendix A213, B211). Teachers are part of an education system which is responsible in training teachers to engage students in learning while managing their behaviour. Ongoing support also needs to be available for teachers with behaviour management issues in their class.

Purdie, Hattie and Carroll, (2002) examined 74 studies to find which interventions for children with ADHD produced better educational outcomes. They found that much of the research was based in the psychological and medical disciplines, and few studies had an educational background. “If educational outcomes are to be enhanced for ADHD students, then educational rather than medical answers need to be provided” (Purdie, et al., 2002, p. 88).

Graham (2006) talks about the changes to the Queensland education system that could explain the increase in the diagnosis of behaviour disorders. Things like:

“lowering of school entry ages (pre-school costs), increased emphasis on academic learning and seat work (parent pressure on teachers too), pressure for children to learn to read earlier and better, crowding of the curriculum, the shortening of children’s recess and lunch times” (Graham, p. 15).

These are decisions made by the education system and society, not necessarily individual teachers. As a result, it is the education system and our society which has a responsibility to ensure that educational practices give maximum support for its teachers, students and families.

Conclusion

“A sociocultural analysis requires considering how individuals, groups and communities transform as they together constitute and are constituted by sociocultural activity”(Rogoff, 1995, p. 161). The participants in this study perceived many positive changes for themselves and their families once they adopted a diet in accordance with their food intolerance, including their children’s behaviour and learning. However, they experienced difficulties on the interpersonal and community planes. O’Connor (2002, p. 69) suggests, “laypeople’s experiences of effects outside the range of scientific familiarity or statistical significance ought to pique our interest, even if difficult to investigate”.

Rogoff (2003, p. 354) believes that, “rather than assuming that other communities ways are simply either noble or barbaric, it is to everyone’s benefit to learn from each other’s ways”. If each individual was to adopt a more broadminded approach to food intolerance, relationships with this minority group would be enriched and communities could become be more accommodating and

function more effectively. Remembering that culture is something to which people contribute and create, and it is not just an entity of influence on individuals (Rogoff, 2003).

With food allergies rising to around 10% of the population in Australia (Allen, et al., 2009), beliefs, values and assumptions about food intolerance and allergies need to change. The challenge is to develop a culture that has “capacity for constantly expanding the range and accuracy of one’s perceptions of meanings” (Dewey, 1966, p. 123).

These participants believed that there was a link between food, behaviour and learning. The perceptions of the parents in this study revealed that on a personal level their lives are better from understanding their food intolerances. This is despite reports that their relationships with their extended families have become more difficult and their sense of intolerance from schools, child care centres and community groups. All parents need people to support them in their parenting journey, especially parents dealing with food intolerance issues. The children in these families need teachers and carers who recognize their individual needs and aspire to accommodate them in an inclusive environment. More awareness of food intolerance issues is needed to create more tolerant communities for people with a food intolerance.

Justification for Using Two Discussion Approaches

Using two discussion approaches was beneficial to this study as it provided a multifaceted perspective on the data. It gave the researcher different approaches to draw out multiple dimensions from the data, looking beyond the surface to reveal more in depth issues.

The grounded theory approach allowed the researcher to look “unmotivated” (Psathas, 1995) at the data presented. It gave the researcher a framework to look beyond what may have been expected and to hear what the data revealed in itself. The data divulged recurring themes among the participants. Some of the participants answered the questions in a similar way and when their responses were put together, the similarities and differences became apparent. Sometimes similar words were used, and other times participants elaborated on their answers to provide further understanding around the issue.

The socio-cultural approach was able to combine the themes into the three planes of focus from Rogoff (1995) and create a fresh perspective on the data. It gave the researcher the opportunity to consider the personal, interpersonal and community planes within the data. The three planes provided a framework in which to think about the data in new ways and give further insights into the participants’ stories. It provided a basis to connect the data in different ways and brought a number of diverse themes to light.

The feelings expressed by the participants were given more significance and meaning when they were aligned on a personal, interpersonal and community level. The participants’ feelings were different on each of these levels and this was only recognized through the use of this framework. The participants in this study felt good, on a personal level, about the changes they had made to the family diet to accommodate food intolerances. Yet they shared frustration on an interpersonal and community level based on the indifference they experienced from family members, teachers and childcare workers. Some of the participants also expressed a deep concern for the welfare of others in the community with health issues that they felt may be attributed to food intolerance.

Vital connections were made in the data using the grounded approach, while more complex

connections were formed with the socio-cultural approach. Both approaches played a significant role in the discussion of this research. Using one approach without the other would have only told part of the participants' experiences. A grounded approach together with a sociocultural framework contributed to the acumen achieved in this research.

Limitations and Implications for Further Research

The following limitations and implications are highlighted in this chapter, including the size of study and the types of participants. While four participants is a manageable size study for a single researcher and is enough to create interest in what may be learned from a larger study with a bigger sample size, it is not enough to draw any firm conclusions about the whole 160 members of the Food Intolerance Network or about issues related to food intolerance in the general community. However this small sample size gave us an indepth understanding of the beliefs and values of each participant.

The study was structured around understanding the parental view point of their child's food intolerance. Parents are an important resource to consider in understanding a child's food intolerance issues, however the view of the husbands and fathers in these families is silent in this study. It did not exclude fathers, however only mothers of these children volunteered to participate. While this study allowed us to delve into the maternal perspective on food intolerance, it remains a significant limitation of this study to only have this perspective. The male voice is not expressed through this study and this could be an aspect worthy to consider in future studies. Further research could review the beliefs and values of men around food intolerance. It could investigate further the role that men have in food choices in the family, and what their beliefs are about food, behaviour and learning. The number of male members of the food intolerance network could be explored along with how males feel about and engage with food intolerance and alternative therapies.

The perspectives of the pre-school and school teachers on the learning and behaviour of the children involved would have been particularly useful. Other significant people in a child's life, grandparents, other family members and carers could have also been included in this research and enhanced it further. Medical professionals and teachers did not have a direct part in this research, and while they were mentioned by some of the participants, this can only be considered as the point of view of the participant.

A larger study taking a holistic approach to the child and considering the perspectives of all the significant people in a child's life including, mothers and fathers, grandparents, teachers, childcare

workers, medical professionals and the child themselves, could present a broader understanding of the types of behaviours observed and the many varied understandings of food intolerance. It would be interesting to identify the way that these observations may interplay with each other. It could also include how they understand each other's perspectives.

Future studies could explore the role that schools and teachers play in family food choices. The beliefs and values of educators in regards to food intolerance could be investigated. Is there a need to be aware of creating tolerant environments for people with food intolerances? Are there measures to be proactive in supporting and educating others in how to be supportive of these families? Does education need to play a bigger part in supporting families with food intolerances? Are teachers influential in the food choices of families and if so, in what ways?

One aspect of this study was the age range of the participant's children (Figure 1, p.40). Camille and Donna had pre-school children aged between two and four years, and Bernice and Abbey's children were aged between seven and fourteen years. This study includes data from a broad range of age groups, though its limitation is that it does not focus specifically on one age group. While they all began the elimination diet with pre-school children, the experiences of those with older children were different compared to those with younger children. This could be due to the handing of responsibility to the children, the children's attitudes towards the diet as they get older, new information that is now available, different support networks, the memory of events or that the older children are further through the journey. Those with older children had to try and remember what they experienced years before, whereas those with younger children were able to draw on more recent events. It would be beneficial to conduct a study of parental perceptions particularly focused on children in the pre-school age group to verify the findings from this research and those mentioned in the review.

Children did not directly take part in this study. We learned the mother's beliefs of their child's feelings. We do not know the child's own thoughts about food intolerance, food choices or behaviour and learning. There is a need for research about food intolerance from a child's point of view. A qualitative study could include video recordings of children during dramatic play in a home corner to get a sense of their perception of food choices and preparation in their family. It could also gauge their understanding of the family values about food and food intolerance issues.

These perceptions and understandings could then be discussed with the children to establish their personal attitudes and opinions.

A study which asked children directly about their experiences with food intolerance could be valuable in this area and whether they think that food influences behaviour or learning. Smith (2011) states that, “young children’s participation rights entitle them to have their voices heard and taken into account” (p. 11). She suggests research with children can be conducted in a more “contextualized way” by “trying to understand children’s standpoints in the contexts of their own lives” (p. 12). “If children’s ‘voice’ is being sought, then children have to be positioned as participating subjects, knowers and social actors, rather than objects of the researcher’s gaze” (Smith, 2011, p. 14).

The models of learning (Matsov, 1999; Rogoff, 1994) explained in the literature review, were not directly explored with the participants in this study. The beliefs of participants about these models could be assumed from the data obtained, but it was not discussed in detail. A future study could develop these with parents further, to gain more insights into their beliefs about learning.

Each participant in this study had a unique story to tell about their experiences with food intolerance. This suggests that food intolerance is not general, it is specific to the individual. The health literature reviewed for this study, documented tests of particular food additives or colours on children, either from clinical trials or the general population. This qualitative scientific type of approach to research in the food intolerance area is limited because food intolerance is difficult to generalise. Different people can be sensitive to different substances and food groups in varying degrees, therefore testing a single substance may not be a true indication of a person’s sensitivity or intolerance. People with similar symptoms may not all be sensitive to one type of food and those who are sensitive to a particular type of food may not have the same symptoms. Symptoms can look different in each person, where one might have sleep issues, another could be more irritable. By taking the existing research further, our knowledge about food intolerance can grow.

Willett, Singer and Martin (1998) suggest that “to measure individual change well, a truly longitudinal perspective must be adopted” (p. 397). There is potential to understand more about

food intolerance through longitudinal studies of children and their diets. Following groups of children on specific elimination diets with their parents and comparing their development with a pretest and a post test, we would see their progress over a longer period of time. Each child's school results could be recorded through existing tests like the Naplan. Teacher perspectives could be used in conjunction with parent observations. This approach could expand on the Rowe Behaviour Rating Inventory (Rowe, 1988) which was designed to be used in educational research. Some of the behaviours included are, over-activity, restlessness, impulsiveness, distractibility, low frustration tolerance, overt aggression, short attention span and sleep disturbance. The varied behaviours described by the participants in this study could also be included.

There needs to be further research into food intolerance issues in the preschool years. Future studies could attempt to explain why, as mentioned in the literature review, the preschool age group responds more frequently than older children to trials. It would be of interest to conduct a study to focus particularly on families with pre-school aged children. Those who volunteered for this study had preschool children when they began investigating food intolerance, however at the time of the study some of them were of school and high school age. These participants had to rely on their memory to recall their approach to managing the diet. Future studies could explore reasons for the seemingly prevalent food intolerance issues in preschoolers. They could explore issues related to this age group including the time spent with parents, expectations, ability to learn social norms, types of environments in which they are observed. Development plays a part, but environmental factors are critical.

Of particular interest in this study were participants admitting guilt related to making changes to their families diets to accommodate food intolerances. The further exploration of this guilt was of interest especially since they believed that they were doing their best for their child. Participants could describe the inner conflict that they felt to establish why they felt responsible and how it could be changed.

There is a possibility that parents are more patient towards their children because of the guilt they feel related to the changes they have made to their diet. Further research could establish if an understanding of food intolerance has changed their attitude toward their child's behaviour, or if it is because they have changed their diet too. It is possible that parents who are on-diet, may be more able to deal with their child's behaviour effectively. A future study could explore further

how parents who modify their diet to accommodate their food intolerance may be better able to manage their child's behaviour as they have achieved a sense of personal well being.

Future research also needs to consider the support networks available in our communities for families who want to try alternative and complimentary therapies. There are discussion groups on the internet and the participants in this study felt they were very effective. Further research could explore the effects of internet support networks and their impact on marginalized groups. It could suggest ways to improve these valuable forums and make similar support services available to a wider range of people. It could also establish whether there is a need to sort the types of comments and information presented, and if so, how this could be achieved.

The participants in this study perceived the need for more tolerance in our communities towards people with food intolerance. They described their frustration in communicating with childcare providers and schools about their child's needs in regards to food intolerance. Further research could investigate effective strategies to build awareness of food intolerance issues among professionals caring for children and in the broader community to improve communication.

The limitations observed in this study suggest many areas of interest for further studies. The perspectives of children and other significant people in a child's life is one place to start. Research that can contribute to building positive communication between families, schools and community groups about food intolerance is needed. There is a need to continue to provide parents who wish to undertake this journey with essential skills to navigate their food intolerance wisely. Knowing that one diet does not work for all persons, future research needs to take a longitudinal approach, looking more broadly at symptoms and trigger foods related to food intolerance, while incorporating health, education and psychology perspectives.

Conclusion

The individual nature of food intolerance has been highlighted in this study by the research cited and the participants themselves. Foods that may be good for some can cause severe symptoms in others. If Feingold's (1975) hypothesis was to be rewritten today, it would say that some food and food additives can cause a variety of symptoms, including hyperactivity, sleep disturbances and health issues. This could implicate the way in which health is taught to children and how food related activities are conducted in our schools.

There are different levels of acceptance between food allergy and food intolerance. The signs and symptoms of food allergy are more outward and seem to be therefore easier for people to accept and understand. Food intolerance does not necessarily mean that you cannot eat certain foods, as in some cases a limited amount can be consumed. Acceptable quantities of any type of food can vary from one person to the next and a person's individual tolerance can vary at different times in their lives. With food intolerance, symptoms occur when a certain amount of those types of foods have been consumed. Some foods might be eaten sparingly, while other foods need to be avoided completely.

When one's belief system or health requires the restriction of certain food types, there is a potential for seclusion, exclusion or both, depending on the availability and social understanding of the diet. Catering for allergies is particularly difficult and it would be especially problematic for those with allergies to eat away from home. This must have a particularly isolating effect on the whole family with the important place that food holds in our social culture.

This study found that people who are investigating food intolerance find many social difficulties associated with their decisions. Close families and friends can seem to distance themselves or the participants themselves may begin to avoid social interactions with people who do not understand food intolerance. Since it is not widely known or understood, it leaves a small minority group of people, happy to socialize with each other even if it is on the internet. The support received from each other is enough to sustain them as they go through a difficult transition in transforming their eating habits to investigate food intolerance issues.

People with an understanding of food intolerance are able to communicate with each other about products and services that have worked for them on the Food Intolerance Network. The internet has been a way for them to maintain a sense of community with others of like mind, though they may not live in physical proximity to each other. It has provided opportunities for this minority group to discuss their ideas in a way that has not been possible prior to this medium being so readily available and as a result has played an important role in the journey of these participants. Referring to gifted children, Gilligan (1996) states that, “if they could find others like themselves, their social problems might well disappear”, and this sentiment could also relate to minority groups like those in this study.

A socio-cultural perspective considered the social aspect of food intolerance as many people see eating as an opportunity to be social. Catching up with friends and family usually happens over a meal. Ordering or making a different meal to accommodate food intolerances can exacerbate the feeling of being different and may be isolating for some people. Eating different food is conspicuous as it is an integral part of what we do and is needed for survival. We do it frequently out of necessity and there are few things that we do more often. The food we eat can be seen by all those with whom we work and associate. Other beliefs do not need to be disclosed unless a person feels comfortable to do so, though what we choose to eat is often visible and is a readily accepted topic of conversation.

Food preferences based on religious beliefs, such as halal and kosher, are more widely accepted and prominent. Understandably, these minority groups often choose to live near each other. They may do this to be close to the synagogue or other landmark or community that brings them together. As a result of living in close proximity, either existing businesses adapt or new businesses appear to cater for the food preferences of their local clientele. Those with specific dietary requirements appreciate having their preferred food options readily available. Vegan and gluten free options appear more regularly on menus, as there has been an increasing acceptance of these food preferences in the last twenty-five years. With food allergies and intolerances on the rise it is possible that there will be an even wider acceptance of various diets in the future.

Limited food choices when eating out is just one of the difficulties faced by parents wanting to begin to investigate food intolerance. The complexity of recognizing an individual journey coupled

with so many elimination diets to choose from also make it hard. Being committed to reading and learning as much as possible, seeing a dietitian, taking extra time to do the shopping and cooking are a few of the changes the participants in this study accepted. Follow this up with increased difficulties socializing and misunderstanding among different community groups, it would be difficult to understand why anyone would do it. For Bernice the difficulties “outweigh” the rewards (Appendix B216).

There were a range of reasons that the participants in this study began to investigate food intolerance from behavioural, personal health to sleep difficulties. The participants experienced success in achieving the goals they set out to achieve with sleep issues, behavioural issues and health issues becoming more manageable. They also discovered unexpected benefits including learning, language development and an ability to think clearly. This emphasizes that there are many symptoms associated with food intolerance and that there may be other symptoms which can be managed through diet other than those that initially motivated the diet.

While the participants all believed that aspects of their lives were much better since they had changed their diets to accommodate their food intolerance, all of them expressed a desire to continue to learn and discover more. Each one talked about the next thing that they would try, as if seeking the next piece to a puzzle. There is a sense that the picture keeps on growing and it may never be finished, continually enhanced. It possibly even grows bigger and clearer but not completed. Life and living is never completed either. We moved into our house and there is still work to be done. I’ve been told that thesis’ are bound, but never finished. Like with many things in life there is always more to do, always more to know, more to add, upkeep and maintain.

The challenge of investigating food intolerance can be seen from different perspectives. Differences can be confronting, especially when they may challenge the choices that we have made. We may struggle to reconcile differences in our minds, other times we justify our logic. Donna spoke about how she was sure other parents looked at the things she did and felt that she was depriving her child (Appendix D180). Parents look and compare at each other. It begins before conception with how long it takes to conceive to the size of the baby when it is born. While comparisons are rarely helpful, it seems to be something we all do. During my interviews for a pilot study and for this research, there were times when the participants talked about another parents choices unfavourably. There were comparisons made between themselves as parents and

other parents. When asked about their child making choices at parties, one reported, “(I) wouldn’t take my own food to a party for them”, referring to another parent who had done this.

Parenting is about making choices that we believe are best for our children. Parents know their children better than anyone else and are best placed to make decisions for, about and with them. Given the same situation, with their knowledge and their children we may make the same decisions as some parents. There may also be times when we need to embrace the many different ways that we can provide for the needs of children. Imagine if we began, “taking difference seriously, treating it as an opportunity rather than a threat and finding ways to relate to others, without making them the same” (Dahlberg, 1999, p. 57). Maybe we would learn more from each other and spend less time criticizing and model this acceptance for our children and change the fabric of our culture to be more inclusive and embracing of differences. We could focus on our common goals and accept that diversity is our strength. It is possible to learn from each other and be enriched by trying different ideas.

The belief that they are being judged by other parents could be part of the cause for the feelings of guilt experienced by the participants in this study. With further acceptance among our communities, there may be less reason for parents investigating food intolerance to feel guilty. It is not necessary to agree with each other, though everyone deserves respect for their values and point of view.

The participants in this study value learning about themselves and being open to new ideas. These are similar values to pioneers who are not afraid to venture into the land of the unknown. They are able to trust their instincts and sort through all the information to find what is necessary and important. They demonstrate the ability to create the better life that they desire through prioritising health, relationships and education.

The participants in this study believe that health, relationships and education are enhanced with a diet that considers individual food intolerances. They hold these values regardless of common popular belief which contradicts their own. These values mean that they have to be prepared to be different to the crowd and be willing to stand as a minority. They believe that it is more important for them to follow their instincts rather than waiting for scientific evidence. These

participants have adopted practices that are conducive to their values and in doing so have questioned the everyday practices accepted by the majority. This takes courage and their reasons for doing it are to achieve a better life for their families, better health, education, relationships and personal wellbeing. At the core of these values is their desire to give their children the best and that is what makes a “good” parent (Ehrensaft, 1997, p. 239). Supporting parents in their decisions as to what they believe is best for their children is the role of our communities and this can be achieved through more tolerance of those with food intolerance.

Personal Conclusion

My personal journey continued along with this research journey. As a researcher immersing myself in the literature, reflecting on the experiences of my participants and their values has been a rewarding experience. Their unique stories have highlighted the diversity among those in the Food Intolerance Network and have given a broad view of the types of issues around food intolerance.

Personally, I started out with my beliefs about food additives, learning and behaviour. These beliefs have grown, developed and even changed as this thesis has evolved. As I consider the experiences of the participants in this study, there are similarities and differences to my own journey. I love a challenge and seem to thrive on doing things that stretch my abilities further than seems possible. My experience is similar to Abbey as we both felt that it was more difficult to adjust to the diet in the beginning (Appendix A248). It was difficult for me to change the beliefs I held about food, though once I had established a new set of values the rest has been surprisingly easy.

I have always been part of a minority as a vegetarian, and have always eaten different foods to my peers, so this aspect of food intolerance has not been a difficult adjustment for me. This may be why I do not feel guilt as expressed by the participants in this study. I ate differently to my peers as a child and any feelings of embarrassment about my school lunch were counterbalanced with praise from my teachers. As an adult I appreciate what my mother was trying to achieve for me and am proud, not ashamed. I did not struggle socially as I had great friends through each phase of my life. I was able to find people who appreciated and accepted my values. I see friendship as a relationship that demonstrates mutual respect towards differences. I have reconciled that we are all different and do not try to be the same as everyone else. I celebrate the differences of

others and enjoy the company of others who value diversity. Often there is common ground that can be shared with people from all types of backgrounds.

I have experienced people who are unwilling to find common ground with the issues around food intolerance and I can empathise with how the participants feel misunderstood by others. From my experience, I think that those who lack understanding are a minority. I continue to be amazed by the number of people I talk to everyday who avoid one type of food or another because they have found that it causes a specific symptom or does not agree with them. I think that food intolerance is possibly more widespread than we realise. While those with a food intolerance are believed to be a minority, this may change with time especially if acceptance of food intolerance issues continues to grow.

I have accepted the individual differences of my children's food intolerance. This journey requires an ongoing commitment which I am willing to accept, confident that the effort is worthwhile. This acceptance may have been easier as I had already accepted my own food intolerance issues. My son has had significantly better health since he has less dairy products. My daughter's sleep patterns have improved since starting a diet low in fructans. Where possible we eat similar foods as a family, though I also need my children to be aware that sometimes we choose to eat different foods. I endeavour to help my children be aware of the effect food has on their bodies, so that they can accept that they can make informed decisions for themselves. My children have opportunities to make food choices based on options that we have learned are best for them. I believe that giving children choices is an important part of developing their independence, though as a parent I provide the boundaries for these choices. I am aware of the many aspects that can influence a child's behaviour and I aim to distinguish what is a reaction to food, what is tiredness, boredom or typical childhood behaviour in my children. When we are invited to parties, we eat nutritious food before we go and try to focus on moderation. When we host parties, we have healthy choices and focus more on the games and fun.

I would like to take what I have learned from this study and generate more awareness about food intolerance to help families in some small way. I would like to present my findings to as many schools, child care centres and community groups to help build bridges of understanding and tolerance. Maybe it would make the journey a little easier for families with food intolerance

issues, knowing that they are supported by their families and community. Knowing the resources they have available, knowing they are not alone and that it is no longer a silent issue in our communities. We have seen social acceptance grow in many different ways over time and food intolerance may be one of those areas in the future.

My hope for schools, childcare centres, kindergartens, families and individuals who hear about this study, is to be more aware of food intolerance issues and to show their support through their understanding. It is a complex issue that requires considerable effort to understand, and like all knowledge, the more you know, the more you realize there is to know. Learning is living, why not embrace our differences and embrace opportunities to learn new things. These families could benefit from trained professionals who are prepared to be open to include alternative treatments, including elimination diets to investigate food intolerance.

When planning shared experiences, incentives and rewards, teachers would be more inclusive if they considered students food intolerance issues. There are many non food related options that would be appropriate to ensure that all students felt included and part of the group. Choosing a variety of activities, games, special privileges, or rewards of time appropriate to the interests of the class, would avoid excluding those with food related issues. Differences that do arise can be used as an opportunity to teach students about acceptance and tolerance.

While many child care workers take the time to listen to parents and learn from their experience in dealing with their child, there is a need to recognise the importance of food intolerance issues for some parents. This could enhance their relationship with parents, and more fully achieve their goal in creating an optimal learning environment for the child. They could benefit from more fully adopting an inclusive philosophy which recognizes that “children grow up in a wonderful and remarkable diversity of cultural communities around the world. Every cultural community provides developmental pathways for children within some ecological-cultural context”(Weisner, 2002, p. 275).

I hope that the increased awareness from sharing the stories of these participants through this study and beyond, will bring more understanding about those who investigate food intolerance. Through increasing the awareness of food intolerance issues, I would like to help build bridges of

acceptance and make food intolerance more tolerable in our communities. Imagine if there was more tolerance of each other and especially more tolerance towards those with food intolerance issues.

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Appendices

Appendix A

Transcript of interview with Abbey

What are the issues that you see associated with food intolerance?

1. Poor behaviour, inability to learn, illness, asthma, eczema, auto immune diseases, misdiagnosis, (Added later learning, reading, relating to their peers and difficulty communicating and that food intolerance is really a symptom of chemical overload, autistic children.)

What are the main issues for your child?

2. Inability to learn and poor behaviour. (Alan) gets asthma and both get eczema when they eat
3. artificals. We probably would have had a misdiagnosis of something had I not discovered food
4. intolerance, (Alan) would have been diagnosed with something. What I don't know but he was
5. not moving, so he would have either on aspergers, ADD, ADHD, would have been in there
6. somewhere.

What's the most important experience that you would like to share?

7. How much food does make a difference. It's really quite unbelievable.

(Prompt) Do you have a story with that?

8. Well I suppose with (Alan) for example, 3 days after we changed his diet he spoke his first ever
9. sentence. That's probably the biggest OMG. I nearly drove off the rode. Cause it was in the car
10. and I went "What, say that again." Otherwise he would have been, you see all these kids having
11. difficulty learning, reading, relating to their peers and all you need to do is change what they
12. eat.

(Prompt) So we've added some here (referring to mapping).

13. Oh and difficulty communicating. When we do the NET she sort of goes back in time and sees
14. little issues that they've held on to and one of those issues that keeps coming up for (Alan) is
15. his inability to communicate. Last time when it came up, when he was probably six months old
16. and he should have really been starting to speak and learn things, but it's also the same time
17. that you introduce food. So he came up with an issue about that that he was holding onto
18. personally .

(Prompt)What does NET stand for?

19. Neuro emotional therapy

(Prompt)Can you describe it a little bit for me?

20. NET is a branch of kinesiology.

(Prompt)How is it different to what I would know about kinesiology?

21. She only deals with the neuro emotional side, she doesn't do all the other things of kinesiology,
22. so it's a very specialized branch and it's about your emotions that you're holding onto and she
23. deals with it in how it's effecting their body, so for example, I have a problem with my shoulder.
24. If something stresses me I get a sore shoulder and it won't go away until I deal with what my
25. stress is. It's weird.

(Prompt) So you're doing this with her as well?

26. Oh, I've done it once. If something comes up, immediately within 20 mins I get a sore shoulder,
27. I don't know if it's psychosomatic or not, but yeah. So (Adam) the other day, all the emotions he
28. was holding the other day were liver emotions. And so she cleared all those and that's why he
29. needed to go cause your liver holds your toxins and whatever.

Would you like to expand on anything?

30. Probably in my latest, because we are now exploring biomedicine, and so I don't know a lot
31. about it. Food intolerance is really a symptom of chemical overload in the body, that's where
32. I'm leading at the moment. So people aren't born with food intolerance if you like, we create it
33. by chemicals, in utero and just by in your natural environment. I'm not saying that you're taking
34. drugs or your taking whatever, in your natural environment getting vaccinated with the flu,
35. when your baby comes out they get vitamin K, they get and all those things have aluminum and
36. other things in them that effect the immune system. That then creates food intolerance. And
37. food intolerance now to me seems like it is more of a spectrum, so my kids are probably at the
38. top of the spectrum and fairly not too badly influenced by it, but autistic kids are the worst
39. effected. It's just the spectrum. So it's really a spectrum of food intolerance or chemical
40. intolerance and what you would probably refer to the worst cases are children with autism.
41. That's not saying all children with autism can be healed by changing their food, cause some of
42. them can't. Cause some of them are genuinely genetically autistic, but some of them are only
42. displaying severe food intolerance symptoms.

Tell me a story to describe the relationship you see between food and your child's learning.

43. It's probably when we really discovered food intolerance. So (Alan) was sick for three days and
44. didn't eat any food. And he completely changed. He became more cuddly, more loving, used
45. more words but it took a bit more to get lots of words and he would use so for example please
46. and thank yous . When he was talking at three year old, he was always told to use please and
47. thank yous but never never would, and they were just popping out everywhere. It was just like
48. amazing. Just watching him going, this is unreal. And then he got better, and I started to feed

49. him and the deterioration was almost instantaneous, it was like giving him drugs. It was a really
50. amazing thing.

(Prompt)A deterioration in the words . .

51. The words the mood, he lost his smile, he started to smile and he just stopped smiling and he
52. got grumpy, furrowed brow, he was sad. And I just went, Oh, you know what, it's gotta (*sic*)be
53. done. It's gotta (*sic*) be done.

You saw a glimpse.

54. Yes, saw a glimpse of the real child. And that's a common theme when you talk to people who
55. start the diet. They'll come and go "Oh I can see my real kid, it's really amazing, and they're
56. really nice." I think it's sad that people never see their real children. I think it's really really sad.
57. And then people feel sad about it like they go," OMG I've been poisoning my child." And I go,
58. "Oh, you know, you can only do what you know, so does that answer your question?

Yes, you sure did.

Tell me a story to describe the relationship you see between food and child's behaviour.

59. Well that one probably fits it to doesn't it, let me think of one with (Adam). So we went out on
60. the weekend and (Adam) had some fish and chips from a place that I don't know and evidently
61. the fish had something in it and he just turned into an absolute horror head, he was so
62. oppositional and overly emotional and it was just ridiculous. Uncontrollable. Uncontrollable. I
63. threw him out of the house, it was terrible. I said, "Don't speak to me like that," awful. The
64. joys.

Ordinarily . .

65. Ordinarily he's easy to get on with and he's polite and well mannered. It's like Jekel and Hide.
66. Schizophrenia. You just kinda go, OMG are you right, what's happened? And actually (Adam)
67. went to a party, and I said to him now you need to be careful and choose your foods and you're
68. old enough to do that. He went to the party happy, balanced, and he came home and within
69. half an hour his face changed. To having a frown on and a furrowed brow. I took one look at
70. him and I said, "You're reacting to whatever you ate at the party, you need to right now go to
71. your room and have some quiet time and I'm gonna (*sic*) tell you every single time that you start
72. to do it and you just need to walk away and do it. The face was just unbelievable and his eyes
73. go really like this . . it's scary.

Describe specifically what was involved in your child's and/or your elimination diet.

74. So we removed all artificial colours, flavours, preservatives, antioxidants – the failsafe diet.
75. MSG, salicylates and amines that's it. And for Alan, he was drinking soy, we removed soy but
76. I'm not sure whether it's the soy that was the problem, it could have been something else in soy

77. milk. Cause he was OK on soy and then he started to go a bit off, so we just took it away. So
78. they might have changed their ingredients or who knows. They don't drink dairy, they have
79. dairy in baked items and the occasional ice-cream. (Alan)'s ice-cream needs to be limited
80. reasonably severely because he'll get a stomach upset. Yeah, so and generally if we make stuff
81. we use A2 milk instead of A1. But in bought baked goods they just have whatever's in it.
82. They're fine on wheat apparently.

(Prompt)Did you do challenges?

83. Yes we challenged salicylates, I was too scared to do. . well let me tell you, I made a mistake
84. early in the diet with amines and we had aged meat, so I'm calling that a challenge, because oh
85. it was terrible. It was just so bad and it took so long to get over, about 2 weeks. So when we
86. moved on to the salicylate challenge I was way too afraid to give the six serves a day. So I gave
87. (Adam) half an apple and (Alan) a quarter of an apple and I waited. Within half an hour they
88. both had what I would consider a reaction, they became emotional , small things were being
89. silly and so I let them get over that and I did it again, and I got the same reaction. So that was
90. their challenge for that. I didn't bother challenging any artificials, there's no point, but they do
91. react to them because I can see it when they have mistakes.

92. Salicylates and amines they react to, although they can have chocolate in limited amounts.
93. Which is a different type of amines. So we just discovered that by accident. They can have
94. cocoa and any chocolate without artificial colours or flavours they can eat you know, they tend
95. to like to eat all day if I say you can have some chocolate then they will have a reaction.

(Prompt)How did you discover the dairy?

96. I've never been a big fan of dairy, (Adam), when he was 1 and he went onto cows milk, he
97. started to wake up in the middle of the night. I went to my doctor and said, "my kids waking up
98. in the middle of the night." He said, "take him off dairy and put him on soy". That worked
99. overnight, literally. So I never even bothered with dairy for (Alan), I just thought oh whatever,
100. I'm not even going to go there. Cause I just think cows milk is for cows.

What resources did you use when doing the elimination diet? Eg. Health professionals, books, internet, support groups.

101. I used the internet cause I downloaded the failsafe booklet off the internet because I couldn't
102. get my hands on the book and I was impatient to start, so I just downloaded the book. And
103. support groups on the internet, that's how I did it. FIN M yahoo support group, failsafe basic
104. and I'm now on a new one which is failsafe companions. Failsafe companions is kinda (*sic*) for
105. people who failsafe didn't completely work for and they're trying other things or they're failsafe
106. like me, and found they can't add things back in which is how I found out about the biomed stuff.

(Prompt)Have you tried any of these other things that people have been looking at?

107. I tried Namprasad Allergy Elimination Technique (NAET), which is a part of kinesiology and it
108. completely didn't work. However, having said that I think it does make a difference the
109. practitioner you go to and I only tried one. Two, (Alan) had developed an intolerance to sugar,
110. so you give him sugar and he'd go off his tree, she cleared that and fixed that which is a problem
111. for sugar when you're on failsafe, because everything has got sugar in it. She did clear that but,
112. she didn't make a difference with any of the other things.

(Prompt)So the idea of that is to rid them of the sensitivity is it?

113. Yes, it's to do with energy points. I think it's to do with why you're intolerant to that food for it
114. to work or not.

115. We also did acupuncture because my doctor does it and he had had success, quite a bit of
116. success treating hay fever with it. So I just said, "we'll give it a crack." And it completely didn't
117. work either.

118. We do the chiro (*sic*), that doesn't work in fixing the food intolerance and neither does the NET,
119. but it helps to deal with the fallout from food intolerance, so (Alan), because he was food
120. intolerant when he was a toddler, he didn't go through the stage when they make friends
121. individually, so he was at crèche at 2 and he had no friends. And he was still separation anxiety
122. and so he hadn't had the time to learn those social skills so he had a very poor self image. So
123. the NET, so he was coming to school and crying everyday and I was like don't worry, you'll have
124. fun, I'll miss you. Right, well we went and did NET and he in fact felt bad that he was leaving me
125. alone. So I had to not say, I'll miss you and he got special self affirmation words to say and from
126. the very next day he never ever cried again until he had a food reaction. Yeah, so it helps with
127. the fall out from things. Because he missed all that learning time it's helped him to catch up.
128. Because he had a poor self image as well he wouldn't try at school and because he also had
129. (Adam) as a brother it's very hard to live up to (Adam), so one of his things is I'm good enough
130. and what I do is good enough. The other things was this year, not writing very much and the
131. teachers felt it was more of a self confidence issue, so we added I'm allowed to do my best.
132. From the day after we added that he wrote pages, well a page. It's really amazing.

133. So now we're going down the bio med. We've had blood testing done, and we're basically
134. testing for pyroluria or, hi or lo histamine. So this one in particular (pyroluria) is linked to the
135. food intolerance, so for one reason or another the body goes into stress and it secretes zinc and
136. vitamin B6 and zinc is used in a TNZ processes in the body. The B6 pushing toxins or whatever
137. through the liver to be cleansed out of the body, so you get food reactions when foods aren't
138. digested properly, from the lack of enzymes. When the blood is not cleansed properly, through
139. the liver. With Pyroluria, in particular, 50% of people who they reckon are alcoholic are
140. pyroluria sufferers and ADHD and schizophrenia, and bipolar and OCD, they reckon have this.
141. So if you look into your family history, and our family history has lots of alcoholics, so people
142. who like to drink.

143. Then they test also other minerals that can leach out the zinc and certain things and so one of
144. the things they are testing because (Alan) has red hair, is copper. Cause lots of red heads hold
145. copper. Then I did some reading on that and it can effect reading ability and writing ability,
146. having too much copper. Then I was doing reading in class and I was reading with the low group
147. and three out of the five have got red hair. I know there's red heads who don't have the
148. problem but I thought it was interesting. What if they take the copper out will his hair be less
149. red. Because he's strawberry blonde, I'm thinking if they take it out will his hair just go blonde.

(Prompt)How do they take it out?

150. You have to take an alternating mineral, they don't take it out, they take something out that
151. balances it, or adds something that balances it, or takes it out.

Tell me about your child's involvement in the process .

152. When we did elimination they helped me cook their food their fun foods, and initially they had
153. two shelves on the pantry with smiley face stickers on all the items and they could eat them
154. whenever they wanted, I didn't care. They could have rice bubbles for lunch, breakfast, dinner,
155. didn't matter, as long as they were eating stuff without chemicals I didn't care. And
156. interestingly enough they ate less food, because they weren't craving the chemical anymore I
157. think. They had free rein and they hardly ever went in there and it was all good stuff, like cakes
158. and . .

What goals did you hope to achieve for your child on the diet?

159. I don't know that I had any specific goals, I just wanted to see did it make him (Alan) stop
160. crying really. That was it. Initially, (Adam) I didn't think had any issues and then you do the diet
161. and you see that there are actually issues there and it fixes them. The issues that I was blaming
162. on other things, do you want me to expand on that?

(Prompt)In connection to your goals, did your goals then change?

163. Once I saw exactly the difference it made, like when I heard (Alan) speak for example, no one
164. had told him his speech was delayed and I had a slight inkling, but then I was comparing him to
165. (Adam), which is not a fair thing to do, so I thought, "Oh my goodness, we can fix all these other
166. things and he'll be able to reach – I didn't realize that he wasn't reaching his potential, if you like
167. – so my goal was to then keep him there so that he would be able to continue on learning
168. properly if you like. So my goal, it kinda (*sic*) changed but not really only when I saw what was
169. possible, did my goal change. So yeah it was really about his behaviour and his mood. But then
170. when I saw the other things, the learning ability change, my long term goal then became to stay
171. there so he could continue learning if you like.

172. And then with (Adam), he was a very anxious, like he would be afraid of dying. He would come
173. out and say I'm afraid of dying and, or he would over think things. Like when he was three I had
174. to explain how gravity works, because he was afraid of the cars flying away. When we went on

175. the diet it stopped. And now it's one of the things if he goes off the diet, if he has salicylates, he
176. will now have a full on panic attack because he hasn't got the practice in dealing with it
177. anymore. So he'll come running out to me, "OMG, I think I'm going to die, I'm afraid of dying."
178. "You need to remember how you deal with this". Because he doesn't have to deal with it, so I
179. had put that down to having a very busy mind. In actual fact it's not. And so a lot of gifted
180. syndromes are blamed on gifted when in fact it's not, it's food intolerance, you can see them go
181. away. You can sit there and see these little kids in their little world, but I think if you changed
182. their food they become more normal, less insular, to some point. Well you see he knew how to
183. deal with his anxiety, but because he has had lack of practice, it sneaks up on him. Now it's
184. probably more acute, but when he's on the diet it's not there.

(Prompt)Did you consider any other treatments, but maybe not pursued?

185. I asked about kealation, but my doctor said no your kids aren't bad enough to warrant the risk of
186. kealation.

(Prompt)And kealation is?

187. It is removing heavy metals from the body and I'm not sure how they do it but it is quite a
188. dangerous process, although the chiro (*sic*) brought it up with me the other day. She said that
189. some natural company has got a really gentle one to do it, but I think we'll see how we go on
190. biomed before we do it. Nah there probably wasn't anything else that I was looking at.

In your journal, you mentioned a study linking Alzheimer's to the chemicals found in hot dogs. Can you tell me more?

191. I don't know the study, I can't tell you the exact name but if you google it you'll find it. There's
192. plenty. Did I tell you the story about how the kids would never eat hot dogs again? Yeah, so
193. when they understand that it can cause that it's quite, I think it was in the newspaper the other
194. week. It was, this week it was in the newspaper, I'm sure about eating processed meats, so
195. eating salami or whatever is linked to Alzheimer's and I think now it is also linked to bowel
196. cancer and I think that's what the article was about. But Alzheimer's was more illustrative thing
197. for the children. I can't tell you the study, sorry. Google nitrates Alzheimer's. And there's
198. several studies, so yeah.

In reference to (Adam) at parties, you said, "He has learnt through experience to make better food choices". Can you tell me about some of these experiences?

199. That's probably a lie now, because now he just chooses to have the food, but the experience
200. would have been, yeah he chooses the wrong food and then he comes home and he will either
201. have, if he has the anxiety attack, he will tend to avoid those cause that's too scary, but the
202. oppositional behaviour, when he's doing it, he can't see that he's doing it and even after he
203. doesn't understand that he's done it. So I don't know when he's going to learn that. The
204. anxiety he will avoid, I will say to him now that will give you an anxiety attack.

(Prompt)So there are specific foods . .

205. Generally salicylates will give him anxiety and some artificial but I wouldn't know what they
206. were.

(Prompt)Oppositional you would say is caused from . .

207. Probably amines and I would say artificial as well. He knows to avoid the salicylates, because
208. that is probably more scary for him I think, but the oppositional he just doesn't get it. He just
209. thinks he's right and I'm wrong, I tell you. I'm going to video him next time and also he's coming
210. into that age, where everyone else is eating that food and it's difficult not to eat it. I understand
211. that.

You mentioned your frustration with your children's peers "clearly reacting to food chemicals" and the disruptive behaviour "making it hard for your children to learn". What does this look like?

212. Drives me insane. Particularly this year. Just kids who can't behave in class, they can't sit down
213. they won't listen, they're defiant, the teacher spends more time with their behaviour than
214. teaching. That's about it and in particular it really effects (Alan). (Adam) leans a bit more
215. towards the autistic side and he is in his own world if he's doing something, he doesn't hear all
216. of that and because of where he is placed intellectually he gets his own program and the
217. teacher is very conscious of that and so he's always looked after. But (Alan) being in the middle
218. of the pack , so he should just be getting the normal stuff so he's not of particular interest and
219. he is easily distracted by what else is happening in the classroom. And he doesn't like the
220. conflict in the classroom either. And this year in particular is driving me insane, because there is
221. about 5 of them in there and I'm going Oh, you need to fix it. So I go in the classroom and I sit
222. there and I go, Oh, I know how to fix you. I feel sorry for the children themselves who are
223. causing the difficulty because I think you poor things, you know you're always getting in trouble
224. and you're not learning what you need to learn and you're not even. Some of them can't
225. develop friendships , they can't play and it breaks my heart to see that. That's terrible, it's
226. really sad. And then I worry about them when they're gonna (*sic*) be teenagers and cry. I can't
227. do it anymore, I can't go in. It makes me cry (*with tears in her eyes*).

What do you think your children would say are the benefits of the diet?

228. (Adam) would say nothing's good about it cause he just sees the difference that he can't have
229. but I think if I put words into his mouth, he is glad that he doesn't have those anxiety attacks
230. anymore. And I think that he would be glad that things are more harmonious when he's not
231. getting into trouble the whole time, when he's not oppositional.

232. And I'd have to put words in (Alan)'s mouth. He gets sick he gets, he ends up with a chest
233. infection so clearly he doesn't like to be sick and he was so little. He certainly likes being able to
234. communicate just judging from what comes up in the NET sessions. He likes being able to
235. communicate how he's feeling and stuff like that and to feel in control I think.

What do you think they would say is a problem with the diet?

236. (Adam) just sees what he can't have. (Alan), he has no problem with it. He is more than happy,
237. he takes his own lunchbox to parties, he has absolutely no problem and I think perhaps because
238. he was younger when we did, probably makes a big big difference. Also, he was probably worse
239. effected.

How do you think your children see food, behaviour and learning?

240. (Alan) has probably just started to say things like, "if they didn't eat that they'd behave better"
241. or just started to link it, that was probably due to last term as well because they had that mini
242. master chef thing. And so they were talking about healthy foods and not healthy foods and it
243. was just a big issue. So we would then talk about what certain foods, how certain foods made
244. kids behave.
245. (Adam), I don't even think he thinks about it. It's not on his radar to even care about.

What is your reaction to these statements?

Foods without food additives appeal to parents who do not like commercially processed food (Cruz & Bahna, 2006).

246. Yes. I would agree with that.

"Dietary intervention is difficult, but where there is improvement, parents report it is better than managing a difficult child"(Breakey, et al., 1991, p. 93).

247. Yes. Yes and no. Dietary intervention is not difficult, it is much easier than dealing with a
248. difficult child. It's difficult to start, but once you've done it, it's not hard. It's difficult to, it's
249. probably difficult mentally, to be different and because it's not accepted, people probably look
250. at you like you're some kind of psycho person. So that's difficult, but it's so much easier than
251. dealing with a difficult child, I can't understand people who are putting up with these kids,
252. taking them to psychologists and they're medicating them with speed and they're doing
253. whatever. Just stop feeding your kid red cordial, give them water.

"It (also) may be easier for the parents to accept the idea that their child's behavioral problem is due to a dietary factor than to psychosocial issues that are often difficult to evaluate and tackle. (Cruz & Bahna, 2006, p. 728).

254. Yes, I think yes. Isn't it nicer to think that the food affects my child rather than there's
255. something wrong with my child. Yeah well that's, I've got a girlfriend whose got a child whose
256. had some serious issues. I go, but aren't you glad that you found out it was the food and not
257. him. It's not your kid, it's the food making your kid do stuff and yeah.

3b. (an elimination diet) gives the family a sense of solving the problem and provides the child with substantial attention”(Cruz & Bahna, 2006, p. 728).

258. It gives you a chance to solve it, the attention – I don’t know about that, no. Don’t know about
259. that.

Changing diet to manage a child’s behaviour can reduce a parent’s feeling of guilt about the situation (Harley, Matthews, et al., 1978).

260. Yes. Well I guess it depends on what you’re feeling guilty about. I certainly felt guilty that I had
261. been poisoning my children, yeah. But I didn’t feel, probably because they were young and they
262. weren’t big issues, I don’t know, if you had big issues, you’d feel guilty that your child wasn’t
263. coping with school or whatever, I don’t know. I haven’t been there. But I felt guilty that I had
264. been poisoning my children. I didn’t feel guilty that he couldn’t read or write. It didn’t ease any
265. guilt, it probably created guilt in actual fact, because I had been poisoning my child. But I didn’t
266. know so, you can only do what you can only do.

Would you like to expand on anything?

267. I recently became aware of other science that was out there about what’s in immunizations and
268. in particular I read Jenny McCarthy’s book healing and preventing autism, that she wrote in
269. conjunction with her pediatrician. Now her pediatrician and his wife adopted a baby from a
270. drug addicted mother and he was reasonably normal, he had some issues. Then at 12 months
271. he had the big whack of immunizations and he completely had lots and lots of trouble. His wife
272. went to him and said, you broke him, you fix him. He was pro immunization and now he’s anti
273. immunization. Now they’ve got all this way to fix it, that’s neither here nor there. But it’s just
274. the fact that these things have got aluminum and all these kinds of things that change your
275. immune system and that causes then the food intolerances, then causes all these behavioural
276. problems. So, yeah it’s a complicated circle.

277. Amish people have no autistic children, they don’t immunize, they live a less chemical filled life
278. if you like, so it’s not just down to immunization but that’s a good example of it.

279. There’s a study up at the chiropractors, people who had 2 flu injections in the 1980’s are now
280. 50% more likely to have Alzheimer’s. I mean, I haven’t looked at the full study but you just go,
281. what does that tell you. People need to start asking questions. In America they’ve got this big
282. things about, it’s like anti terrorists, immunization refusal and it’s treated like it’s a medical
283. disorder. Like parents going no I don’t want my kid to be immunized have got something wrong
284. with them. And there’s whole forums about how you fix parents who have immunization
285. refusal.

286. The other day at the supermarket, they’ve got those Allen’s lolly jars. I want the lolly jar, so you
287. can either buy the lolly jar for \$10 or buy 2 packets of lollies and get the lolly jar for free. Buy
288. the lollies. So I didn’t pig out and eat the whole packet, over a few days, and then this day I felt

289. so sick. I had indigestion, I had a headache and I was so lethargic it was just ridiculous and I
290. thought no wonder these kids feel horrible and they sit and play computers all day and they
291. don't run around and they don't do anything, because "I feel horrid". I just felt so bad, I couldn't
292. believe it. So I dosed myself up on calcium and magnesium, and drank about 2 litres of water
293. and by the end of the day I was feeling better but , yeah. I thought no wonder these poor kids
294. feel horrible.

Appendix B

Transcript of interview with Bernice

What are the issues that you see associated with food intolerance?

1. Socializing can be difficult, particularly with people that don't have food issues. Everything
2. revolves around food. Time, basically I have to keep pulling back from work because I think, I'd
3. estimate 2 days a week is spent cooking, shopping extra to what other people would do,
4. because I have to go to certain places for food and the freezer needs to be full of certain things.
5. So I feel like it's a bit of a handicap in some ways, you know and it's not acknowledged like if I
6. had a disability I'd get some sort of assistance or something, but . . I'm probably a bit angry
7. about that every now and then (*chuckle*).
8. That's probably all the negative side but there's the positive side as well in that prior to
9. discovering about the food intolerances, we all had issues that have reasonably well cleared up,
10. in terms of personality clashes and arguments, you know we used to have some awful times.
11. Things aren't 100% perfect now but they are usually bad when we are off diet. When we're on
12. diet it's really amazing the way we relate to each other, so I think we have discovered a lot
13. about how to be a family together. It has improved our relationships.
14. I think as well another positive because I'm on the diet with my daughter, I think it has really
15. strengthened our relationship because she respects the fact that I live it and don't just talk it.
16. And she can see how I struggle with it and how I try to deal with it and I believe that's what
17. encourages her to stick to it as well, as well as the fact that she feels better on it. Like I see
18. mum's that have just children on the diet and not the mum and dad, and it doesn't work as well
19. in a lot of ways. My husband is not strictly on it like, but I'd say 99.9% on it because we notice
20. big changes in him, if he goes and eats certain foods for the next two days, we'd rather he didn't
21. come home, you know so.

What are the main issues for your child?

22. Originally it was behavioural, and it still is there's massive ODD with dairy and flavours in most
23. things. We've both gone low fructose as well and that seems to have helped again. Another
24. added dimension of difficulty again, but she wasn't tolerating shop processed wheat anyway
25. there was something not right there. We've developed other issues with her this year, though
26. um last year. With hyperglycemic episodes with high salicylate foods, so where she just loses
27. awareness of what she's doing and where she is, even though she doesn't really lose
28. consciousness as such she would be walking and talking but she won't remember it. I've just
29. recently had to pull back into ultra low salicylates and I'm hoping that'll do it I was very reluctant
30. to do it. I let it go too long, I was kidding myself about how low we were with the salicylates,
31. and I think not low enough. So that's had a huge impact on her schooling over the last year and
32. a half. She's just given up in maths and we're still dealing with that.

33. That's the other thing, I look to the future with school camps and potential overseas trips, but I
34. don't know which ones of them we will be able to attempt. Probably not the overseas because
35. if she started behaving in a strange way, you know we'd have to pay for her to come home at
36. our own expense. It's extra on top of that, so anyway. Some places are good when you talk to
37. them about sorting out foods, other places are just hopeless. We'll wait and see.

Would you like to expand on anything?

38. The difficulties communicating things to, for instance the school, the teachers. You know I go
39. through it all one year for one group of teachers. None of it's handed over to new teachers, I
40. feel like I just have to do it every term I have to go and individually speak to each teacher and
41. sort it out. But I end up missing it half the time and teachers you know they do things like they
42. have – there's one teacher you know, she loves the class, loves the teacher and the teacher had
43. chocolate day every Thursday – they'd have hot chocolates or bars of chocolate or whatever, it
44. adds difficulty to things you know. Even though (Bess) understands and accepts, she
45. has a type of dairy free chocolate and soy free that I had been allowing her and she sort of just
46. sticks to a few pieces of that or a homemade chocolate cupcake. She doesn't tolerate carob
47. either. But who is to say how much of those amines are impacting on things as well. (stopped
48. to ask Bess what she had had for lunch yesterday)

Tell me a story to describe the relationship you see between food and your child's learning.

49. I remember back in the early days, six months after we had done our first elimination diet and I
50. hadn't realized how strongly impacted her learning was. She basically had massive problems
51. with reading and writing, so then the six months we were into it, she was coming along really
52. nicely and we challenged antioxidants. Within two and a half days, she basically just lost the
53. ability to write. So she developed it, well she was sort of low down, then it shot up in six
54. months and then she totally lost it. She got really really angry because the connection between
55. her brain and her hand had gone and she was just so angry. Cause she knew something wasn't
56. right. I think she was about 7 when that happened. The same thing again recently, these
57. episodes with salicylates it's basically taken her from performing to standard to performing
58. under standard now with maths. She's doing fine with most other things, more than fine. I
59. think it's that reasoning thing that maths requires that is the first thing to go when she's
60. reacting. It's had a huge impact, hopefully we'll be able to pull it back in a little bit. Well we've
61. been in talks with it for months and she's just convinced herself that it's not necessary and that
62. she can't do it. So we've got to get her to the end of the year and they can stream her into an
63. easier maths, I think, but yeah it's just a shame it's another way that it's impacted on her, that I
64. feel it isn't really her fault.

Tell me a story to describe the relationship you see between food and child's behaviour.

65. Probably a really typical one or just the one that we think of, we let her have dairy and it was
66. about three days in, it usually takes 2 and a 1/2 days, quite often when she is reacting, her and
67. her father butt heads, like badly and this one particular time she used to sleep upstairs, she's

68. down now, but after screaming abuse at each other for a few hours, probably not even that
69. long, over something stupid, she went upstairs and there was silence for a long time then (Brian,
70. my husband) poked his head up the stairwell to see what she was up to and she'd barricaded
71. the top of the stairwell with every bit of furniture she could move, so that no one could come
72. up. It was funny but it was just really . . . she just gets really really strong, I think it was the same
73. time or just before that happened she pitched something down the stairwell at him and it was
74. something quite big. So she gets really strong when angry and there's a dint in the wall from
75. where he ducked but I can't remember what it was. It's funny how your brain removes these
76. things.

77. She's just really nice to be around when she's on diet. She's got loads and loads of friends who
78. all seem to want to be around her, whereas pre-diet I could tell she didn't have any, and it was
79. very upsetting actually being the only child to I was thinking "what's with this?" you know, no
80. amount of encouragement made any difference.

81. The contrast depends on whether her dad is reacting, he's very much, becomes almost like
82. aspergers where just the tunnel vision and push push push with his point of view and doesn't
83. hear what's being said, so if they are both reacting at the same time. I can be, if I'm reacting too
84. I exhibit differently, I become more irrational, I guess. So if we are all on diet then life hums
85. along quite happily. None of these interactions or if we do one of us will very quickly apologise
86. and say "that was silly" or "didn't mean that" or whatever. Instead of it just being high tension
87. all the time.

Describe specifically what was involved in your child's and/or your elimination diet.

88. We did RPAH elimination diet. I didn't go through all the additives, I challenged a few and
89. thought, I don't really want to do this anyway. Inadvertantly now we've noticed reactions to
90. some of them because of different foods that we've had. Like with myself antioxidants give me
91. extreme anxiety, so I don't even eat hot chips while we are out or anything like that. It spoilt a
92. couple of our holidays really big time you know so. It was funny it wasn't until we got back
93. home after six weeks on the road and I'm getting calm that I realized, Oh the only time I felt
94. relaxed was when we were staying with someone where I was able to cook for ourselves. I
95. thought well what was I eating every day? 'hot chips'. Oh.

96. But the elimination diet, the process, basically took everything out came back to a really
97. baseline diet and then started to introduce salicylates, amines, glutamates and had a reaction to
98. them all. I probably didn't do it properly, I wasn't seeing a dietician cause I've got this
99. abhorrence of health professionals from my experiences with them over the years so I tend to
100. try and manage on my own. But I muddled my way through with the help of the online groups
101. and I kept going back there. I didn't do the salicylates long enough, we had a quick reaction. If I
102. had kept it up I might have seen other symptoms that now I know that we have to it, but I didn't
103. realize at the time. Also I didn't take out dairy, or soy initially and that was a big mistake. That
104. took me probably a year to sort out what was going on. Especially where it's hidden in the

105. ingredients. Then gluten I didn't take that out of my own diet till about 2 and ½ years ago and
 106. then wheat for (my daughter) almost a year ago. Now I'm starting to not write things down and
 107. starting to lose where they've happened which is bad news for trying to trace your trail.
 108. Sometimes you need to but you know, at least I don't have to justify to anyone much other than
 109. (*pointing to Bess' bedroom door*).
110. With reducing the salicylates, we might have to do a proper challenge which I'll talk to her about
 111. it. Cause she was not too sure that it was going to be of any benefit but we will see. She might
 112. actually feel better in herself and agree with me that she doesn't want to challenge, I don't
 113. know.
114. We started the process of eliminating additives and then like most people we thought, Oh that
 115. should be enough. That will help us and we did notice a bit of a difference. Six months later and
 116. we were away with family over Christmas and we had this episode when we were out in the car,
 117. where I thought someone was going to kill someone, it was just really horrible. So we left the
 118. function we were at and went back to where we were staying and packed up and went home
 119. pretty quickly. I thought right, that's it, we've got to do the whole diet, because I don't like
 120. living like this. It became obvious, really quickly. First by removing everything, and things
 121. become calm, happy. Strikes me though, we all have problems with it, I think "is it just my
 122. family that we've all got food intolerance issues, or does everybody have some sort of food
 123. intolerance issue that they are just not aware of and they sure as hell won't want to look."
124. Even my mother you know, she says Oh, I'd just rather take a pill. So she does. She eats all this
 125. stuff and takes her medication. A big box load full of it. That's pretty common I guess.
126. You see anger, violence, family breakdown, learning difficulties, it's just everywhere. But
 127. people have to be ready. How widespread is this problem?

What resources did you use when doing the elimination diet? Eg. Health professionals, books, internet, support groups.

128. Online support groups were absolutely crucial to me finding the last elements of what was
 129. keeping us from a baseline of good behaviour or good symptoms. Initially it was for the failsafe
 130. online groups but then also the fructose group, I use that as well. Actually now I've developed
 131. one that combines the two and there's 40 or 50 people on that so far it's very quiet because
 132. they post elsewhere but it will grow I think. And of course there's Sue Dengate's website and
 133. her books and that sort of thing. I wouldn't have been able to do it without Sue's information
 134. that's how I was brought to it. Someone handed me the book. She lives locally, her daughter
 135. went to school with mine, but she is a difficult type of person. She's one of those ones who has
 136. her son on it but won't do it for herself and it's quite obvious that she needs it herself.
137. Meeting people through that group locally that have been a support and invariably when you're
 138. having issues you talk about it and they'll pass on some sort of information that sets off a light
 139. bulb for you, you know. No matter how busy I am I always keep up those links, because that's

140. our life line you know. Even though sometimes I'm like Oh, the crap that people come out with
141. on these groups and you've got to try and keep bringing them back to focus, it's very very
142. awkward. But what do you do, it's worth the price I guess.

Tell me about your child's involvement in the process (if applicable).

143. It was a long time ago now but I think I explained to her the process and the it would only be
144. for a short time and that it would help us to not have as many arguments and to be happier.
145. I must have related it to friends and reading and things like that, that it could improve that
146. and I showed her all the nice things she could have, all the sugary treats, yeah what she
147. could have and she seemed quite happy with that, and was willing to have a go. Also I said I
148. was going to be doing it with you, you won't be on your own. It hasn't been easy at all for her
149. though, I can remember occasions when you're going through the challenges and they're
150. reacting they don't know they are reacting. It's everyone else's fault. So you have to wait until
151. the challenge is over and cleared before you can discuss it and generally she is aware then at
152. that point. And generally calls it for herself, you know. So I've been very impressed, very proud
153. of the way she's responded to that side of things. But it does take that strength to initially pull
154. her in on something or to conduct the challenge. You have to set it up to start with to show
155. them what it looks like before and after and how things could be different.
156. More surprising was my own differences with it, the fact that I can be a calm, rational, friendly
157. person to almost a crazed psycho. Just the total change from just from having one thing off
158. diet, depending on the thing, but usually it's more insidious than that, it's a slow creep and
159. eventually you realize you're in a place that you don't want to be. I don't think there were a lot
160. of surprises as such, I suspected she had problems with learning and knew she had problems
161. with interacting socializing and basically getting along. Although I guess these recent things
162. with the health, the hypoglycemic episodes, yeah that's been a surprise. That's potentially been
163. there all along. When she was very young she used to have breath holding attacks where she'd
164. pass out. To me it's sort of similar in some way, I can't quite describe it, but it's just the
165. consciousness is altered. I think even though I'm not surprised by the learning and the
166. behaviour and that sort of thing it still did stuns me. When you see the stark contrast between
167. one and the other just how much of a difference it makes still stuns you. I think that's the
168. positive thing to having slip ups now and again you see them again and it's really in your face
169. and reminds you why you're doing these things.

What goals did you hope to achieve for your child on the diet?

170. Interacting with the family, being able to enjoy each other's company.

Did you consider any alternative therapies/treatments? If so, which ones?

171. We'd looked around at a range of different things and we'd seen the psychologist at school who
172. said, "Nothing wrong with you" and looked at me funny. The same with the school nurse when
173. she was a bit younger than that the school would have a social worker come in to 'teach me

174. how to parent'. And I was doing a great job she reckoned, leaving (Bess) in her room
175. screaming for hours, you know that's normal. OK. It didn't feel very normal to me. Just before
176. we found the diet, I was also seeing like an energy - Chi Gong and that did actually work to a
177. fair degree. She gave her flower essence drops and I'm not even sure what the actual treatment
178. was but it basically took her anger levels down and there was probably more. Even while we
179. have been on the diet, I've been to see chiropractors, they can help to alleviate things. Even did
180. a stint at Advanced allergy elimination which cost us a bloomin'(sic) fortune. Ended up being
181. bloody useless. Initially it seemed to work, it seemed to take away the sensitivities but it didn't
182. last. So if something is not sustainable it's not really useful, I don't think. Although I do know of
183. one failsafer that basically goes for a top up, she only treats for amines and salicylates and she
184. goes for a top up every six months type of thing. But I don't know.

A social worker from the community came to give you parenting strategies to help you manage your daughter. How would you compare the outcomes of diet and the outcomes of this parenting advice?

185. Ok. Well the parenting advice didn't work. It gave me confidence in one way because the
186. 'expert' from the council was telling me if I do it this way then I'm OK as a parent. So instead of
187. feeling like I was a total mess at least I thought well, I can do this. So I can get by, but I didn't
188. like it. I wasn't happy. I didn't want my life to look like that. Whereas with the diet it gave me,
189. because it worked, because it removed the problem totally, it was justification in one way - no
190. wonder I've been feeling so uncomfortable because this wasn't right. And it just worked. It
191. gave me the child and the life that I had always known was there.

What may have been the effect of the diet alone/the advice alone? Would you suggest to use one or both?

192. Some people need, as well as the diet, they do need advice on behaviour management, you
193. know. I'd usually recommend one, two, three magic now after implementing that. That's
194. something else that I've learnt through Sue Dengate as well, but it won't work without the diet.
195. Diet first, then behaviour management.

You observed that your daughter was displaying problems with achieving results at school and was friendless. Paint this picture for me by describing it with words?

196. Just with the interactions I observed, I just remember feeling that constant ache that it just
197. wasn't right. That something was very very wrong. I'd witness interactions and see other kids
198. not liking and they'd be pulling back, it was understandable in that it was just difficult to relate
199. to that sort of behaviour. With the reading in particular I think, from a very early age, you do
200. what most parents do you read to them have books around and actively try to advance in
201. whatever way you can and it just wasn't really going anywhere. She was enjoying that, but it
202. wasn't developing anything. Also even in Prep we observed that she couldn't complete anything
203. and it's the start of my issues with schools, you don't find out till the end of the year. I
204. remember that I must try and pull out her Prep report. The prep teacher said the most horrible
205. things in her report at the end of the year, it really really hurt. A shocker she was. She needs to

206. try harder to be a nicer person. Because it's an issue I had been attempting to work on myself, I
207. guess it takes one to know one doesn't it. You've got to keep your sense of humour too. I tend
208. to lose that depending on what I'm reacting to, it's one of the first things to go my sense of
209. humour.

You mentioned your frustration with your children's peers and how "the behaviour of others interferes with the whole classes learning". If I were in the room, what would I see?

210. It's been an ongoing issue actually. It severely impacts on her ability to learn. Basically the
211. teachers spend more than half their time attempting to bring the kids back to focus and it's loud
212. and the kids aren't there to learn. They're not learning so they do other stuff. Socializing and
213. just being very loud. It's really really difficult to learn under those circumstances.

You said that your daughter believes you are the "lucky ones". If you were to ask her, what do you think she would say is beneficial about the diet? And what do you think she would say is a problem with the diet?

214. Probably that she can see the difference between the other kids and herself and she knows that
215. it's related to the food and she can see the improvements that have come about in all our lives
216. because of it. So on the balance, the scales when you weigh it up, the benefits outweigh the
217. difficulties. I'm sure she sees that too. Even though, like me you complain about the difficult
218. bits at times. I feel like asking her to come out and tell you, but I think it's the fact that she's
219. different, but I don't think, and I'm not so sure that's what it is for her. I think it's just that it
220. would be easier to eat what's around sometimes, instead of having to make a fuss. Like if she's
221. at a party or sleep over and I've sent food and the people don't bring it out and heat it at the
222. right time, she often just goes without, just so she's not a trouble. Or sometimes she eats off
223. diet instead. Not very often, but sometimes. Because it's easier, not because she really wants
224. to do that as such.

You said, "I don't know if I would still be alive". Do you think that diet changes could save lives?

225. For sure. I see all the issues with mental health and violence and if we've experienced all of
226. those in our family to the point of nearly being in crisis quite a few times, then it's gotta (*sic*)
227. have some impact on society in general. When we eat a diet for us that's similar to what they
228. would have eaten 50 or 60 years ago now, we don't have any issues. So how many more people
229. have developed those issues simply because of diet? People just don't get it though. I was
230. talking to one woman a couple of weeks ago, standard story, talking about how she has trouble
231. sleeping. And I said, "I do too, if I'm eating foods that don't agree with me, cause a reaction. I
232. could help you find out more if you like". She said, "Oh no, foods don't affect me, but I can't
233. sleep." It's not usually important enough for me to ram it home because it's difficult. Unless
234. they are inquiring or they're a closer friend and sometimes even then it's difficult anyway.

What does a Low FODMAP diet look like?

235. It's very difficult to incorporate it with the failsafe because all of the low natural chemical fruits
236. are very high in FODMAPS. The hybrid diet is not very easy at all and at the moment we are
237. probably on celery, chives, swede, lettuce, potato, choko. We've allowed bananas because you
238. can't have pears they're through the roof with fructose and we were doing cantaloupe, but
239. salicylates. So we've pulled that back out. So it looks fairly light on. Also with the FODMAP
240. there's a lot of things that they include in dairy free foods that aren't acceptable, vegetable
241. gums. There's a whole range of things that we can't have because of the FODMAPs as well. So
242. basically it comes back to a handful of ingredients and you make stuff from it. We do have,
243. (Bess) is only wheat free, she's not gluten free, so there's a millet bread that I buy where
244. they add gluten to make it nice and that works quite well. I don't tolerate it unfortunately. I
245. can give you a list of the actual foods, it's on the fridge.

246. I haven't actually done official challenges as such, but we've had inadvertent slip ups that have
247. proven to us that we are on the right track. In the early days we thought we'd discovered this
248. super new vermicelli noodles thing but didn't realize that it was made from pea flour, or bean
249. shoots. And we both got as sick as a dog, like really really crook that whole week, like the flu
250. and we took that out and felt better. We don't get sick generally, as a general rule. When she
251. had wheat in class, because the teacher stuffed up and didn't provide the right flour, she got
252. really sick. She was off for a couple of weeks. It was too close in timing to be anything else but.
253. Some of the veggies I wonder about trialing, but I think we'll just see if we can get well with
254. (Bess') episodes, taking the salicylates out again and I just know I've gotta (*sic*) spend more
255. time cooking at home, because it makes it more worthwhile, makes it easier for (Bess).

Describe what being a part of the Food Intolerance network has meant to you to?

256. I couldn't have done it without that resource. If ever I'm having difficulty I jump onto the
257. computer. Also I spend quite a bit of time talking to others that are having difficulties and it
258. often lightens your load when you see others worse off. It's actually provided me with two of
259. my closest friends who are failsafers now. I actually prefer to do social events with these two
260. and their families because I don't have to worry about all the guff that usually happens. So even
261. though I've got some really really good friends, tomorrow for my birthday, I'm having these two
262. and their families over and I was hesitating with inviting anyone else and I know why, but it's
263. sort of sad in a way. I just like to have some peace, sometimes.

Who makes the food choices in your family?

264. We probably all put in a bit. I ask (Bess) what she'd like to eat for certain meals. I guess
265. it's me that runs the kitchen and the shopping. There's certain meals that my husband cooks,
266. he's in control of those. So I plan those for days when it's easier for him to cook. I enjoy those
267. days off.

You said, "enabling (Bess) to do it for herself is my ultimate goal" – What would this look like?

268. Her being able to maintain it, make it sustainable for herself after she leaves home. She does
 269. know how to cook some of the recipes but she's not that keen to get in there and do it. It's not
 270. a matter of her having to do it, it's a matter of her knowing how to do it. I have given her
 271. recipes to certain things so that she's got them, but I think they get lost. At the moment, she
 272. has a stockpile in the freezer of meat sauce, white sauce, gluten free wraps, little sausage bits,
 273. so she's gonna have to learn how to make that up for herself if she wants to have access to that
 274. as a resource. I sort of want to make up a bit of a handover book almost, and probably will do
 275. that, with a list of convenience freezer foods and how to get to that point. So breaking it down
 276. into step by step. You do an hour of this on a Monday, that sort of thing, to make it work.
 277. Cause if you just look at it, and try to do it all in one day, then you'd go absolutely insane,
 278. because I've done that before. It doesn't work that way. You've got to split it up and do a little
 279. bit as you go.

What is your reaction to these statements?

1. **Foods without food additives appeal to parents who do not like commercially processed food** (Cruz & Bahna, 2006).

280. That's a big thing that, most parents that I come across are interested in reducing additives. The
 281. ones that are seeking it out obviously. The otherside of it is a lot of parents also don't like
 282. processed foods. They're happier to go back to cooking from scratch because it's more natural.
 283. It's actually quite difficult for them to consider the natural food chemicals, which I think is really
 284. huge I think with most people and they don't realize it. I try to liken it, that it's just another
 285. form of additive because it's new to our food. So it's something that has been added in the last
 286. x number of years. But it's very difficult for people to get their head around. To go from such a
 287. huge variety and assortment of food that you're allowed to have to such a restricted amount
 288. can make you feel really unhealthy, cause you're fighting against what everyone is telling you
 289. that variety is healthy. So I think that's why people stick with the food additives, and they can
 290. see that that probably isn't good. But I think they probably need to go further, most parents.

2. **"Dietary intervention is difficult, but where there is improvement, parents report it is better than managing a difficult child"**(Breakey, et al., 1991, p. 93).

291. I think most failsafers would agree with that. In some ways you feel like you've swapped one
 292. difficulty for another, because you can't ever relax, you can't just not think about food. But it
 293. comes down to that difficulty is within your control, something you decide that you're going to
 294. do. Whereas the other difficulty pushes down on you and wears you out. With the cooking as
 295. long as you manage it, it's bearable most of the time.

3. **"It (also) may be easier for the parents to accept the idea that their child's behavioral problem is due to a dietary factor than to psychosocial issues that are often difficult to evaluate and tackle** (Cruz & Bahna, 2006, p. 728).

296. I think that's a commonly held view that parents are almost control freaks and they are trying to
297. control it using a method that isn't really the problem. I believe that so much effort is spent
298. trying to treat those psychosocial issues and it doesn't work. It just doesn't work. I see it not
299. working all the time, all around me and all the effort and the money that goes into that and it's
300. just so much simpler to come underneath and attack the real problem rather than just the
301. symptoms.

3b. (an elimination diet) gives the family a sense of solving the problem and provides the child with substantial attention"(Cruz & Bahna, 2006, p. 728).

302. Oh yeah, big time. I think that's been the positive for us. We all feel in some part responsible
303. for our own well being now and (Bess) can see and really respect how much energy and
304. effort I put into it and that if I'm doing it I must have a great regard for her. I think occasionally
305. she doesn't want fuss and trouble sometimes and that bothers her a bit. She's like "don't do
306. that if it's gonna (*sic*) be a fuss". But I think overall she, of course is going to prefer to be looked
307. after like that than the way it used to be, which you know we just couldn't relate to each other
308. at all.

4. Changing diet to manage a child's behaviour can reduce a parent's feeling of guilt about the situation (Harley, Matthews, et al., 1978).

309. I think there's a huge amount of guilt there because of all the restrictions on the child. You just
310. wish it was different. You wish it didn't have to be that way. So the question was that it took
311. the guilt out, was it, I don't think so. Not at all. It's definitely still, but I think as mothers we are
312. good at guilt aren't we. So much revolves around food and treats and when you're socializing,
313. and your child is isolated from that and not totally included like when – what's that thing with all
314. the lollies in it and a stick at a party? (piñata)- yeah, so many things like that. If they are at Knox
315. city and they can all buy whatever they want, she's only got a couple of places up each end that
316. she can get something. It's isolating I think, if you allow it in some ways it is. You just have to
317. accept that that's the way it is. To counteract that, I just acknowledge that I need to cook a
318. certain amount more and that balances that out. I've taken away, I have to give back.

Would you like to expand on anything?

319. It's awkward at times with all the work and thinking involved but there are so many more
320. people worse off than us, you know. At least it's under our control. Every now and again I feel
321. these floating worries about if certain ingredients aren't available to us that we're so hyper
322. sensitive what will we do but, so of like if the world ends and they don't make rice flour
323. anymore or whatever, well then I guess we'll just have to live on meat and eggs, or whatever. I

324. just try not to focus on it too much but it comes in every now and again, because you're
325. focusing on food so much I think these little things come up.
326. I can't believe how much control people have given over to these big corporations, totally
327. control their lives. They don't know, if they did they wouldn't do it would they, perhaps. It's
328. easier, take the pill.

Appendix C

Transcript of interview with Camille

What are the issues that you see associated with food intolerance?

1. Limited choices, lots of cooking, the ability to plan my life – so better health I guess it comes
2. down to, knowing that I will feel well enough on any one day to actually commit to doing things,
3. there's a whole pile of frustration in there, you know the whole why me?, I'm not quite sure
4. what that emotion is, somewhere between jealousy and . . . not quite sure.

(Prompt) Going back to pre diet, so you weren't well enough to commit to doing things?

5. I probably did commit but I often didn't feel well and was therefore sort of pushing myself to do
6. stuff that perhaps I shouldn't have been doing. Whereas when I follow the diet I have more
7. stability and therefore tend to be better on a day to day basis. I'm thinking . .

What are the main issues for your child if you have noticed, otherwise for yourself?

8. That's why I started to do this, because I had been ill for some time. It seemed to make sense to
9. try something different and it did seem to work which is why I've kept doing it for a while.

(Prompt) What type of ill?

10. Mostly fatigue and heady symptoms where you never feel quite competent and as though
11. you're not thinking properly and just making everything more of a struggle. Just day to day life
12. being more of a struggle.

(Prompt) You were aware of feeling this way and that it could be different?

13. Yeah, there was a definite onset, a distinct onset before which I was pretty much normal and
14. after which I was not normal.

(Prompt) Do you know what caused the onset?

15. Well I got a cold. Like a viral, I assume it was a virus because it didn't seem to be anything else.
16. It was one of those ones that didn't really go away for a few weeks and I had two rounds of
17. antibiotics. I was working I didn't really have sick leave, I wasn't secure in the work I was doing
18. at the time, so I guess I sort of pushed myself to keep going to work and to keep doing things
19. and I just never got better after it. So I kept that, you know how when you've got a cold for the
20. first few days you've got that sort of your heads a bit weird. It sort of stayed like that. That
21. was 13 years ago. It wasn't constant, it wasn't like it was like that every day. I did have better
22. periods and I've had worse periods. But I never really found any real links other than if I didn't
23. work I felt better. But it's not practical to stop working. Can't be on holiday all the time and the
24. food seemed to make quite a lot of difference. So most days now I don't have that feeling.

(Prompt) What started you on the food?

25. I thought for a while that there was a food factor in this. I just didn't know what it was and so I
26. tried going low GI and I tried cutting out wheat and I tried cutting out dairy, but nothing seemed
27. to make an overall difference. So I hadn't pursued it and then when this one was little (*pointing*
28. *to Chris*) and I was breastfeeding her, she every other night would literally scream
29. between six o'clock and nine o'clock at night. Like she would not settle, she would just scream.
30. So I started on the internet reading things and I came across some of the food intolerance
31. things, yeah came across some of the literature and started reading some more about it. While I
32. wasn't sure if it fitted her it seemed to fit me. So I thought OK let's try it. It did seem to make
33. quite a difference. She sort of seemed to grow out of it, I'm sure she's still sensitive to
34. something but it's nowhere near at the level that I am at.

(Prompt) How long would you say it took for her to grow out of it?

35. Within a couple of months from when it started really, it wasn't sort of like a, you know it didn't
36. go on for months and months and months. It was really quite quick.

What's the most important experience that you would like to share?

37. I guess my most important experience would be more of a word of caution. In that if you do
38. take everything out of the diet that it can be really hard to get things back in. You know and you
39. don't want to be stuck eating an extremely limited diet for a long period of time. I've never
40. really been at a stable baseline, so even my baseline is still a little bit up and down, so it makes it
41. really difficult to do challenges and things like that. I have had periods where I have relaxed a
42. little bit and then I can eat a little bit more, so I know it's possible to put more in, it's just that I
43. don't have the full answers about how much more I can put in before it becomes an issue. So I
44. guess it's going to take me a lot longer than I expected.

45. I went back to a normal diet for a while, after the older one was born. It was about 2 and ½
46. years ago that I started the food intolerance diets. RPAH, and then fructose as well. Sugar is
47. definitely an issue for me, I'm not sure if it's fructose per say or if it's all sugars. It definitely
48. makes a huge difference to not have sugar in my life.

Tell me a story to describe the relationship you see between food and your child's learning or your learning.

49. I guess the biggest thing that I notice now is if I have a day where I'm reacting and my heads not
50. right and I'm at work concentrating, I am so aware that I can't concentrate that it's astonishing.
51. And yet I lived like that and worked like that for nine years. I have no idea how I did it. And I
52. have a good reputation at my work as being someone who gets things done and is good at what
53. I do. I'm just astounded that I managed to do it. Absolutely astonished. It's just so much easier
54. to concentrate and to achieve things when your body is actually there in one piece.

Tell me a story to describe the relationship you see between food and behaviour.

55. For me, if I start having sugar I start to get anxious. I sense that sort of anxiety, I get anxious
56. and a bit teary sometimes and just feel as though I'm losing control, not as much patience, yell
57. at the children more than I'd like to. So there's a definite link that I've found for me, and I
58. certainly prefer not being like that.

Describe specifically what was involved in your child's and/or your elimination diet.

59. I haven't had a lot of wheat since I started doing this diet again. When I tried to challenge wheat
60. I had the same reaction as what I did to fructose. So I think that for me wheat might be a
61. problem purely because of the amount of sugar that it does have in it. So I think it comes back
62. to sugar. With the dairy side of things I think it effects my bowel movements a little bit. Which
63. again can make me cranky if I'm not feeling 100%. So it's like a slightly different pathway, and it
64. might be something different, but it's deep down in there. It's that fogginess that I have not
65. been able to work out.
66. Salicylates and amines, I react to both of them. I haven't done a lot of the other challenges
67. cause I just never got to them. I'm fairly sure that I react badly to sulphites as well, and what
68. else. . I never did the colour tests because if you can't do wheat, dairy and sugar then there's no
69. colours in your life anyway. I never got to half of those, oh the antioxidant in oil, I react to that
70. as well.
71. I basically don't eat it if it comes in a packet. Unless it's just packaged because it's oats or rice.

What resources did you use when doing the elimination diet? Eg. Health professionals, books, internet, support groups.

72. I used the internet, I got the friendly foods book, Sue Dengate's books as well. I have seen a
73. couple of doctors as well. One of them is an allergist specialist who works with a nutritionist
74. and the other one was a GP with interest in food intolerance.

What goals did you hope to achieve?

75. Initially I hoped to have a really clear idea of what I could eat. I hoped that I would be well, and I
76. hoped that I would know that I could eat this this and this much of this and it would be really
77. really clear. But it's not really really clear, it's still murky completely. And I've pretty much given
78. up on the chance to actually finish all the challenges because I don't think it's going to happen.
79. So I guess now I'm hoping, my goals have sort of changed from that ideal fantasy land to having
80. some form of normality in my diet while still feeling quite reasonable. I guess finding that
81. balance between eating exactly what I want and feeling fantastic.

Did you consider any alternative therapies/treatments? If so, which ones?

82. Well over the years I've done lots of different things. I've seen naturopaths and I've done
83. reflexology. I saw a chronic fatigue specialist for a while. They're probably the main ones that
84. had any vague impact on anything. The natropath and reflexologist, with both of those two

85. they seemed to help. I seemed to be better while I was seeing them, but never 100%. I was
86. better than I had been without seeing them, but not perfect. There were still lots and lots of up
87. and downs. But better enough that I did sort of keep going. But not better enough to make me
88. really want to keep doing it and to feel that this was a definite answer.

89. The chronic fatigue specialist, I don't think that really did a whole lot for me. There's no test for
90. chronic fatigue syndrome and to a large extent they are still quite experimental. He did a few
91. tests and put me on some tablets and he made me take these questionnaires. I know I did two
92. of them and the first one I did I was feeling quite ordinary and the test came back quite
93. ordinary. The second time I saw him I was feeling quite a bit better but I don't believe that that
94. was because of the tablets that he had me on I think that was one of those phases when I went
95. up and down. So needless to say I didn't keep going. It didn't seem to be going anywhere. And
96. I didn't feel right about just taking tablets for no apparent reason.

97. I stopped seeing the allergist specialist, his nutritionist was quite good but he was horrible. So
98. I've actually moved on again. I'm now seeing a biomed GP. A new one that I've just started
99. seeing. I'm part of the failsafe yahoo group and quite a few of them have had success with
100. biomed doctors. Another one of my friends who has had food issues has also had success with
101. the GP that I'm about to see. I've seen her once. I've only seen her once so it's all a bit new but
102. she has a few different ideas, which seem to make sense. She thinks my symptoms are
103. consistent with a concept called adrenal fatigue. So she's given me a test that I have to do at
104. some stage when I get over my cold, to test how my adrenal glands are producing I think it's
105. cortisol, the stress regulating that they produce. And she gave me a book to read that I've
106. only actually read the first couple of chapters but it does sound quite similar to a lot of my
107. symptoms. So she thinks that might be causing the food intolerances that I'm seeing rather
108. than the other way around. I guess I've gotten to the feeling that I guess there is something
109. underlying it anyway because the food wasn't the whole answer. It's like let's move on to the
110. next thing.

111. The book suggests that it's more about modifying lifestyle that there's no specific drug that you
112. can take or anything like that, that sometimes some vitamins might help but then it often
113. causes sugar inconsistencies in your body so you tend to do better on a low GI diet which I
114. already found I do. Just reducing your environmental stressors, chemical stressors, work
115. stressors, you know all those sorts of things. Try and change your life a little bit so you're a bit
116. more balanced.

You mentioned a support group online, how did this work?

117. It's a yahoo group and people just post questions and answers and have discussions. Some of
118. which is obviously relevant to you if you're reading and some which is completely irrelevant. So
119. I guess I read bits of it and every now and again ask questions or respond to people, but I'm not
120. hugely active on it. It's sort of interesting at least on one level you hear about other people who
121. are struggling to have some sort of life while having a ridiculous diet. It's quite nice.

You had Chronic fatigue, can you describe what this was like and how you dealt with it?

122. Well for me it meant that I was tired, more tired than everybody else, had less capability to cope
123. with anything outside of my day to day life. It meant that my life was a struggle and for me gave
124. me those heady symptoms that I was talking about earlier and I guess most of the time I coped
125. with it by limiting my life because nobody seemed to have any answers.

You wrote that you “always believed there was a food link”, where in your experience do you think this belief may have come from?

126. That’s a very good question, when I say always it was probably a few years in. Where did it
127. come from? I remember reading books, I don’t remember thinking about it much before this -
128. the time that I’m about to start thinking about – I do remember sitting at work when I was quite
129. recently ill and literally eating my way through the day. Like I never seemed to stop eating and I
130. know that if I’d stop eating that I’d start again quite quickly. Not necessarily eating foods that
131. I’d want to be eating. And I do remember in 2001/2002 reading books, I actually bought a few
132. books about the sugar, people who had sugar intolerance and about low GI and all of that sort
133. of thing, I’m not sure whether that’s when that became quite apparent in the media or if I just
134. stumbled across a book in a book shelf and it seemed to make sense. I can’t remember the
135. links. But I know that when I did go low GI it did make enough difference for me to have noticed
136. it and I did at that stage try keeping a food journal to see if I could make any links. But when I
137. was low GI I was high fruit, so I would have been high fructose and high this and high that. And I
138. was eating you know curries and what have you with all the preservatives and stuff that you’d
139. find in those. So with hindsight of course it didn’t work but you know there was far too much
140. noise, but I did try it for over a year writing down everything that I was doing everyday to try
141. and see if I could find any patterns and I couldn’t. So it definitely goes back to then, that I was
142. trying to work things out but quite how it came into my brain. Growing up we ate a reasonably
143. healthy diet, you know with moderation in everything, so it wasn’t like there was anything
144. specifically excluded that we weren’t allowed. If I do think back I know that if my mum had a
145. new packet of cream biscuits that I could eat pretty much the whole packet in one sitting it was
146. very hard for me to limit myself to just one or two. Which is probably the same sort of issues
147. that I still have. But there wouldn’t have been a discussion about it or anything like that.

Some benefits you describe of the elimination diet, are that you, “enjoy life”, greater “emotional involvement”, “more energy”, “think clearly all the time now”, “calmer, more stable, happier, more positive and able to plan things” – how does this look?

148. I guess it just means that I’m not fighting all the time. It just makes life easier to not always be
149. fighting against something and that it’s sort of nice to actually feel happy and stable.

Tell me a story to illustrate some of the symptoms you associate with food intolerance, such as fuzzy brain, forgetting nouns, and being more withdrawn.

150. I don't know that I have a story. Well the whole thing at work and not being able to think
151. straight. That was just my life. Forgetting nouns just gets embarrassing doesn't it. You're
152. talking to someone who you know perfectly well and all of a sudden you have to use their name
153. and it's just not there. And some days it wasn't even names it would be something else and I
154. would be grasping for these words. And I don't think I have a specific story when it all comes
155. together.

You also said that you have observed children who were 'glazed over' and 'unable to sit still'. If I was in the room, describe what would I see?

156. It was at daycare. I was there to read the children a story and you know there was a group of 25
157. kids all sitting on the floor and the ones at the front of the room were quite cooperative and
158. involved and what have you and there were a few children in the back of the room that were,
159. there were a couple who couldn't sit still so they were monkeying around and screalling (*sic*) and
160. wriggling and there were others who were, they were sitting there quite calmly but you could
161. tell their faces were blank they weren't involved. You expect a small child to be engaged and
162. they clearly weren't. I guess it was the contrast more than anything else between the children
163. who were at the front and were listening and you know, I want to ask a question and can I tell
164. you about this and you know standard behaviour that you would expect from a 3 or 4 year old
165. compared to a child whose just sitting there and not just sitting there like I can't be bothered,
166. but just looking blank, almost unwell I guess.

How do you feel about your journey to discover your food intolerances?

167. I think my journey was too long. That's my main feel about it, that I'm really disappointed that
168. doctors couldn't at the start would just say, oh you'll get better. And nothing, that it's not
169. possible for them to have any ideas about things that you could try and other places you could
170. go to try and get some answers.

Describe an example of when (Cate) doesn't want to eat food and says "it may make me sick"?

171. It usually happens, she has stopped recently which is really good, it usually was happening if I
172. made a risotto or something where everything was, where food was all mixed together. And
173. then she'd pick something out and say, "I don't want to eat this, it will make me sick" and be
174. looking at it, like it's a piece of swede or it wasn't usually a pea but sometimes it was a bean
175. sprout or something like that, and it's something completely innocuous, but for whatever
176. reason she just wasn't interested eating that day. Now she's moved on to asking whether it will
177. make me sick.

Who chooses the food in your family? How does this look?

178. Me. I write the shopping list. Usually I do the shopping or we go to the market Saturday
179. morning, so we buy our fruit and vegetables and meat at the market as a family. I pretty much
180. decide the base of what we're buying. Sometime (Cate) will, if we are at the vegetable

181. shop, she'll say can I have this vegetable and yeah, I don't force them to eat exactly what I eat.
 182. So they'll have broccoli, or mushrooms and carrots and what have you. So she'll choose some of
 183. those sorts of things.

Create a picture of words to describe how meals are prepared in your home.

184. Meals are prepared by me. Usually I do the basic vegetable preparation after we get home from
 185. the market so we wash all the veggies, top and tail all the beans and get the right bits of the
 186. broccoli, cauli and all those sorts of things. Then on a daily basis, if it's a day that I'm not
 187. working, it's late in the afternoon that I'll start cutting up vegetables and working out what we
 188. are going to eat, then get round to cooking it on the stove in between sorting out children's
 189. activities. So it's pretty much me with the children. They help out a bit.

What is your reaction to these statements?

1. **Foods without food additives appeal to parents who do not like commercially processed food**
 (Cruz & Bahna, 2006).
 190. I'd say that is probably quite true I think a lot of people these days are a bit suspicious of
 191. commercially processed food and suspicious about what is being put into our foods and that
 192. seems to be more widespread than just in these food intolerance communities. So there does
 193. seem to be some people who are quite suspicious but they're not quite certain what they're
 194. suspicious of. So I think some more education is probably needed.

2. **"Dietary intervention is difficult, but where there is improvement, parents report it is better
 than managing a difficult child"**(Breakey, et al., 1991, p. 93).
 195. I don't know about a child, so I'll put it into context for me, it is difficult, it's a lot of work ,
 196. there's a lot of explaining to do to people about why I can't just eat this and can't you know do
 197. bla bla bla (*sic*). But I don't want to be sick so yes there is definitely a level where eating
 198. different foods is the right choice for me, so I can only imagine that that would be true for other
 199. people as well.

3. **"It (also) may be easier for the parents to accept the idea that their child's behavioral problem
 is due to a dietary factor than to psychosocial issues that are often difficult to evaluate and
 tackle.**
 200. You know I do actually wonder that, whether that's true sometimes. I've seen enough in myself
 201. to know that there are definitely some food things there but at the same time there is a point
 202. where you are in control of your behaviour, even if it's harder when you're reacting there's still
 203. a point where you can get more control or less control that I've found. So I would say that
 204. behavioural issues are probably a mix of both, and that while food might be some of the answer
 205. it is certainly beneficial teaching children how they ought to behave and trying to work out, I

206. guess do your best to teach them how to function in a way that would work in our society,
207. because they need those skills regardless.

4. **(an elimination diet) gives the family a sense of solving the problem and provides the child with substantial attention"**(Cruz & Bahna, 2006, p. 728).

208. That's an interesting concept. I guess it could work like that. I'm not sure that I can relate that
209. back to my life because well I guess in some ways I am giving myself attention so it does sort of
210. feel as though I'm doing something rather than sitting around doing nothing. But that's an
211. adults view of the world not a child's view of the world.

5. **Changing diet to manage a child's behaviour can reduce a parent's feeling of guilt about the situation** (Harley, Matthews, et al., 1978).

212. Possibly if something works or seems to work then Yeah, I can see that could impact the way
213. you feel. Although from my own experience, I'd have to say that my girls haven't done the diet,
214. but they don't really do additives and there are certain times when I feel as though I'm reducing
215. their food choices and so I guess that's sort of guilt on the other way around. I don't know. I
216. don't think there's easy answers to these things.

Would you like to expand on anything?

217. I don't think so, I don't think there is anything to expand on.

Appendix D

Transcript of interview with Donna

What are the issues that you see associated with food intolerance?

1. Gut symptoms, bloating, wind, excess gas, full range of stomach cramps, gastro, pain symptoms
2. – feet, joints, anywhere, skin problems, rashes, bumps, dry skin, psychological, in terms of
3. feeling depressed or anxious, behavioural in terms of kids having tantrums, and feeling tired, not
4. sure where that fits.

What are the main issues for your child?

5. Sleep, skin, gastro, behaviours, interrupted sleep, how long it takes to get to sleep, over the
6. years probably gastro is the big one, because that causes pain, pain in the gut is a big one. I can
7. tell he's reacting by how long it takes him to get to sleep and by how many times he wakes up
8. during the night and also what time he wakes up. He'll sleep for a different length of time
9. depending on what he's eaten. I can tell if he wakes up in 3 hours I can tell what it will take to
10. get him to sleep, if he wakes up at 4am it's a different issue.

What's the most important experience that you would like to share?

11. I think probably that it's not easy and you have to keep searching and it could be anything.
12. Despite that the dietician specializes in a particular diet, does not mean it's that. There comes a
13. point in the diet where you say, "well that actually didn't work. It's not because I'm not doing it
14. right, it's because that is not actually the problem." We tried various diets. I would find the
15. local dietician who specialized in that diet, got all the information. In my experience
16. naturopaths, dieticians around here in Melbourne, I have not really found anyone who has a
17. really good across the board view, to say "OK those symptoms is in line with this, let's try this
18. one." Most of them seem to specialize. This person knows about fructose malabsorption, this
19. person is good with failsafe. We do a low oxalate diet and supplements. Supplements have
20. made as much if not more of a difference than diet, B6 and zinc are the big ones, but also
21. probiotic strains.

Would you like to expand on anything?

22. Oxalates they are like salicylates they're a protective mechanism for plants but they are not so
23. great inside the body. If you have a normal gut you absorb between 1 and 5% of them and your
24. body gets rid of them, all the bacteria in your gut competes with them and excretes them. If
25. you have a weaker gut then you absorb 50% and if you've got certain deficiencies in your body
26. then you'll make them as well. There's no known role for them in your body. They make kidney
27. stones and they can form crystals, if you have an old injury they can form crystals there.
28. They are found in things like spinach, beetroot, and nuts.

Tell me a story to describe the relationship you see between food and your child's learning.

29. I look at his reactions to food and he is tired because he hasn't had as much sleep, he tends to
30. be more anxious and clingy, and would just be generally grumpier. I assume he's grumpy

31. because he's probably not feeling all that great and yeah, you put all that together and a one
32. year old or two year old is less likely to run around the room, less likely to play or learn some
33. things. Less likely to be out and about and paying attention. If you're feeling grumpy you're less
34. likely to be adventurous and things. On a good day he will be a whole lot more chattier and
35. relaxed, if you're more relaxed then you'll stick at something for longer, more adventurous at
36. trying new things . It's just like adults when you're feeling confident things are great.

Tell me a story to describe the relationship you see between food and child's behaviour.

37. One of the things is chickpeas. If he has chickpeas at childcare, because we don't have them at
38. home, I can guarantee that night we will have some kind of meltdown that night over something
39. very tiny, like whether I put carrot on his plate, he won't be able to cope. Ordinarily he would
40. say "I don't like carrots".

Describe specifically what was involved in your child's and/or your elimination diet.

41. When I started it off, I had tried various other diets and I was fairly frustrated, I decided that I'd
42. give it six months solid trial. I wouldn't look at it day to day, I'd look at it again in 3 months time
43. if things were not too great. The decision making point yep, I thought at 6 months, at the 3
44. months point is that you know things aren't vastly different clearly no benefits then I would
45. have ended it, otherwise I'd do it for six months. One of the key things was buying a thermomix.
46. I would have found it, I'm sure it's possible if we were to do egg and dairy free, doing it without
47. that would have been really difficult. The first thing I learned to do was to make rice milk. It
48. was one of the things that enabled me to do the diet.

49. I'm a member of a yahoo group and it's an American based group. The lady who runs it is a
50. scientist researcher and very thorough with the research. She won't let any – there is so much
51. untested on the internet – She won't let those slip by. They all talk about American foods and
52. American places that we have different names for and all their food testing is obviously done on
53. American foods and it's the same with salicylates I guess – where it depends on how it's
54. cultured and where it's grown. For me it took a little bit to work through that but we didn't
55. really do challenges as such because with oxalates it's not necessarily an immediate effect, a bit
56. like salicylates. I guess in my experience doing failsafe challenges I was so busy reading the
57. common mistakes and not put any more than 2 drops of vanilla in the muffins and things like
58. that the challenges were a lost cause. I didn't really do it like that, it was more gradually
59. working my way and learning what was high what was low, what was good, what worked and
60. what didn't. And coming up ways to do thing, and I guess I probably then spent more time on
61. the supplements. They recommend supplements and I had already worked out that some
62. things worked and some things didn't. After six months when I looked back, it's like yes, we are
63. not quite where we want to be but things had improved. There was no waking up in the middle
64. of the night, and screaming for half an hour and yes things had improved.

What resources did you use when doing the elimination diet? Eg. Health professionals, books, internet, support groups.

- 65. Lactation consultant – Hodge podge, “in my experience, don’t eat”
- 66. Dietician – removed top 8 allergens
- 67. Failsafe – dietician, all the books by Sue Dengate – her cookbook , RPAH, Elimination diet book –
- 68. Friendly foods
- 69. Candida diet – self taught through internet
- 70. Fructose malabsorption – dietician
- 71. Naturopath – NAET treatments for desensitization and supplements
- 72. Rocko the dietician – whole foods diet – it was a disaster. He was lovely but the reactions to the
- 73. food he gave were so strong that that was what led me to try low-oxalate diet. So it was
- 74. instrumental.
- 75. Low-oxalate diet - Yahoo group, Vulvodynia Association cookbook
- 76. <http://www.thevpfoundation.org/vpfoxalate.htm>

Tell me about your child’s involvement in the process (if applicable).

- 77. Eats when he’s told.

What goals did you hope to achieve for your child on the diet?

- 78. My big goal is to feel instinctively that foods are not an issue. And I’ll know that because I will
- 79. have a happy healthy child who sleeps through the night, doesn’t have rashes on his arms and
- 80. his legs, doesn’t take an hour to go to sleep and who doesn’t have big tantrums. I know he’s an
- 81. easy going happy little kid, sometimes he’s distracted because he’s not feeling well.

You mentioned that your lactation consultant was the most useful practitioner in guiding you through an elimination diet. Describe this for me.

- 82. I’d love to go back to every person I have seen and say “look this was the answer you completely
- 83. missed it”, and I’d like to say it to her. On the other hand she was instrumental, she believed me
- 84. at that stage. (Dale) was five months old and I was having a hard time trying to get anyone to
- 85. believe me that it was actually food, she did, he had dairy and egg allergy. So I wasn’t making it
- 86. up. And she took me seriously. She said “Yes, you’re on the right track”. So it was instrumental.

You tried the elimination diet for your baby and unexpectedly found personal benefits, describe how this looked.

- 87. I’m much healthier. I have a much better understanding of health and food. I have a much
- 88. better understanding about what goes into processing food, I had no idea, or the effect that it
- 89. has on me personally. I’m much healthier now. And I guess the other thing it has confirmed to,
- 90. is to make decisions based on instinct. Now I trust my instincts more, because I knew I was right.
- 91. Not more trusting, I am more confident about pursuing my instincts.

Tell me a story to illustrate your experience on an elimination diet. You have said that, “Being on an elimination diet has helped me to listen to my body more closely, and to realize lots of little symptoms that by themselves may be bearable, are all related to food.”

92. If I eat sunflowers or sunflower oil, or vegetable oil that has sunflower in it, I get a rash on my
93. arm. It's not especially itchy, or ugly or anything like that but now I don't get it. Cause now I've
94. worked it out.

What do you think are the priorities of bodies that regulate the standards of our food?

95. I think they place priorities on food manufacturers needs. What are cheap readily available
96. ways to cook our food? How can they obtain products easily and cheaply to sell more products?
97. To make it prettier, or last on the shelf longer or whatever, regardless of what concerns people
98. might have about eating it. I think their focus is on manufacturers and food retailers. I think
99. they should tell us not only what's in the food but also what's involved and what chemical
100. processes are involved in making food.

“I (also) feel like I am now respecting our bodies more and teaching my son to listen to and respect his body.” Can you describe what it looks like when you teach this to your son?

101. Other parents might disagree with this, when I . . let's say he has tantrum at night, cause I know
102. he's eaten foods that don't agree with him at childcare, I don't know exactly how that makes
103. him feel but I'm thinking that he's really upset and he's not feeling very well. His meltdown
104. might be disproportional to what has happened, so I'm making a judgment that food is making
105. him feel bad, and because of that how I'll deal with that is more with sympathy or empathy
106. rather than taking a more firmer approach I guess. I'm trying to say to him that I respect that
107. he's not having a meltdown because he's not allowed to buy something at the supermarket or
108. something like that, but because he's tired and he's not feeling great, so yeah. I'll get a theory
109. about how I think he's feeling and I'll ask him if that's the way he's feeling and he'll say yes or
110. no, that kind of thing. We'll go through that, and I might say, we're doing this because . . More
111. abstractly, I'm actively demonstrating to him that I care about it and that I want to put energy
112. into that and to put energy into the way you're feeling and to be healthy. It's a philosophical
113. approach to health in our house that I think I've got from my mum and I think I'm giving to him.
114. And when we go to a GP and the GP says “no, you're wrong”. I don't go “Oh OK, I'll just accept
115. that on the basis of the GP's authority”, I won't, I will actively move forward.

How do you think your son feels about the family diet?

116. I don't think he's unhappy. I think he's fine about it. I guess like any parents when we are at the
117. supermarket I get pestered to buy certain foods but the foods I get pestered for are peas and
118. corn. He loves his peas and corn. Loves his peas. We don't go down the lolly aisle. At the
119. airport the other day he's picking at the Picnics and things but he doesn't know what they are.
120. He says, “Dad likes these”. But it's like, you've never seen your father eat one.

Describe your shopping trips with your child.

121. He has choices and he wants certain foods, he wants his bread, he wants cherries, he wants
122. peas, he wants rice bubbles.

You describe that it is difficult to explain these diets to people unfamiliar with them. Tell me about some of your experiences with this.

123. Oh, I don't do it very often. Mum asks but . .my mother in law wanted to know, she doesn't
124. understand but she wanted to know what foods he can currently have and they just ordered
125. him a cappuccino and covered it in chocolate because I hadn't got in first to say no chocolate. I
126. was like if he has chocolate he won't sleep very well, and he goes and sleeps through the night.
127. An experience at childcare, I say no tomatoes. They say "What happens if he has tomatoes, is it
128. like an allergic reaction?" I say, it's more like food intolerance, and the eyes start to glaze over
129. and they say, Oh look at these things and the eyes completely glaze over and they are like
130. looking around the room. And you're like right, OK, interest level zero. Then one day when the
131. normal chef was on holidays they made spaghetti bolognaise. And I was asking, Oh what did
132. (Dale) have? Yeah he had spaghetti bolognaise. Oh well what kind of sauce did he have on it,
133. did he just have meat? No, no tomato sauce. I'm like, isn't tomatoes on his no list? And they're
134. like, "oh do you mean like canned tomatoes, we thought you just meant not fresh tomatoes." A
135. tomato is a tomato.

You said you don't have "any hard scientific evidence", but your "instinct" is that diet makes a difference. What kinds of behaviour support you saying this?

136. It's just night and day. Nowadays as a three year old he'll play independently, he'll get really
137. engrossed in something, he'll stay at it, he'll try new things, like he might be building something
138. and he'll build something new or yeah and versus, being grumpy, clingy, yeah those kinds of
139. things. His sleep is a big indicator, like sleep's not necessarily the most difficult thing. But like
140. I said before if he wakes up after three hours I know one thing is going on, or if he sleeps
141. through the night.

What advice would you give to other parents in regards to food intolerance?

142. Trust your instinct. If you think it's food then it's food.

What is your reaction to these statements?

1. **Foods without food additives appeal to parents who do not like commercially processed food**
(Cruz & Bahna, 2006).

143. I guess, yes. Food without food additives appeal because I don't like food additives, not because
144. I don't like commercially prepared foods. I'd love some commercially prepared foods that were
145. low oxalate, low preservative, no artificial colours, that would be the best thing. It's not that I

146. don't, I have nothing against commercially prepared foods, I have everything against the crap
147. they put in them.

2. **"Dietary intervention is difficult, but where there is improvement, parents report it is better than managing a difficult child"**(Breakey, Hill, Reilly, & Connell, 1991, p. 93).

148. Yes, I agree with that but it's not 100%. I will on occasion like, I don't like sulphite preservatives
149. in sausages, but at a pinch I will allow (Dale) to have a sausage with preservatives in it and
150. deal with the consequences. I guess there is always a trade off. Parenting has lots of tradeoffs
151. and that's just another one. Sometimes I'll deal with that later for a benefit now. I would never
152. give him the ultimate evil, spinach, and I would probably be stricter about things. Like chocolate
153. he has now and again, I don't think he is about to become a chocoholic. The foods he is
154. intolerant to I guess, when he has his allergies then that's kind of different, I don't mess about
155. with that so much. Food intolerance is not, I just might have to live with it for a day, or I might
156. just have less sleep tonight.

157. That's also a decision I made with child care as well, I take out – they have a list of foods that I
158. really don't want him to have, but within the rest of it they have a lot of flexibility. He has a lot
159. of food at childcare that he wouldn't have at home, and that's partly because I can't think of
160. alternatives for them and partly because I just don't want the look of 'you're an absolutely crazy
161. parent'.

3. **"It (also) may be easier for the parents to accept the idea that their child's behavioral problem is due to a dietary factor than to psychosocial issues that are often difficult to evaluate and tackle. (an elimination diet) gives the family a sense of solving the problem and provides the child with substantial attention"**(Cruz & Bahna, 2006, p. 728).

162. A bit provocative. If you've got a 14 year old child who is running a mock. If you've got a six
163. month old whose screaming in the middle of the night. I didn't want the screaming, I didn't
164. want the attention, I didn't want to be carting my 6 month old son to see anyone, I wanted him
165. to be asleep. It depends on the parent, maybe I'm just judging other parents, but I know my
166. instinct. I know my parenting choices weren't that off. With a six month old you haven't had
167. enough time to create terribly bad habits. And the other thing, I'm a psychologist and three or
168. four years ago, one of my nephews was 8 or 9 years old and was absolutely raging at home. Like
169. he would lose his temper and he would be really quite aggressive. And my sister said to me that
170. she was taking him to see the doctor first. And I was like yeah, what for. She said well just to
171. check that there is no physical issue and I was on the other end of the phone saying right,
172. there's no – I can tell it's from your parenting. You and your husband, you know and if you sort
173. that out then your son will be alright. So I was completely discounting it. Now, I understand the
174. way food makes me feel and I understand when I take the supplements versus when I don't. I
175. feel completely different. So now I would say yes absolutely go to the GP and find out if there's
176. any issues. Try out the diet stuff first and then yeah. You can always try new things in your
177. parenting. No parent has got it all worked out.

4. Changing diet to manage a child's behaviour can reduce a parent's feeling of guilt about the situation (Harley, Matthews, & Eichman, 1978).

178. I don't know that it reduces any of the guilt. In a way I'm experimenting with my child, there is
179. increased guilt. Increased worry. It doesn't reduce my guilt. When I give him a new
180. supplement, what if this is bad for him. Or that I'm not giving him certain vegetables other
181. people would argue that those are very healthy vegetables and would say I'm depriving my child
182. of healthy vegetables because yeah. I'm sure other people look at what I give him on his
183. birthday, what his special treats are say "you are depriving this child, it's his birthday".

Would you like to expand on anything?

184. It was interesting seeing the allergist for my son at 6 months. He said, "Do you want me to write
185. to your GP?" I was like, you can if you want. He hasn't been especially helpful. He said yeah, in
186. his experience parents know more about it than any other (professionals). He himself had
187. absolutely no interest in food intolerances.
188. I've read lots of good stuff about autism, between autism and allergies, the thing. I think you're
189. right, it will change.

Appendix E

Explanatory Statement and Consent Form

Explanatory Statement

July 2011

Explanatory Statement – (name of participant)

Title:

What are the motivations and experiences of those who have tried an additive free or elimination diet?

This information sheet is for you to keep.

Student research project

My name is Dianne Golemac and I am conducting a research project with Dr Jill Robbins a Senior Lecturer in the Department of Education towards a Master of Education at Monash University. This means that I will be writing a thesis which is the equivalent of a 300 page book.

Thank you for contacting me to be a part of this research. The aim of this study is to record why people choose to try an additive free or elimination diet and how they found it. I am conducting this research to find out more about the experiences of different people on these diets. I am hoping that this research will give valuable insights to others about these diets and increase more awareness on the topic.

What does the research involve?

The study involves participants completing a journal of their experiences on an additive free or elimination diet. This will be followed by a semi-structured interview to clarify what is recorded in the journal.

How much time will the research take?

It is expected that the journal may take a couple of hours to record as many experiences as possible. Interviews will take approximately 45 minutes to complete.

Inconvenience/discomfort

This research involves sharing and discussing personal issues about health with the researcher.

Can I withdraw from the research?

Being in this study is voluntary and you are under no obligation to consent to participation. However, if you do consent to participate, you may only withdraw prior to the submission of your journal.

Confidentiality

Journals will not have names recorded on them. They will be colour coded in a way that only the researcher will be able to identify the author, for research purposes only. The researcher will then be able to match the journal with the interviews for analysis. Pseudonyms will be used instead of names for the thesis and future publications.

Storage of data

Storage of the data collected will adhere to the University regulations and kept on University premises in a locked cupboard/filing cabinet for 5 years. A report of the study may be submitted for publication, but individual participants will not be identifiable in such a report.

Use of data for other purposes

The data collected from this study may be used for other purposes. However because pseudonyms will be used, it would be difficult to identify participants.

Results

If you would like to be informed of the aggregate research finding, please contact Dianne Golemac on [REDACTED] The findings are accessible for <insert time frame>.

If you would like to contact the researchers about any aspect of this study, please contact the Chief Investigator:	If you have a complaint concerning the manner in which this research CF09/3566 – 2009001923 is being conducted, please contact:
Dr Kerith Power Senior Lecturer in Early Childhood Education Monash Univeristy Faculty of Education Peninsula Campus PO Box 527 Frankston VIC 3199 Australia	Executive Officer, Human Research Ethics Monash University Human Research Ethics Committee (MUHREC) Building 3e Room 111 Research Office Monash University VIC 3800 Tel: +61 3 9905 2052 Fax: +61 3 9905 3831

Phone +61 3 9904 4450 Fax +61 3 9904 4027 Email	Email: muhrec@adm.monash.edu.au IMORTANT: For projects in non-English speaking countries, a local person who is also fluent in English must be nominated to receive complaints and pass them onto MUHREC. Please replace above section (in blue) with the details of that person.
---	---

Thank you.

Dianne Golemac

Consent Form

<Name of participant group if more than one>

Title: <Exactly as it appears on your MUHREC Application Form and your Explanatory Statement>

NOTE: This consent form will remain with the Monash University researcher for their records

I agree to take part in the Monash University research project specified above. I have had the project explained to me, and I have read the Explanatory Statement, which I keep for my records. I understand that agreeing to take part means that:

I agree to complete a journal outlining my experiences
on an additive free or elimination diet

☐ Yes ☐ No

I agree to be interviewed by the researcher

☐ Yes ☐ No

I agree to allow the interview to be audio-taped

☐ Yes ☐ No

I agree to make myself available for a further interview if required

☐ Yes ☐ No

and

I understand that my participation is voluntary, that I can choose not to participate in part or all of the project, and that I can withdraw at any stage of the project without being penalised or disadvantaged in any way.

and

I understand that any data that the researcher extracts from the journal or interview for use in reports or published findings will not, under any circumstances, contain names or identifying characteristics.

and

I understand that I will be given a transcript of data concerning me for my approval before it is included in the write up of the research.

and

I understand that any information I provide is confidential, and that no information that could lead to the identification of any individual will be disclosed in any reports on the project, or to any other party.

and/or

I understand that data from the journal, interview, transcript, audio-tape will be kept in a secure storage and accessible to the research team. I also understand that the data will be destroyed after a 5 year period unless I consent to it being used in future research.

Participant's name

Signature

Date

Appendix F

Journal prompting questions

Thank you for participating in this study exploring the experiences of people who have tried a low food additive or elimination diet.

Over the next couple of weeks, I would appreciate it if you could write your thoughts about your experiences on one of these diets. To guide your thoughts here are some questions that may help prompt different ideas.

How did you hear about low food additive/elimination diets?

What were the reasons you investigated food intolerance?

What did you hope to achieve?

What were your goals?

Why were these goals important to you?

Did you achieve your goals?

Have your goals changed over time?

Has it been a worthwhile experience? Why?

Do you think that food plays a role in learning? Why, or why not?

Do you believe behaviour plays a role? If yes, describe.

How did your child/children respond to the dietary changes?

Describe your shopping and food preparation times. Who takes part? What happens?

Have these roles changed?

Appendix G

Interview questions

Introduction

Mapping

What are the issues that you see associated with **food intolerance**?

What are the main issues for your child?

What's the most important experience that you would like to share?

Would you like to expand on anything?

Body

Tell me a story to describe the relationship you see between food and your child's learning.

Tell me a story to describe the relationship you see between food and child's behaviour.

Elimination diet

Describe specifically what was involved in your child's and/or your elimination diet.

What resources did you use when doing the elimination diet? Eg. Health professionals, books, internet, support groups.

Tell me about your child's involvement in the process (if applicable).

What goals did you hope to achieve for your child on the diet.

Did you consider any alternative therapies/treatments? If so, which ones?

Journals

See **Appendix H** with specific questions for participants based on responses in their journals.

Conclusion

What is your reaction to these statements?

1. Foods without food additives appeal to parents who do not like commercially processed food (Cruz & Bahna, 2006).
2. "Dietary intervention is difficult, but where there is improvement, parents report it is better than managing a difficult child" (Breakey, et al., 1991, p. 93).
3. "It (also) may be easier for the parents to accept the idea that their child's behavioral problem is due to a dietary factor than to psychosocial issues that are often difficult to evaluate and tackle. (an elimination diet) gives the family a sense of solving the problem and provides the child with substantial attention"(Cruz & Bahna, 2006, p. 728).

What do you think?

4. Changing diet to manage a child's behaviour can **reduce a parent's feeling of guilt** about the situation (Harley, Matthews, et al., 1978).
5. Would you like to expand on anything?

Appendix H

Interview questions based on journal responses

Abbey

In your journal, you mentioned a study linking Alzheimer's to the chemicals found in hot dogs. Tell me more.

In reference to your son at parties, you said, "He has learnt through experience to make better food choices". Can you tell me about some of these experiences?

You mentioned your frustration with your children's peers and the disruptive behaviour "making it hard for your children to learn". What does this look like?

What benefits do your children see from this diet?

How do your children see food, behaviour and learning?

Bernice

A social worker from the community came to give you parenting strategies to help you manage your daughter. How would you compare the role of diet and the role of this parenting advice?

What may have been the effect of the diet alone/the advice alone? Would you suggest to use one or both?

You observed that your daughter was displaying problems with achieving results at school and was friendless. What did this look like?

You mentioned your frustration with your children's peers and how "the behaviour of others interferes with the whole classes learning". What did this look like?

How did you learn about your own intolerances?

Daughter believes you are the "lucky ones". What are the benefits that she sees from your diet?

You said, "I don't know if I would still be alive". Do you think that diet changes could save lives?

What does a Low FODMAP diet look like?

What has the Food Intolerance network helped you learn?

Who makes the food choices in your family?

You said, "enabling her to do it for herself is my ultimate goal" – What would this look like?

Camille

You mentioned a support group online, how did this work?

You had Chronic fatigue, how did this look and how did you deal with it?

You “always believed there was a food link, where in your experience do you think this belief may have come from?

In altering your food choices, how have your goals changed over time?

Some benefits you describe are that you, “enjoy life”, greater “emotional involvement”, “more energy”, “think clearly all the time now”, “calmer, more stable, happier, more positive and able to plan things” – how does this look?

Fuzzy brain, forgetting nouns, and being more withdrawn are some of the symptoms you associate with food intolerance. You said that you have observed children who were ‘glazed over’ and ‘unable to sit still’. How does this look?

How do you feel about the effort involved in this pathway?

What literature have you used? Why?

Describe the scenario when your daughter doesn’t want to eat food and says “it may make me sick”?

Who chooses the food in your family? How does this look?

Who cooks in your family? How does this look?

Donna

Describe the ways in which the practioners involved in your baby’s nutrition helped.

You tried the elimination diet for your baby and unexpectedly found personal benefits, describe how this looked.

“Being on an elimination diet has helped me to listen to my body more closely, and to realize lots of little symptoms that by themselves may be bearable are all related to food.” How does this look?

What does a “Low oxalate diet” look like?

What do you think are the priorities of bodies that regulate the standards of our food?

“I (also) feel like I am now respecting our bodies more and teaching my son to listen to and respect his body.” Can you describe what this looks like when you teach this to your son?

How does he feel about the family diet?

Describe your shopping trips with your child.

How are menu choices made?

What have been the reactions when you share your experiences with those unfamiliar with elimination diets?

You said you don't have "any hard scientific evidence", but your "instinct" is that diet makes a difference. What kinds of behaviour support your instincts?

What advice would you give to other parents?

Appendix I

Ethics approval



MONASH University

Monash University Human Research Ethics Committee (MUHREC)
Research Office

Human Ethics Certificate of Approval

Date: 1 March 2010

Project Number: CF09/3566 – 2009001923

Project Title: Multiple case study of people who have investigated food intolerance

Chief Investigator: Dr Jill Robbins

Approved: From: 1 March 2010 To: 1 March 2015

Terms of approval

1. The Chief investigator is responsible for ensuring that permission letters are obtained, if relevant, and a copy forwarded to MUHREC before any data collection can occur at the specified organisation. **Failure to provide permission letters to MUHREC before data collection commences is in breach of the National Statement on Ethical Conduct in Human Research and the Australian Code for the Responsible Conduct of Research.**
2. Approval is only valid whilst you hold a position at Monash University.
3. It is the responsibility of the Chief Investigator to ensure that all investigators are aware of the terms of approval and to ensure the project is conducted as approved by MUHREC.
4. You should notify MUHREC immediately of any serious or unexpected adverse effects on participants or unforeseen events affecting the ethical acceptability of the project.
5. The Explanatory Statement must be on Monash University letterhead and the Monash University complaints clause must contain your project number.
6. **Amendments to the approved project (including changes in personnel):** Requires the submission of a Request for Amendment form to MUHREC and must not begin without written approval from MUHREC. Substantial variations may require a new application.
7. **Future correspondence:** Please quote the project number and project title above in any further correspondence.
8. **Annual reports:** Continued approval of this project is dependent on the submission of an Annual Report. This is determined by the date of your letter of approval.
9. **Final report:** A Final Report should be provided at the conclusion of the project. MUHREC should be notified if the project is discontinued before the expected date of completion.
10. **Monitoring:** Projects may be subject to an audit or any other form of monitoring by MUHREC at any time.
11. **Retention and storage of data:** The Chief Investigator is responsible for the storage and retention of original data pertaining to a project for a minimum period of five years.



Professor Ben Canny
Chair, MUHREC

cc: Rev Dr Beverley Jane, Mrs Dianne Golemac

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Dr Jill Robbins
Faculty of Education
Monash Peninsula Campus

24 May 2010

CF09/3566 – 2009001923: Multiple case study of people who have investigated food intolerance

Dear Researchers,

Thank you for submitting a Request for Amendment to the above named project.

This is to advise that the following amendments have been approved and the project can proceed according to your approval given on 1 March 2010.

1. Amended journal questions:
 - (a) to ask participants to share their beliefs about food, behaviour and learning.
 - (b) to add questions about goals and the role of children in food preparation.

Thank you for keeping the Committee informed.

Professor Ben Canny
Chair, MUHREC

cc: Rev Dr Beverley Jane; Mrs Dianne Golemac

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Human Ethics
Monash Research Office
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Monash University, Clayton 3800
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email: muhrec@adm.monash.edu.au
<http://www.monash.edu.au/researchoffice/human/>

Appendix J

Table of alternative therapies and resources used by participants

	Abbey	Bernice	Camille	Donna
Advanced Allergy Elimination		✓		
Acupressure	✓			
Allergist specialist and nutritionist			✓	
Bio med doctor	✓		✓	
Chi Gong		✓		
Chiropractor	✓	✓		
Chronic fatigue specialist			✓	
Dietician				✓
*failsafe				✓
*fructose malabsorption				✓
*top 8 allergens				✓
*whole foods				✓
Candida diet - self taught from Internet				✓
Lactation consultant				✓
Low oxalate cookbook				✓
Naturopath - supplements			✓	✓
NAET	✓			✓
NET	✓			
Psychologist		✓		
Reflexology			✓	
RPAH elimination diet book				✓
School nurse		✓		
Social worker		✓		
Sue Dengate's books	✓	✓	✓	✓
Sue Dengate's website	✓	✓	✓	
Yahoo FIN* network			✓	
-Failsafe basic	✓	✓		
-Failsafe companion	✓			
-FODMAP**		✓		
-FODMAP** and Failsafe		✓		
-Low oxalate				✓
Vulvodynia Assoc cookbook				✓

*FIN – Food Intolerance Network

**FODMAP – Fermentable Oligo-saccharides, Di-saccharides, Mono-saccharides and Polyols

Colours represent the degree of success that the participants experienced.

White – not enough information

Red - not useful

Yellow - somewhat useful

Green - very useful