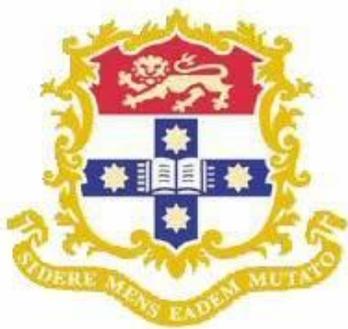


A Whole New World: Diet Modification in Children with ASD *An in-depth qualitative study*

A major project submitted in partial fulfilment of the degree
Master of Nutrition and Dietetics



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ABSTRACT

Introduction. There has been considerable interest on the effect of diet on individuals with ASD, but in the absence of large randomly controlled clinical trials, diet modification is still classified as a complementary and alternative medical (CAM) therapy. The implementation of a modified diet among children with ASD has been increasing, however at present there is minimal research on the factors involved in the management of such diets.

Aims. To investigate parental beliefs regarding ASD and diet. Particularly, to explore the experiences, long term outcomes, and problems that may come about with diet modification, as well as to discover parents' views on what is needed to manage these diet modifications.

Methods. This qualitative study used in-depth interviews as the primary tool for data collection. To achieve the aims of the study, topics covered in the interviews included the child's current or previous diet/s, the parent's sources of information and support, any lifestyle changes made, and their opinions on what was necessary to successfully manage a modified diet. All interviews were recorded and transcribed verbatim. Key concepts and themes were identified from the transcripts and a framework for coding the data was developed. Analysis was done using qualitative analysis techniques.

Results. A total of 20 in-depth interviews with parents of children with ASD were conducted. It was found that parents modified their child's diet to resolve some behaviour issues (65%) and GI issues (50%). The majority of parents (80%) reported noticing positive improvements in their children, particularly in behaviour and communication. It was reported that shopping and cooking habits required the most changes. In addition, social functions, an overall lack of support, and their child's food selectivity were the biggest difficulties encountered. Parents also reported that being organized and perseverance were the main means used to successfully implement a diet.

Conclusion. This study has established that parents have found diet modification as a challenging experience to take on, however due to the observed improvements in their children, most have found that the benefits outweigh the difficulties. Parents believe that an increase in support systems (both emotional and educational) will be beneficial in the future management of a modified diet.

INTRODUCTION

Pervasive Developmental Disorders (PDD) are a group of neurodevelopmental disorders that are distinguished by the presence of a ‘triad of impairments’, particularly in the development of communication and social skills, as well as the presence of restricted interests and repetitive behaviours [1-3]. Autistic Spectrum Disorders (ASD) is an umbrella term used to describe a number of PDDs, which are Autistic Disorder, Atypical Autism or Pervasive Developmental Disorder Not Otherwise Specified (PDDNOS), Asperger’s Syndrome, Rett’s Disorder, and Childhood Disintegrative Disorder [4]. ASDs are differentiated from each other through the severity of impairments, such as the presence or absence of mental retardation or language delay [4].

Recent epidemiological studies have indicated that the diagnosis of PDDs has been rising, with the current rates being about 60 cases per 10,000. The most common of these disorders being Autism (13 per 10,000) and Asperger’s Syndrome (3 per 10,000) [5].

There has been considerable interest on the effect of diet on individuals with ASD, but in the absence of large randomly controlled clinical trials, dietary modification is still classified as a complementary and alternative medical (CAM) therapy [6, 7]. Additionally, due to the fact that there are still no curative treatments for ASD, the use of CAM therapies has been increasing [8]. The most popular of these CAM therapies being dietary modification that eliminates food containing either gluten or casein, or both [9].

The rationale behind gluten and casein free (GF/CF) is based on the theory that individuals with ASD have increased intestinal permeability, more commonly known as the “leaky gut syndrome” [7, 10, 11]. It is hypothesised that due to the “leaky gut”, excess peptides from the incomplete breakdown of foods containing gluten and casein cross the blood-brain barrier and interfere with the functioning of the central nervous system (CNS) which then leads to the behavioural problems seen in ASD [10].

Christison et al (2006) recently published a review of published trials of GF/CF diets in children with ASD. The authors have concluded that current evidence cannot clearly support or counter the anecdotal reports of the benefits of GF/CF diets, therefore there is a great need for well controlled randomized studies to arrive at any firm conclusions. On the other hand, a large number of testimonials from parents and caregivers of children with ASD who have implemented a GF/CF diet are widely available in the lay media, such as books and the internet. These testimonials describe improvements in their children, particularly improvements in social and communication skills [9, 12].

Compared to typically developing children, children with ASD exhibit more feeding problems such as food refusal, the need for specific utensils and particular presentation, and eating a limited variety of foods [13]. Diet modification is not easy or cheap to implement. Aside from the children’s feeding problems, parents face difficulties such as social isolation due to the inability to eat out, as well as major changes in shopping and cooking routines, and also a lack of knowledge and support from medical practitioners [6]. Therefore parents often have to weigh the benefits of the diet against the difficulties of implementation.

At present there is minimal research on the factors involved in the implementation and management of a modified diet on children with ASD, to our knowledge, the study by Cornish (2002) is so far the only published literature that has looked into the experiences of mothers during the implementation of a GF/CF diet on their children with autism [6].

The aim of this study was to investigate parental beliefs regarding ASD and diet. Particularly, to explore the experiences, long term outcomes, and problems that may come about with diet modification, as well as to discover the parents' views on what is needed to manage these diet modifications.

METHODS

Study Design

This is a qualitative study using a phenomenological approach to investigate the aims of this project. Phenomenological studies aim to answer the question ‘What is it like to have a certain experience’ [14]. Hence, intensive one-on-one interviews or ‘in-depth interviews’ were used as the primary tool for data collection.

In-depth interviews with 20 parents of children with ASD were conducted to explore their experiences with diet modification. These took place either at the participant’s home or at the Royal Prince Alfred Hospital Allergy Unit. All interviews were digitally recorded with the participant’s consent.

An interview guide which lists predetermined questions and possible probes, was utilized during the interviews (see Appendix 1). Topics included the child’s current or previous diet/s, the parent’s sources of information and support, any lifestyle changes made, and their opinions on what is necessary to successfully manage a modified diet. The length of the audio recordings varied from 18 minutes to 50 minutes, with the interviewer interrupting only to ask the predetermined questions, or to clarify points.

Ethics Approval

The study was approved by the Ethics Review Committee (RPAH Zone) of the Sydney South West Area Health Service.

Participant Selection

Participants were drawn from a cohort of parents of children who have previously been seen at the RPAH Allergy Unit and have participated in the Dietary Issues in Children With and Without ASD study. The parents were initially contacted by phone, the study was explained and if verbal consent of participation was given, information packs (see Appendix 2-4) were sent by mail or e-mail. Information packs included a letter reminding them of the interview date, a letter with information about the study and an Expression of Interest (EOI) form, which also served as written consent for study participation. The EOI forms were collected at the time of the interview.

Sample Size

Determining the sample size in qualitative studies is difficult, because there are no set rules or statistical methods to determine the sample size, and often the number is dependent on the subjective assessment of the researcher [14]. In this study, 20 parents were interviewed in order to ensure that data saturation had been reached. Data saturation is the point where no new information is gathered or when the researcher recognizes common themes in the interviews [14].

Data Analysis

All audio recordings of the interviews were transcribed verbatim. Key concepts and themes were identified from the transcripts and a framework for coding the data was developed (see Appendix 5). The main themes were grouped into categories and relationships between them were identified. Analysis was done using thematic and content analysis techniques.

RESULTS

A total of 20 in-depth interviews ($n = 20$) were conducted, and the data from the in-depth interviews have been organised into categories:

1. Overview of Trends in Diet Modification
 - 1.1. Current Diet
 - 1.2. Reason for diet modification
 - 1.3. Sources of information
 - 1.4. Sources of support
2. Implementation of Diet Modification
 - 2.1. Changes made
 - 2.2. Difficulties encountered
 - 2.3. Role of cooking skills
3. Outcomes of Diet Modification
 - 3.1. Changes noticed on child
 - 3.2. Satisfaction with diet
4. Management of Diet Modification
 - 4.1. Secrets of success
 - 4.2. Wish list

1. Overview of Trends in Diet Modification

1.1. Current Diet

The most popular diet being implemented is a low chemical or the elimination diet, with 70% ($n=14$) of the interviewed parents implementing this diet. Parents following this diet avoid foods

containing salicylates, amines, glutamate, and food additives such as preservatives, colours and flavours. The other leading diets being implemented are casein free (60%, $n=12$), gluten free (45%, $n=9$), and soy free (25%, $n=5$).

The majority of these parents implement these diets in various combinations such as, the elimination diet plus gluten free (GF) and casein free (CF), or elimination diet and CF, etc. (see Appendix 6)

1.2. Reason for diet modification

A number of reasons for initially implementing a modified diet were cited, the most prevalent reason being that the diet was seen as a way to improve their children's behaviour issues (65%, $n=13$), while other parents initially trialed the diet because of their children's gastrointestinal (GI) problems. The diet was used as a test for any food intolerances (50%, $n=10$).

Parents mostly initially heard about the diet from the Royal Prince Alfred Hospital Allergy Unit (RPAH AU), Sue Dengate 'Fed Up' books, other parents, or the media.

1.3. Sources of information

As all of the participants were parents of children previously seen at the RPAH AU, it was cited that the biggest source of information are resources from the RPAH AU (100%, $n=20$). The resources being the information booklets, the shopping list, and a dietitian, (Anne Swain). The other prevalent source of information is the internet (90%, $n=18$), which is mostly used for looking up information on diet and ASD, recipes, and memberships to support groups. Other

sources of information are: the Friendly Food recipe book (60%, $n=12$), the Sue Dengate ‘Failsafe’ books (60%, $n=12$), and other books (60%, $n=12$).

1.4. Sources of support

Family and friends were reported to have provided the most support during diet modification (55%, $n=11$), followed by the RPAH AU and Anne Swain (50%, $n=10$), and other parents with children with ASD (35%, $n=7$).

Family, friends and the other parents mostly provided emotional support and usually kept foods specifically for the children in their own households. Anne Swain was reported to have provided support in regards to the diet implementation itself, through providing information or answers to the parents’ specific implementation dilemmas.

2. Implementation of Diet Modification

2.1. Changes made

The majority of participants (95%, $n=19$) reported that their shopping and cooking habits required the most changes. Eighty five percent ($n=17$) stated the biggest change that had to made was buying specialty products such as gluten free (GF) or preservative free bread or different milk, etc.

“Big shopping change... I’d go down to Woolworths or Coles or where I’d usually shop and I just go from aisle to aisle reading everything and I look in my trolley and there was nothing there that I could really buy and I had to be so careful... so it was a big impact on us, but the rewards were big too.” (*Parent #20*)

“...I was going around health food shops looking, so it was like a whole new world had to be opened up.” (*Parent #9*)

Sixty percent ($n=12$) stated that another change was that there was an increase in cooking and baking since most of the child’s food had to be homemade, while 50% ($n=10$) said that they had to alter or modify what they were cooking, through substitution of the ‘offending’ ingredients:

“...so it just went back to me making a lot more things, like making muesli bars and things like that myself, he eats rice pudding so I was making rice pudding as opposed to buying it.” (*Parent #8*)

“...you have to be really keen to be following the diet otherwise it wouldn’t work cause I think chips is the only thing I can buy from the shop for him, without having to cook it, and maybe pasta or rice pasta or something , everything requires cooking.” (*Parent #1*)

“...you just can’t buy in a packet at the supermarket, I’m always cooking things like meringues so they can have them at parties, yes always cooking, adding ingredients that they can have.” (*Parent #5*)

2.2. Difficulties encountered

Parents reported a wide range of difficulties encountered during the implementation of the diet, these difficulties were grouped into the following sub-categories:

2.2.1. Social situations

Seventy percent ($n=14$) of the parents reported that socializing is very difficult on a modified diet. Social functions such as parties and eating out at restaurants, were a “nightmare” (*Parent #2*), because restaurants do not have ‘modified’ recipes and the danger of cross-contamination is high, also food served at children’s birthday parties are often unsuitable to the modified diets and often tempt the children to break their modified diets:

“...and the other difficulty was just going out to restaurants, there’s just nothing he can eat, so we just couldn’t go out to restaurants, and going to peoples’ houses, you have to take your own food everywhere. Parties, even family functions, I had to take all our own stuff, nobody sort of caters for us. So it’s pretty hard work.” (*Parent #9*)

2.2.2. Lack of support from medical professionals

The lack of support from medical professionals was the second major difficulty (65%, $n=13$). Thus parents have to raise the issue so that dietary intervention will be considered, with doctors often discouraging parents to trial a modified diet due to the lack of statistical evidence.

“...I found that unless I ask for help in regard to diet, that doctors won’t send you in that direction, they’re more likely to want to prescribe something... I found I had to ask and say, could I be referred, could we look further into the diet.” (*Parent #5*)

Parents have reported feeling that this lack of support is due to insufficient knowledge in the relationship of diet and behaviour, and have stated that this lack of support is upsetting and adds stress to the already stressful situation.

“...every parent needs to be informed and need to be offered. With my son I was told that there’s no hope, can’t do anything, and that it is a long life disability, poor me... doctors, I didn’t see any hope, any light, but something can be done.” (*Parent #11*)

“...but you would think that if you go to a paediatrician you wouldn’t get the eyes rolling up in the air when you talk about the elimination diet. And they say ‘oh it’s not concrete yet, it still needs more research’, I just wish that they’d keep an open mind... but when your emotional, when your just grasping you just don’t need those extra unhelpful people.” (*Parent #20*)

2.2.3. Children’s food selectivity

Children with ASD are often selective of their food choices and 60% ($n=12$) of the interviewed parents have reported that this is another difficulty that they face, as their children simply refuse to try new food:

“Huge amount of changes for (*child’s name*), the other children probably wouldn’t have been so major, but because he was obsessive with his food, and he’s got a very limited range of what he eats anyway. That was the really difficult bit because he only eats a very limited menu, and when you take half of that away, so lots and lots of trauma.” (*Participant #18*)

2.2.4. Lack of public awareness and support

Another recurrent difficulty was the lack of public awareness and concern regarding the diets (55%, $n=11$), it was reported that the public are now aware of food allergies and anaphylaxis, but not about food intolerances or the association of ASD and diet. Parents have stated that this lack of knowledge and empathy “undoes” their hard work:

“...you know every school all of a sudden becomes ‘diet aware’ when an anaphylactic child comes into the school. I mean forget about the fact that you’ve got a child who’s been diagnosed with 2 behavioural disorders and Asperger’s and a learning difficulty and you’ve got letters from everyone that his diet needs to be watched...

...I can’t be at home trying to help my child, you know and they’re, for a better use of a word, inadvertently sabotaging the whole thing by turning a blind eye, ‘Oh it’s only (*child’s name*) we won’t worry about it’. Excuse me?! I’ve spent 8 years trying to help my child, I finally found it and you’re sabotaging me!” (*Participant #15*)

2.2.5. Change in shopping and cooking habits

Lastly, the big change in shopping and cooking habits was stated as another challenge (55%, $n=11$). Parents have reported that the restricted supply of the specialty foods and the amount of skill needed to cook or bake the modified foods, were the main difficulties that arose.

2.3. Role of cooking skills

As previously mentioned, parents reported that shopping and cooking habits required the most changes when modifying a diet and this change in habits was also considered as a difficulty.

Parents were asked what the role of cooking skills played in diet modification, and 90% ($n=18$)

stated that it plays a big role, while the remaining 10% ($n=2$) stated that knowledge about ingredients plays a bigger role than cooking skills itself.

The reasons why the majority of parents state that cooking skills play a big role are as follows; commercially made or pre-packaged foods are unsuitable for the diet therefore foods have to be homemade, another reason is that these modified foods are generally hard to make, and finally, the children's food selectivity requires a lot of experimenting on the parent's part to find out what the child will eat.

“...you need those (*cooking*) skills because you can't just take things out of the packet on this diet, you've got to be able to start from scratch and create it from scratch.”

(*Parent #14*)

“Umm working out what foods to cook him, actually cooking, making bread was really hard, I used to try and make bread all the time, and it was just nightmarish because it never tasted very good, and you spend all this time making it and it would just be horrible really.” (*Parent #2*)

“Probably quite a lot (*role of cooking skills*) because they're so fussy autistic children, I'm the main cook, if say (*the husband*) cooks his chicken and it's slightly too brown, or the colours not quite right or if it's not quite cooked enough, he'll refuse to eat it...”

(*Parent #9*)

3. Outcomes of Diet Modification

3.1. Changes noticed on child

Upon implementation of a modified diet, 80% ($n=16$) of the interviewed parents reported noticing improvements in the child's behaviour (see Appendix 7). Improved concentration and longer attention span was a behavioural improvement that was observed by parents (25%, $n=5$), however the most dominant improvement observed was an increased tolerance to change (65%, $n=13$), which led to less aggressive/explosive behaviours such as tantrums:

“... he got a bit calmer, he could somehow cope a little bit better with change of routines, like he will tolerate and he will understand that he will have to wait for something. Before he would just scream...” (*Parent #11*)

Improvements in the children's communication skills were reported by 30% ($n=6$) of the parents, these include the increased ability to communicate feelings, a bigger vocabulary, and an overall improvement in conversation skills:

“So because his speech improved he started to really communicate his feelings, so rather than getting upset over little things he would really just communicate what was bothering him and which has made a huge difference in his behaviour...” (*Parent #3*)

3.2. Satisfaction with diet

Eighty percent ($n=16$) of the interviewed parents have stated that they are committed to following a modified diet, mainly due to the positive changes observed in their children, these improvements particularly in behaviour, have been these parents' main motivation:

“Many people disagree with this diet, some of my friends say why put anyone on this diet... people in prison don’t have this diet... but I tell them that I’m confident that this diet will change my son... they have heard (*of the changes*) but they don’t try, but I’m happy that I tried, I say I’ll try anything in the world to try and help my son...” (*Parent #11*)

“...it’s just a big difference for me because as I said earlier I went from a mother going ‘Oh why me, why do I have this child’... resenting my child’s behaviour, to now loving being a mother, I love being with (*child’s name*), I’ve seen the improvements and you know she just makes me happy.” (*Parent #20*)

The remaining 4 parents (20%) have stated 3 reasons as to why they are no longer following a modified diet, 2 parents ceased the diet because they did not observe any positive changes in their child, while 1 parent ceased the diet due to other family issues, and 1 due to her child’s other medical conditions. However, while these 4 parents perceive that they are not following a ‘strict’ modified diet, they have stated that after trialling the elimination diet and not noticing any changes, they have chosen to avoid a number of food additives, such as preservatives, colours, and flavours. Therefore despite the perception of these parents that their child is back to a ‘normal’ diet, some degree of modification is still present.

“...he’s on his own diet now...I made a sort of decision that even though it didn’t appear that he was reacting to a lot of the chemicals, I still made it a principle not to reintroduce those things in the household as much as possible... I’m nowhere near as strict as I was, but I try to keep it colour free and flavour free as possible.” (*Parent #8*)

4. Management of Diet Modification

4.1. Secrets of success

Two main themes emerged regarding the ways parents successfully implement a modified diet, 75% ($n=15$) reported that being planned and organized was extremely important, while perseverance and patience was stated by others as essential (60%, $n=12$).

4.1.1. Planning and organization

Planning ahead of time is crucial particularly when it comes to birthday parties and other social functions, parents had to prepare modified food ahead of time and bring their own food at parties so their children would not be tempted have other foods. Also because most commercially available foods are unsuitable to the modified diets, parents have to prepare and bring appropriate snack foods for their children when leaving their household.

“... we could never go anywhere without a bag full of food. We don't go anywhere without an eskie or a thermos. But you kinda get used to that I suppose I'm more organized too these days, I tend to cook big batches of things and always have a few left over that I can freeze, you know for when you need something in a hurry or to take to a party or whatever.” (*Parent #17*)

4.1.2. Perseverance and patience

Perseverance was also viewed as extremely important since diet modification is not an easy task. Some parents have reported assessing whether the hassle of a modified diet is worth the outcomes. One parent commented that to succeed “you have to be completely determined that you're going to stay in this diet” (*Parent #8*). Another commented that persistence is necessary

since the children will not readily accept the change in food, and improvements or changes do not occur right away:

“You can’t expect it to just be easy and just happen without any effort.” (*Parent #14*)

“ (*Some*) people think it’s gonna happen on the first day, I reckon how many people give up because they don’t understand the time frames and how delayed reactions are... I reckon people just give up...” (*Parent #17*)

Parents also stated that after a period of living with the diet, it becomes a habit and everything becomes routine, and thus a modified diet becomes their way of life.

4.2. *Wish list*

Parents were asked to give suggestions for future management of a modified diet. A variety of answers were obtained, and the most dominant answers were grouped into the following sub categories:

4.2.1. A ‘Start-up kit’

Parents felt it would be beneficial that upon the start of the diet, a ‘start-up kit’ should be handed out, because starting the diet was found to be just too overwhelming and often parents did not know where to begin.

“...I actually remember now that first day going ‘Right!’ absolute panic like I’ve got make everything ok now, which is generally what you feel because you’re so worried about them that you just want to make everything as ok as you possibly can. So I

reckon it would be really useful to have some sort of ‘start-up kit’ (*that*) gives you suggestions on how to start...” (*Parent #2*)

This kit ideally would contain information about the modified diet, a shopping list, some basic recipes, and sample meal plan. It was also suggested that the information and recipes be geared towards children to aid them in the implementation.

4.2.2. Modified diet website

A majority of these parents use the internet as the most convenient source of information. The parents’ ‘ideal website’ would contain up to date information on ASD and modified diets, downloadable recipes, a regularly updated shopping list, a discussion group for parents, and possibly even an online supermarket of specialty products.

4.2.3. Greater support

The forms of support that parents yearn for varies from an individual approach through better access to dietitians, to a broader perspective in the form of education for the general public. Parents also feel that medical professionals and school officials need to be educated about the association of diet and behaviour, with most parents feeling that having solid support systems around them would be extremely beneficial:

“You need positive feedback somehow because it is such a challenging area to embark on, without support you tend to give up.” (*Parent #6*)

Another recurrent form of support that parents aspire for are support groups or discussion groups for parents who are following a modified diet. Some parents have stated that following a diet can “get a little lonely” (*Parent #3*). Parents seek the company of other parents in similar situations mainly because most feel that other parents’ feedback are more in tune than the feedback from those who are not actually living with the diet.

4.2.4. *Nutrition analysis*

A number of parents expressed concerns regarding whether their child is getting enough nutrition, stating that they need a way to be reassured that despite a restricted diet, their child can still achieve their nutritional needs.

“What concerned me the most was whether she was getting enough nutrition, I know it explained in the Friendly Food, I think it needs to be drummed into my head, I think you forget after awhile because you’re fighting against the rest of the world...”
(*Parent #20*)

Parents who have received an analysis of their child’s diet (through a 4 day food diary) reported that this food analysis was helpful and put to rest their fears.

DISCUSSION

The aim of this study was to generate insight into the experiences of parents of children with ASD upon the implementation of a modified diet, as there is very limited research available in this area.

The reasons for the use of CAM therapies such as modified diets have been previously reported in a published survey of parents whose children have been diagnosed with an ASD. The main reasons being; to treat the symptoms of autism, to improve concentration or attention, for relaxation, to relieve GI problems, and to improve speech/communication [8]. Parents in our study have reported that they initially looked into the diet mainly because they were seeking a way to improve their child's behavioural and GI issues. The majority of parents have observed improvements in their children, particularly in behaviour and communication. These positive changes have encouraged these parents to commit to the diet, despite a number of difficulties that they face.

Shopping and cooking habits required the biggest changes when implementing a modified diet. This highlights the significant role that cooking skills have in diet implementation. Parents found that it was necessary not only to buy specialty products but to also prepare food from scratch, as most commercially available foods are unsuitable.

Parents expressed that this change in shopping and cooking was initially daunting, but with time and practice it became routine and developed into their new way of life. To aid in the ease of implementation, parents have expressed a need for a greater amount of information to be

provided at the beginning of the diet, such as a ‘start-up kit’ (see Results 4.1) to lead them in the right direction. Parents felt that the availability of information and support in the form of a comprehensive website would be beneficial.

Cornish (2002) found that socializing was the biggest difficulty faced by mothers following a GF/CF diet, this finding which was confirmed in this study [6]. Social functions, such as birthday parties and dining out were the biggest difficulty encountered; this required parents (specifically mothers) to be organized and always have prepared ‘modified’ food available for their children. Previous studies have indicated that children with ASD have more feeding problems related to food selectivity and refusal [15, 16]. Children with ASD tend to eat a narrower range of foods, and do not adapt to change readily, parents in this study have reported that this makes diet modification more difficult.

Due to the controversial nature of modified diets and CAM therapies in general, other studies have found that parents using CAM therapies receive more negative comments about their child’s care [17]. Although parents found socializing as a major difficulty, the lack of support from medical professionals (MP) and the general public was found to be more emotionally distressing.

In previous studies, parents have rated MP’s knowledge of CAM therapies as poor, and as a result parents tend to not inform MPs about the therapies. In addition there is also a fear that the MPs would not approve [8, 17]. Parents in this study have reported to being discouraged by other MPs, due to the lack of evidence based literature.

Furthermore, parents believe that a lack of knowledge and awareness is the cause for insufficient support and criticism from the general public. Parents are expected to try every possible avenue of therapy to help their child, and parents in this study have expressed that this overall lack of support undermines the effort that they put into trying to help their child. Therefore, parents feel that education for MPs and the general public is crucial, in order to perhaps achieve understanding and acceptance from the public, and a non-judgemental and sensitive advice from MPs.

Parents find implementing a modified diet puts them in a unique situation and this study has found that most feel that feedback from other families going through the same experience, (i.e. a modified diet) is more appropriate and valuable. This is most likely also due to the overall lack of support that they receive, therefore parents yearn for a “community feeling”, to diminish the loneliness that they occasionally feel. This need for support calls for an establishment of support groups for parents with children with ASD going through a modified diet. This group would not only be a source of emotional support, but would be an invaluable source of information, such as recipes and the like.

Additionally although this study provides information about parental beliefs on the benefits of diet modification in their children, the study is not able to provide objective evidence regarding the efficacy of these modified diets. Therefore there is a great need for further research studies that would look into this controversial field. At present, there is a research project in progress at

the Royal Prince Alfred Allergy Unit, which looks into diet modification in the management of ASD [18].

Parents ultimately are the ones who implement and manage their child's care, despite the lifestyle changes and difficulties they encounter. The positive improvements in their children makes everything worthwhile, therefore this calls for a need to develop strategies and resources that would alleviate these difficulties in order to ultimately provide the best possible care for these children with ASD.

STUDY LIMITATIONS AND IMPLICATIONS FOR FUTURE RESEARCH

This in-depth qualitative study represents a step towards a deeper understanding of parental beliefs regarding diet modification in children with ASD. The questions used in this study were broad and open-ended which led to a wide variety of answers, therefore the results presented are broad due to the large amount of information gathered. To obtain more concrete, specific information, future research studies could tackle one aspect of this study at a time (i.e. focus on the difficulties or the wish list, etc).

This study was able to capture a broad snapshot of what it is like to implement a modified diet in children with ASD. It is hoped that this initial information will be used in future research to look further into parents' experiences in order to develop tools to aid in the increase of support systems for parents of children with ASD. Also to upgrade educational materials and resources not only for parents but also for other healthcare professionals and the general public.

In future studies, it would also be ideal to include the perspectives of other individuals involved in the children's care, such as medical professionals, dietitians and other healthcare professionals, school officials and so on, in order to present a more holistic approach.

CONCLUSION

This study has established that parents have found diet modification as a challenging experience to take on, however due to the observed improvements in their children, most have found that the benefits outweigh the difficulties.

This study has also discovered that positive support is what parents long for. Support may come in the form of unbiased views about the diet from medical professionals and the public, to a greater availability of information regarding the implementation of the diet.

In summary, this study provides further insight into specific issues that parents experience when implementing a modified diet. Parental beliefs are invaluable and provide significant information. It is hoped that the information presented in this study will initiate more research into not only parental perspectives regarding diet implementation, but also the relationship of diet and ASD as a whole, in order to improve treatment practices and ultimately increase the quality care for these children with ASD.

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APPENDICES

Appendix 1: In-depth Interview Questions

Appendix 2: Information Package: Information Letter

Appendix 3: Information Package: Expression of Interest
Form

Appendix 4: Information Package: Reminder Letter

Appendix 5: Results: Coding Frame

Appendix 6: Results: Table 1

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APPENDIX 1: In-depth Interview Questions

<u>Questions:</u>	<u>Responses & Observations</u>
<p>1. What type of diet is your child/ren currently on? Probes:</p> <ul style="list-style-type: none"> ○ How long has your child/ren been on the diet? ○ Has your child/ren been on the full elimination diet before and for how long? ○ What other diets have they been on (casein free/gluten free)? 	
<p>2. What was involved in placing your child on an elimination or modified diet? Probes:</p> <ul style="list-style-type: none"> ○ What changes had to be made? ○ What were the difficulties encountered? ○ How did you overcome the difficulties? ○ What were the sources of information? ○ What support did you receive? 	
<p>If child is currently NOT on a modified diet then ask: 3a. What is the reason for not following a modified diet? Probes:</p> <ul style="list-style-type: none"> ○ Did you notice any changes in your child? (What were they?) ○ What difficulties did you encounter in following the elimination diet? ○ What role did cooking skills have in following the elimination diet? 	
<p>If child is currently ON an elimination/modified diet then ask: 3b. What are the secrets of your success in following the elimination diet? Probes:</p> <ul style="list-style-type: none"> ○ What changes did you notice? ○ How long did it take to notice the changes? ○ What role did cooking skills have in following the elimination diet? 	
<p>4. Based on your experiences, what needs to be done to help manage the elimination/modified diet? Probes:</p> <ul style="list-style-type: none"> ○ What types of recipes need to be developed? ○ What do you think needs to be provided as far as educational material to assist with managing the diet? 	

APPENDIX 2: Information package - Information Letter



Dr Velencia Soutter
RPAH Allergy Unit
Department of Clinical Immunology
Mobile: 0417 217 174
Email: research.diet@email.cs.nsw.gov.au
Phone: (02) 9515 3301/02

ROYAL PRINCE ALFRED HOSPITAL

A tradition of excellence since 1882

Dietary issues in children with and without Autistic Spectrum Disorder (ASD) – Follow Up Interview

Information for Parents

Previously you and your child participated in a study about food and nutrition in children with Autistic Spectrum Disorder (ASD) with Dr Velencia Soutter, Dr Anne Swain and Dr Robert Loblay at the Royal Prince Alfred Hospital (RPAH) Allergy Unit.

We are conducting a brief interview with parents who have participated in the study and have commenced the elimination diet. We are now interested in evaluating the longer term outcomes of dietary modification, and in exploring the process involved in, and experiences associated with children on the diet.

The interview will take approximately one hour and will be conducted by our trained research staff and trained dietetic students, in person at either your home or at the Allergy Unit.

The session will be tape recorded and transcribed so that we can study and analyse what was said. Your participation will help us to better understand your problems, to help other families who have a child with ASD, and to educate other health care professionals about ASD.

Protecting your privacy and confidentiality

If you decide to participate, you will be assigned a study code number which will be recorded on your transcripts. Your personal details (name, home address, telephone numbers, email address) will be kept separately, and only the authorised researchers will have access to this information.

All information obtained during this study will be treated confidentially. A summary of the results will be published in the newsletter of the Autism Association, and detailed results may be published in medical journals or presented at conferences. You and your child will not be identified in any such publication or presentation.

You are under no obligation whatsoever to participate. If you do decide to participate and then change your mind, you and your child are free to withdraw at any time without being disadvantaged in any way.

If you have any questions, or would like to discuss the study further, please contact Velencia Soutter on 0417 217 174 or by email: velencia.soutter@email.cs.nsw.gov.au

This study has been approved by the Ethics Review Committee (RPAH Zone) of the Sydney South West Area Health Service. Any person with concerns or complaints about the conduct of a research study should can contact the Secretary on 02 9515 6766 and quote protocol number X03-0197.

This information sheet is for you to keep.

APPENDIX 3: Information package - Expression of Interest form

ID #



Dr Velencia Soutter
RPAH Allergy Unit
Department of Clinical Immunology
Mobile: 0417 217 174
Email: research.diet@email.cs.nsw.gov.au
Phone (message): (02) 9515 3301/02

ROYAL PRINCE ALFRED HOSPITAL
A tradition of excellence since 1882

DIETARY ISSUES IN CHILDREN WITH AND WITHOUT AUTISTIC SPECTRUM DISORDER (ASD) - Follow Up Interview

EXPRESSION OF INTEREST

If you are interested in participating in this part of the research study (see attached information sheet for details), please fill in the following:

Your Name:.....

Child's name:.....

Your relationship to the child:.....

Your contact details

(Please put a mark (*) against your preferred method for contact):

Home address:.....

.....Postcode:.....

Phone no:..... (Best times to call.....)

Mobile:.....Fax:.....

Email:.....

Preferred day(s) for Interview (please tick): Mon Tue Wed Thur Fri

Preferred Interview time: 8am-12pm 12-4pm 4-7pm

Preferred Location: Allergy Unit Home

PLEASE RETURN THESE DETAILS BY WHICH EVER MEANS IS MOST CONVENIENT:

Phone (message): (02) 9515 3301/02

Fax: (02) 9557 8406

Post:

Reply Paid 61487
RPAH Allergy Unit
9-11 Layton Street
Camperdown NSW 2050

Email: research.diet@email.cs.nsw.gov.au

APPENDIX 4: Information package – Reminder Letter



RPAH Allergy Unit
Department of Clinical Immunology

Phone: (02) 9515 3301/02/18

ROYAL PRINCE ALFRED HOSPITAL

A tradition of excellence since 1882

{Month-day}, 2006

Dear {Participant},

Thank you for agreeing to participate in our follow up study, attached are the information sheet for parents and the expression of interest (EOI) form. The information sheet is for you to keep, and I'll take the EOI form when we have the interview.

Our interview is on {Day}, the {day} of {Month} 2006 at {Time},
at the {Royal Prince Alfred Allergy Unit, 9-11 Layton Street, Camperdown or
participant's home address}.

If you have any concerns or questions please do not hesitate to contact me at a.alano@student.usyd.edu.au or at 95153301/18 or 0424.852.399.

Looking forward to meeting you.

Warm Regards,

Andrea Alano
Research Dietetic Student
University of Sydney

APPENDIX 5: Results: Coding Frame

Initial reason for being on modified diet

Behavioural problems

Hyperactivity

Bad temper

'Angry child'

Eczema

Read information regarding autism and diet

Books

Sue Dengate

Internet

Magazine articles

Suggested by the RPAH Allergy Unit

Suggested by other health care professionals

Private dietitian

Speech therapist

Other parents with children with ASD / behaviour issues

Child has food allergies / intolerances

Parent has allergies / intolerances

Suggested by naturopath

Language difficulties

Gut issues

Lethargic and grey

Feeding problems

2. Factors involved in dietary modification

Changes made

Had to cook/bake everything

Had to buy specialty products

Trial and error

Change what was in the house to reduce temptations

Advise other parents when going to parties

Read labels

Advise the school

Child has separate cutlery and plates

Cooked separately for child

Difficulties encountered

Lack of support from doctors

It's not statistically proven

Has never found anyone to have benefited from the diet

You have to ask about the diet

There's nothing we can do about the child

Never heard of diet

Skeptical of diet

Look at you like you're mad

Lack of support from family and friends

They don't understand

They give the child 'other' foods

No one caters for them

Very critical

Just a hassle for mother

Child dislikes diet, too bland

Child barely eats, diet is over restricted

Child is getting bored of diet

Difficult to shop

Restricted supply / hard to find food

Not in their area

Products are discontinued

Shopping took longer

More expensive

Time consuming

In the kitchen all the time
Shopping almost everyday
Ringing up food companies
Shopping takes longer
Cooking and baking all the time

ASD characteristics

Fussy eating
Obsessive behaviours
Anxiety

Social situations - going out / parties

Feel awkward asking other parents
Finding 'friendly' restaurants
Food at parties

Lack of public awareness / Always having to explain the diet

Schools

Spend time cooking, but end up throwing everything

Impact on family

Other siblings not happy
Whole family affected

Don't know where to start

Delayed reactions

Food swapping at school

Withdrawal symptoms

'Double edged sword' – not getting the help she deserves because the diet is working and child is well

Emotional impact

Why bother, it's so hard

Feelings of guilt

Not giving the child what he wants

Other siblings get to have other food

Diet makes the child's already difficult life more difficult

Taking away foods he likes

Parents are in overload, and diet becomes another thing to take on

Panic to make everything ok

Get paranoid that he's not growing

If child is not ok, the whole family is affected

Concerns regarding nutrition

Need to know that the child's getting proper nutrition

Fat intake is too high

Feel like you're feeding him cardboard

Paranoid that he's not growing

Ways of overcoming difficulties

Avoiding 'temptations'

Not showing other food

Not keeping other foods in the house

Verbal deterrents

Telling the child the food's 'gone off'

'This will make you sick or cranky'

Camouflaging food

Hiding vegetables

Being persistent / Trial and error

Experiment

Being consistent

Being organized

Preparing food ahead of time

Checking the food at parties ahead of time

Bringing own food to parties

Bringing own food everywhere

"Tricks"

Flavouring the food

Blending everything into a meatball

Using rewards

Sources of information

Sue Dengate

‘Fed Up’ books

Failsafe e-mail group / website

RPAH Allergy Unit

Friendly Food

Shopping list

Anne Swain

Information sheets/booklets

Other mothers with children with ASD/food issues

Internet

Recipes

Failsafe net

Yahoo groups

TACA – “Talk about curing autism”

Medical professionals

Dr Anthony Underwood

Books

‘Special Diet for Special Kids’

Recipe books

Tony Atwood

Leanne Pearce

Marilyn LeBreton – “Dietary Intervention & Autism”

Other books

Naturopath

Early Intervention - Lifestar

Browsing at the supermarket

Support group

Magazine article

Sources of support

RPAH Allergy Unit

Anne Swain

Other parents of children with ASD

Family and friends

Always have food for child

Interested to see effect on behaviour

Other parents modify foods at parties

Support groups

Asperger's support group

Medical professionals

Pediatrician

3. Child perceived not to be on "strict modified" diet

Changes noticed on child

None

Mood swings

Worse behavior

Constipation

Reason for not following a modified diet

Did not notice any changes

Other issues, a family member diagnosed with cancer

4. Child currently on a modified diet

Changes noticed on child

Behaviour improved

Child listens more

More reasonable

Can negotiate

Improved concentration

Easier to manage

More sociable

Less tantrums

Calmer

More tolerant to change, less aggressive/explosive

Increased attention span

More aware

Communication improved

Bigger vocabulary

Communicates his feelings

Longer sentences

Language exploded

Child eats more

Toilet trained

'Sudden waking up to the world'

Eczema improved

Stopped hitting himself

Bowels improved

More energy, more alert

Eye contact improved

Dark circles under eyes disappeared

Asthma resolved

Less sensory sensitive

Changes noticed when doing food challenges

Child stuttered

Urinary incontinence

Got agitated

Low attention span

Eyes looked a bit strange

Started hitting himself

Hyperactivity

Laugh for no reason

Emotional

Sleeping problems

Became more aggressive

Bowel problems

Withdrawal

Dark circles under eyes

'Hangover' skin

Reason for not doing challenges

Scared of the effects, not brave enough

No time

Not worth upsetting his appetite

Reason for sticking to diet

Behaviour has improved

5. Role of cooking skills

Everything is homemade

A bit more of a role than with a normal child

You have to like cooking

You have to be experimental

No skill involved, just knowledge

Big role

Modifying previous recipes

Reading labels

Had to learn to cook

Don't need skill, just be organized, and follow a recipe

6. Management of diet

6.1 Recipe development

6.1.1 More variety

6.1.2 Kid friendly foods, i.e. Friendly Food for kids

6.1.2.1 Snacks

6.1.2.2 Main meals

6.1.3 Recipes from other cultures are GF and CF, i.e. South Indian, Vietnamese

6.1.4 Include substitutions

6.2 Educational materials

6.2.1 Suggested meal plan

6.2.2 Update shopping list

6.2.3 One comprehensive book with tried and tested recipes

6.2.4 More information

6.2.4.1 On food intolerances

6.2.4.2 On casein

6.2.4.3 Dietary energy needs

6.2.4.4 Intolerances may lessen in severity

6.2.4.5 Child specific

6.2.5 Up to date research studies

6.2.6 Specific cookbooks

6.2.6.1 Salicylates

6.2.6.2 Dairy free

6.2.7 An card that explains intolerances to give to people

6.2.8 Seminars

6.2.9 Food analysis

6.3 Website / Internet

6.3.1 Support / discussion group

6.3.2 Recipes

- 6.3.3 Updated shopping list
- 6.3.4 Regular e-mails about products
- 6.3.5 Online shopping – foods

- 6.4 Educate the general public
 - 6.4.1 “Allergy and Food Intolerance Day”
 - 6.4.2 Educate new mothers
 - 6.4.3 Go out to schools
 - 6.4.4 Article in Playgroup Association newsletter

- 6.5 Support groups for parents who have tried diet
 - 6.5.1 It can get lonely
 - 6.5.2 Better to get feedback from people who have tried it themselves

- 6.6 ‘Start up Kit’ – with recipes, information, meal plan, etc.

- 6.7 Tips
 - 6.7.1 Be organized
 - 6.7.2 Prepare food ahead of time
 - 6.7.3 Start when they’re young
 - 6.7.4 Have to be keen
 - 6.7.5 Start with one food group at a time /do it slowly
 - 6.7.6 Figure out what you can cope with
 - 6.7.7 It won’t happen in a day

- 6.8 Educate medical professionals
- 6.9 Cooking classes
- 6.10 Hotline
- 6.11 Better access to dietitians
- 6.12 Better access to products, more ‘friendly’ restaurants

APPENDIX 6: Results: Table 1

	Original reason for diet	Current diet	Length of time on diet	Difficulties encountered	Ways of overcoming difficulties	Satisfaction with diet
1	Behavioural issues Read the Sue Dengate book Other parents	Elimination diet Casein free	8 mos (ED) 1 week (CF)	Lack of support Child doesn't like the diet; begs for other food Difficult to cook Difficult to find the food Spend so much time cooking then end up throwing food	Camouflaging the food Being persistent Avoiding temptations	Still waiting for a significant result
2	Child has food allergies Tested for food intolerances	Dairy free Gluten free Soy free Almond free	3 ¾ years	Time consuming Expense Lack of support Social situations Difficult to cook Difficult to find the food Fussy eating	Being persistent Having a passion for cooking	Committed to the diet because of improvements in behaviour and due to food allergies
3	Child has food allergies Tested for food intolerances	Elimination diet Egg free Casein free Soy free Fish free Nut free	3 mos (ED) 7 mos (others)	Child is getting bored of diet; eats less It gets lonely Concerns regarding nutrition Spend so much time cooking then end up throwing food	Being persistent Trial and error Being creative	Committed to the diet because of improvements in behaviour and child feels 'happier'
4	Behavioural issues	Low salicylates Low colours and flavours	5 yrs	Social situations Lack of public awareness	Being prepared Avoiding temptations Consistency	Committed to the diet because of improvements in behaviour, it is now a habit, their way of life

5	Older sibling had gut problems Read the Sue Denger books Suggested by naturopath	Elimination diet Gluten free Casein free	~ 5 yrs	Social situations Lack of support	Being prepared and organized Avoiding temptations	Committed to the diet it's now a habit and routine.
6	Behaviour issues Language difficulty Gut issues Eczema Other parents	Gluten free Casein free Soy free Organic Anti-candida	4 yrs	Difficult to find the food Lack of cooking skills Lack of support Spend so much time cooking then end up throwing food	Introduce new foods slowly	Committed to the diet
7	Read information on the internet / papers re: ASD	Elimination diet Gluten free Casein free Soy free	1 month (ED) 6 mos (GF & CF) 4 mos (SF)	Difficult to find the food	Trial and error Being persistent	Will continue to follow diet to see if there are any further improvements
8	Behavioural issues (ADHD)	'Self-restricted' Vegetarian Colour free Flavour free	7 years	Time consuming Everything's homemade	Being prepared and organized	Currently not following a strict diet
9	Eczema Peanut allergy Gut issues Tested for food intolerances	Gluten free Casein free Low salicylates Low amines	3 years	Difficult to find the food Fussy eating Social situations Lack of support	Camouflaging food Being prepared	Committed to the diet due to dramatic improvements It's now a habit and routine.
10	Mother had allergies	Casein free Colour free	1 yr (DF) 8 mos (colour)	Cooked more Social situations	Being consistent	Committed to the diet because of

			free)	Fussy eating		improvements.
11	Read information on internet re: ASD Tested for food intolerances	Gluten free Casein free Low salicylates	3 yrs (GF & DF) 2 yrs (salicylates)	Cooked more / separately Had separate cutlery and plates Lack of support Child doesn't like the diet; begs for other food Concerns regarding nutrition	Being persistent Avoiding temptations	Committed to the diet because of improvements in behaviour. "Confident that it will change my son"
12	Read the Sue Dengate book Behaviour issues Tested for food intolerances	Elimination diet Gluten free	20 mos (ED) 1 month (GF)	Fussy eating Lack of cooking skills Spend so much time cooking then end up throwing food Concerns regarding nutrition	Being persistent	Committed to the diet because of improvements in behaviour.
13	Problems with feeding Food allergies	On Pediasure		Fussy eating Concerns regarding nutrition Spend so much time cooking then end up throwing food	Worked with a dietitian	Abandoned the diet
14	Behaviour issues (ADHD)	Low additives Low preservatives Low colour	~ 5 yrs	Time consuming	Planning ahead Camouflaging food	Committed to the diet because of improvements in behaviour.
15	Tested for food intolerances	Elimination diet Casein free Soy free	8 mos	Cooked separately Concerns regarding nutrition Lack of support from school	Trial and error	
16	Food intolerances Behaviour issues – attention span	No salicylates No amines No glutamate	3 yrs	Fussy eating Difficult to shop	Trial and error Being organized and efficient	Committed to the diet because of improvements in child.

	Gut issues	Gluten free Casein free			Planning ahead	
17	Behaviour issues	Elimination diet Gluten free Casein free	2 years	Social situations Difficult to cook and shop Spend so much time cooking then end up throwing food	Being organized Using rewards Experimenting Dedication	Committed to the diet because of improvements in child.
18	Behaviour issues	Perceived to not be on a modified diet but avoiding preservatives and colours	~ 10 mos	Child's obsessive behaviours re: food Difficult to shop Required a lot of cooking	Being persistent Experimenting	Currently not following a strict diet
19	Suggested by a speech therapist, due to 'Fed Up' book. Tested for food intolerances	Perceived to not be on a modified diet but avoiding preservatives and colours	~ 7 mos	Difficult due to child's anxiety disorder and sensory sensitivities Required a lot of cooking Difficult to cook Child's behaviour got worse Concerns regarding nutrition	Being persistent	Currently not following a strict diet
20	Father and grandfather had food allergies Suggested by a private dietitian due to hyperactivity	Elimination diet	~ 7 mos	Lack of support Change in cooking and shopping habits Difficult to shop Overwhelming Concerns regarding nutrition	Perseverance and dedication	Committed to the diet because of improvements in child.

**Elimination diet = Low salicylates, low amines, low glutamate, low food additives (preservatives, colours, and flavours)

APPENDIX 7: Results: Table 2

	Previously on the full elimination diet	Length of time on full elimination diet	Other trialled diets	Changes noticed on child	Length of time to notice changes on child (on diet)
1	Currently on	8 months	Food challenges	Listens more Improved concentration	2 weeks
2	No	N/A	Currently on other diets (see Table 1)	Toilet trained More sociable “Woke up to the world”	3 months
3	Currently on	3 months	Currently on other diets (see Table 1)	Behaviour improved More reasonable Easier to manage Improved speech Communicates his feelings	“right away” ~ 1 week
4	Yes	3 months	Food challenges	Improved bladder control Less agitated	1-2 weeks
5	Currently on	~ 5 yrs	Currently on other diets (see Table 1)	Calmer Eczema improved More tolerant Less aggressive Less gut problems/headaches	A couple of weeks

6	Yes	2 weeks	Corn free Sugar free No CHO diet	Bigger vocabulary Longer sentences Less explosive Eczema improved Gut issues improved.	4-6 mos
7	Currently on	1 month	Currently on other diets (see Table 1)	Appetite improved	2 ½ weeks
8	Yes	5 months		Did not notice any changes	N/A
9	Yes		Currently on other diets (see Table 1)	Gut issues resolved More energy Lost grey colour More alert	1-2 days
10	Yes	3 months	Currently on other diets (see Table 1)	Eye contact Better concentration Dark circles under eyes disappeared	Within a day
11	Yes	1 year	Currently on other diets (see Table 1)	Calmer More tolerant to change Improved speech	A few months
12	Yes	Currently on	Currently on other diets (see Table 1)	Calmer More compliant	More than 12 weeks

13	No	N/A		Did not notice any changes	N/A
14	Yes	4 weeks	Gluten free Casein free 'Feingold diet'	Calmer	2 weeks
15	Currently on	8 months	None	Calmer Was 'there;	3 days
16	Currently on	3 years	Currently on other diets (see Table 1)	Increased attention span Bowel issues resolved	2 - 3 days
17	Currently on	2 years	Currently on other diets (see Table 1)	Behaviour settled More aware Improvements in language Bowels improved Less sensory sensitive	2 weeks
18	Yes	4 weeks	None	Did not notice any changes	N/A
19	Yes	8 weeks	Lactose free	Behaviour got worse Constipation	1 week
20	Currently on	7 months	Food challenges	Improved sleeping Behaviour improved Settled	3 - 4 days