

**Origin of Stress, Depression & Anxiety in Parents of
Autistic Children & the Impact on the Family:
A Quantitative and Qualitative Study**

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ABSTRACT

Introduction: Autistic Spectrum Disorder, (ASD) is a lifelong disability that impairs 3 main areas; communication skills, social interaction and behavioural patterns. The cause of autism is not understood & families trying to cope with ASD are searching for answers. Despite the increasing involvement of parents as the child's therapist in interventions, little is known about the effects of involvement on the whole family. Parenting a child with ASD endures more stress than parenting a child with any other disability & heightens negative outcomes on health. The children & families living with ASD face many practicable & emotional challenges.

Objectives: Minimal research has focussed on the stress & impact on the parents & family of ASD children, & in particular the origin of such stress & depression. Consequently, the present study sought to explore the predictors of stress levels of parents, as well as to examine the degree of impact on the family a child with ASD has.

Methods: A combination of quantitative & qualitative methods was used for this study. Self administered questionnaires were sent to parents; (n= 71) as ASD and (n= 40) as control. Questionnaires aimed to examine the mental status of parents including stress, depression & anxiety, by testing the influence of several variables on them. 6 focus groups of the ASD cohort were conducted to investigate in greater detail the indicators of stress & to identify any other sources not explored in the questionnaire. The combination of quantitative & qualitative data enabled a complete holistic approach to be achieved.

Results & Discussion: Children with ASD show significant learning and behavioural problem & parents of ASD children had far greater levels of stress, anxiety & depression. Key indicators in the questionnaires & focus groups were the personal impact on parents & the limitation socially they experience. A key source of social limitation is the unpredictability of the children's behaviours, and the fear of them having a 'meltdown'. Focus groups represented 27% of the ASD cohort. They reinforced social & personal factors, & highlighted the impact on siblings. Disappointment with the medical profession was also identified in the focus groups as a key issue for parents.

INTRODUCTION

The term ‘Autistic Spectrum Disorder’ (ASD), more commonly known as autism, is an umbrella description which includes Autistic Disorder, Asperger’s Disorder and Atypical Autism. ASD’s are lifelong disabilities that affect the way a person communicates and relates to other people, and the world around them (Autism Association NSW, www.autismnsw.com.au). Autism is characterised by impairments in three areas including reciprocal social interaction, communication and repetitive and stereotyped patterns of interest and behaviour (Gray and Tonge, 2001). These are commonly referred to as the ‘Triad of Impairments’ (Autism Association NSW). Characteristics may include repetitive and ritualistic behaviours, hand flapping, spinning or running in circles, excessive fears, self injury, temper tantrums and sleep and eating disturbances (Gillberg and Wing, 1999; Australian Brain Foundation, www.brainaustralia.org.au).

ASD is described as a developmental disorder of the brain (Autism Association NSW; Australian Brain Foundation), and is included under the description of the Pervasive Developmental Disorders (PDD). The PDD is a category of neurological disorders, characterised by severe and pervasive impairment in several areas of development. The specifications of this category are as per the DSM-IV or ICD-10 diagnosis from the Diagnosis and Statistical Manual of Mental Disorders (Autism Society of America, www.autism-society.org; Autism Association of NSW).

Under the PDD come five disorders; Autism, Asperger’s Disorder, Child Disintegrative Disorder (CDD), Rett's Disorder and PDD – Not Otherwise Specified (PDD-NOS). Autism is the most common of these disorders, and is estimated to affect 10-20 of every 1000 individuals (Autism Society of America; Australian Brain Foundation).

The cause of autism is not understood, and while there are many strategies to enhance communication, promote development progress and manage behavioural difficulties, none are curative (Kidd, 2003; Levy and Hyman, 2003). The effect that diet plays in autism has been well documented, with studies beginning in the 1980’s (Recheilt, Elkrem and Scott, 1990). There is a growing interest in the possible dietary involvement which

may help to alleviate some of the behaviours associated with the disorder, however dietary treatment is still deemed as Complementary and Alternative Medicine (Apel, 2002; Kidd; Levy et al).

Families coping with ASD are searching for answers about causes, diagnosis and treatment (National Institute of Mental Health, 2004). Despite the increasing involvement of parents as the child's therapist in interventions for their autistic child, much research has focussed on the outcome for the child, with little known about the effects of involvement on the whole family (Williams and Wishart, 2003). Several studies have found that parenting a child with an intellectual disability report higher levels of child-related stress, and have been thought that the extra stress for caring for a child with a disability places parents at risk of suffering from depression. (Dunn, Burbine, Bowers and Tantleff, 2001; Olsson and Hwang, 2001; Boyd, 2002). Children and families living with ASD face many emotional and practical challenges, and of all the difficulties that can beset parents, having a child with ASD ranks among the worst (Ives and Munro, 2003; Hewson, Icasiano, Machet and Cooper, 2003). Some psychiatric problems and anxiety traits seen in parents of ASD children have been associated with the burden of caring for their ASD child (Murphy, Bolton, Pickels, Fombonne, Piven and Rutter, 2000). As a result, it is important that parents have a means to cope with such stress, and one factor that has been shown to alleviate parental stress is social support (Boyd). To date, minimal research on autism has focussed on the stress and impact encountered by the family of an ASD child, in particular the origin of such stress and depression. The present study sought to explore the predictors of stress levels within ASD families as well as to examine the impact and to what extent, having a child with ASD has on the family. The present study employs both quantitative and qualitative research methods in an attempt to obtain a complete, holistic approach.

METHODS

Design

In an attempt to establish whether parents of ASD children are experiencing higher levels of depression, anxiety and stress, as well as an increased burden on family members, the study reported incorporated quantitative research methods in the form of questionnaires, and qualitative in the form of focus groups.

A quantitative approach was employed to identify key areas of concern within families and parents of ASD children. The use of qualitative methodology in the form of focus groups was also used to complement and expand on data obtained in the questionnaire literature. Focus group methodology was selected to identify the views of parents in reference to the areas of stress and impact on the family.

Two groups of participants were chosen for this study; parents of ASD children for all quantitative, and parents of children without ASD for qualitative.

Six focus groups were conducted in total across the cohort of parents with ASD children. Criminal record checks were also performed on all people actively involved in the study.

Sampling and Recruitment

Ethics approval was sought and obtained from Central Sydney Area Health Service (CSAHS) prior to commencement.

It is recommended that focus groups comprise between 6 and 10 participants (Hudson, Aranda and McMurray, 2002), so all participants are able to equally express their views. A maximum sample size of 6 and a minimum of 4 Participants per group were chosen for this study.

Participants were recruited from the following areas

- Existing or previously seen patients of the RPAH Allergy Unit diagnosed with ASD

- A group from the Illawarra School for Autistic Children
- People enquiring through the Autism Association of NSW website
- Age matched children without ASD were drawn from the general childcare centres and preschool community within the CSAHS area

Parents of children aged between three and ten years diagnosed with ASD as per DSM IV Criteria-American Psychiatric Association (American Psychiatric Association, 1994), who had shown interest in participating were recruited, as were parents of children without ASD for control purposes. For both cohorts, an exclusion criterion included any known existing mental issues of parents.

A study package was provided to parents who expressed interest in the study and contained the following:

- A letter providing an overview of the research
- An Expression of Interest form, also indicating the parents consent for study participation
- A coded (to identify cohort) self administered questionnaire booklet
- A reply paid envelope for return of questionnaires and expression of interest form

Questionnaires

Parents within both cohorts were supplied with the same self administered questionnaire. The questionnaire had proven to be successfully used in a previous study (Ando. 2003), and so no changes were made. While the questionnaire contained nine parts, three sections were used in this study (Appendix 1), and included the Parent Depression and Anxiety Stress Scale (DASS42), Impact on Family Sale (IFS-24) and the Conners' Rating Scale. Parents could fill these out at their own leisure, and return in a reply paid envelope.

The DASS42 is a validated design, and consists of three self-report scales designed to measure the negative emotional states of depression, anxiety and stress, and mental status of the parents, all assessed by a scoring system (Lovibond, 1995).

The IFS-24 can be used to evaluate the impact that a chronic childhood illness has on the family. The IFS measures the level of impact in four subgroups including financial strain, familial or social strain, personal strain on parents and the mastery. The family's ability to cope over time is measured using a scoring that arises from the child's on-going health condition (Stein and Jessop, 2003).

The Conners' Rating Scale uses observer and self report ratings. It is useful in collecting the parent's perspective on a child's behaviour, measuring hyperactivity, anxiety, conduct, impulsive-hyperactivity, learning and psychosomatic (Conners, 1997). This questionnaire was used to explore whether various aspects of the child's behaviours impacted on the stress levels of the parents and family.

Focus Groups

Parents indicated on the expression of interest if they would be interested in participating in a once off focus group session. The interested parents were contacted via telephone, where the purpose of the session and what was involved was explained. Preferred times and dates were gathered, and following phone contact the interested parents were sent an invitation letter, confirming details of the study, venue, date, time and a map and directions to the location (Appendix 2). A follow up phone call was made 2 days before the session to confirm final numbers.

The choice to use focus groups and questionnaires was made as it was thought a more complete, holistic understanding of the issues associated with raising an ASD child would be given.

Procedures and Data Collection

Questionnaires were returned to the clinic via post, where they were entered into the study database through a coded manner, and the aspects needed were separated.

Focus groups are group discussions organised to explore a specific set of issues. The group is 'focused' in the sense that it involves some kind of collective activity (Kitzinger, 1994).

Six Focus group sessions were held at the Royal Prince Alfred Allergy Clinic. It is recommended that usually focus groups continue until the saturation point is reached, that is the point at which no new information would be obtained by holding more. Six was chosen as it had been suggested that the saturation would be met at this amount (May and Waterhouse, 2003). A discussion guide (Appendix 3) was used to generate dialogue on issues relevant to the study aims. The key questions for each focus group were the same, and additional questions were asked where relevant, in response to particular dialogue throughout each session. The participants were asked to comment on the impact of having a child with ASD on the family, the stress levels within the family, and where they might be originating, their opinion on whether diet plays role on autism, the experiences with medical professionals with help and a wish list for future direction. In addition, an information sheet was read out prior to commencement outlining again the purpose of the session, rules involved, and to reinforce that participation was voluntary (Appendix 4). The moderator only interrupted the discussion to clarify a particular point, or if needed, to redirect the dialogue if participants were providing commentary on issues that were not relevant. All focus group sessions were recorded on audiotape, as well as field notes taken. Refreshments were provided, and as many parents had adopted a Gluten and Casein Free diet, such refreshments were provided. Data recorded on tapes were transcribed at a later date. At completion of the session, parents were given the opportunity for a last say or questions. Each session lasted approximately 50 minutes, and was dependant on the session size. All participants were thanked, and provided with a parking voucher as well as 'Friendly Food' Cookbook for their input. A follow up thankyou letter was sent after completion of each focus group (Appendix 5).

Limitations

A limitation of using focus groups as a research methodology is the inability to determine how the various group dynamics will affect the discussion, or, if the interactions that may occur between the participants place a bias on the outcome. Such bias can be minimised by identifying the main themes that are common within all groups (Kubizniak, 1999).

Data Analysis

Questionnaires

Data was collated from the 3 questionnaires chosen. Statistical analysis was performed using SPSS (Version 12.0, SPSS Inc. Chicago, USA). Mean scores were calculated for both cohorts and compared. Differences between the ASD parents and control parents' mental health status were explored using independent-sample t-tests. Box plots were run for normality of data and to show graphically the differences between groups. Box plots were also used to explore the presence of outliers and where they were situated. Data of a significant nature had non-parametric tests conducted. Step wise regressions were conducted with all subgroups of the Impact on Family Scale and Conners' against the Depression, Anxiety and Stress as dependant variables, to assess the degree to which the various sub-groups can predict depression, anxiety or stress within parents of ASD children. Based on results derived from the statistical analysis, a p-value <0.05 indicated statistical significance, and a p-value >0.05 indicated statistical non-significance.

Focus Groups

Focus group discussions were transcribed and then analysed using the framework approach (Appendix 6). This involved analysing the transcripts for recurrent themes between groups, and comparisons were made between the perceptions and experiences of the group.

RESULTS AND DISCUSSION

The results and discussion for both parts of this report (quantitative and qualitative) will be discussed in a combined manner.

General Characteristics

A total of 111 questionnaires were collected and used for data analysis. Of these, 71 were included as ASD and 40 as controls. The sex ratio in the total ASD sample was 64 boys to 7 females, roughly similar to the national average of 9:1 for Asperger's Syndrome (Smeardon, 1998). A total of 19 parents from the ASD group participated in focus groups, representing 27% of this cohort.

Questionnaires

Tables 1-3 (Appendix 7), show that the ASD cohort calculated larger mean scores for all tested variables apart from the psychosomatic variable. Any score above or below the average for the population (45-55) for the Conners' scale should raise concern. Of the subgroups, ASD learning, impulsive-hyperactivity and hyperactivity were above the average score (75.91: 61.44: 68.29) respectively, and was not surprising, based on findings from previous studies (Andonopoulos, 2003). An elevated mean for the mental status of the parents was expected, as assessed using the DASS. It was predicted due to previous studies findings (Hastings, 2003; Boyd; Dunn et al; Hewson et al, Olsson et al; Ives et al) that parents' of ASD children would have stress levels higher than those of the control parents, which remained within the normal limits. However, it was not expected that the control psychosomatic value (61.47) would be above the ASD group and average range. The results from the IFS were to be expected (Andonopoulos), and while all subgroups were significantly higher for ASD than control, the social and personal variables gave the greatest difference in the means (12.54: 1.43; 9.80:1.50) respectively. It should be noted that although the differences for mastery and financial variables were not as high, there was still a large difference between the two groups.

When tested for the *significant difference* between the means of all variables and both cohorts, according to the results in table 4 (Appendix 7), statistical significant difference

($p < 0.05$) does exist. The difference in the means for conduct and psychosomatic are not statistically different ($p > 0.05$).

In order to highlight the variation between ASD and controls, the variances are presented diagrammatically in figures 1-3. Box plots provide an excellent visual summary of many important aspects of a distribution (College of Saint Benedict, Physics Department. www.physics.csbsju.edu/stats). Box plots in this study were used to convey visually the variation between the ASD and control's sample of data.

Figure 1: Box Plot Representation for the Means Score of the Child's Conners'

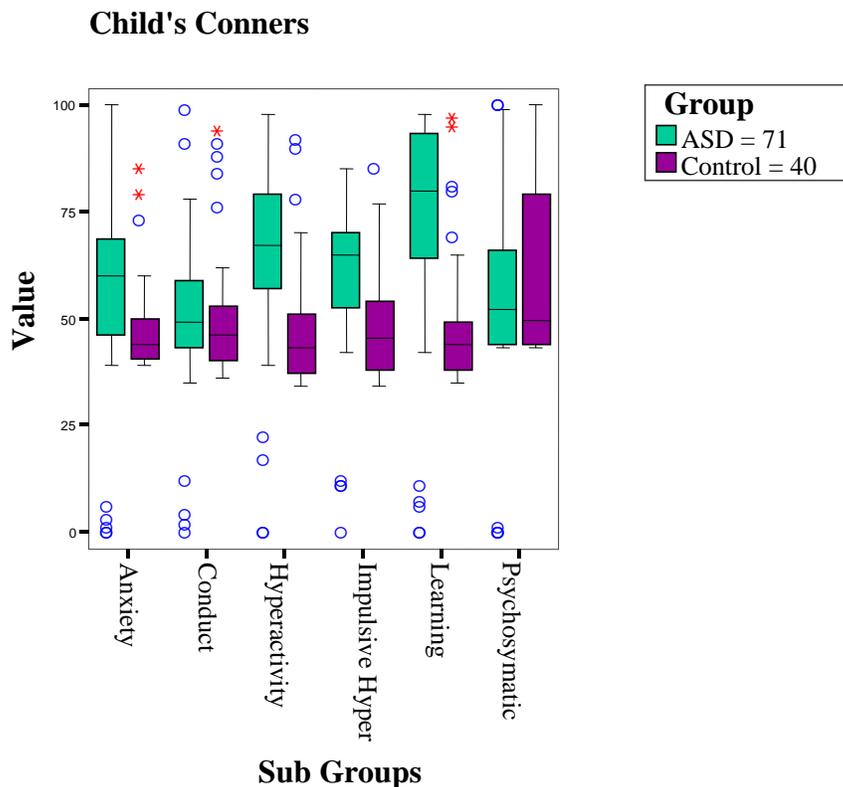


Figure 1 demonstrates great variance between cohorts, with several outliers shown in both, for many of the subgroups. The figure demonstrates that within the ASD's subgroups, there are children at opposite end of the spectrum. In particular anxiety, conduct, and learning have high values of 100, and the lowest at 0, with outliers being at 0, and the 90th percentile at 100. The control's values do not show any value less than 35, which is interesting to note, as the ASD shows many outliers below the 10th percentile.

For the ASD sample, learning shows the most concerning result, with the hyperactivity subgroup just below it. Within the control group several outliers exist, as well as some extremes. Results may be slightly skewed as a consequence. Figure 1 clearly shows children with ASD have significant learning and behavioural problems in comparison to children without ASD.

Figure 2 clearly shows higher results for depression, anxiety and stress for the ASD cohort. Stress levels within controls are substantially higher than for depression and anxiety; however, exhibit outliers which are well out of the 90th percentile range, and could explain the elevated value for the control sample. Stress for ASD is shown to be the highest, with the 90th percentile range approximately at 33. Many outliers are present within the ASD cohort subgroups. Figure 2 confirms there are defiantly higher levels of stress, anxiety and depression within parents of ASD children.

Figure 2: Box Plot Representation for the Means Score of the DASS

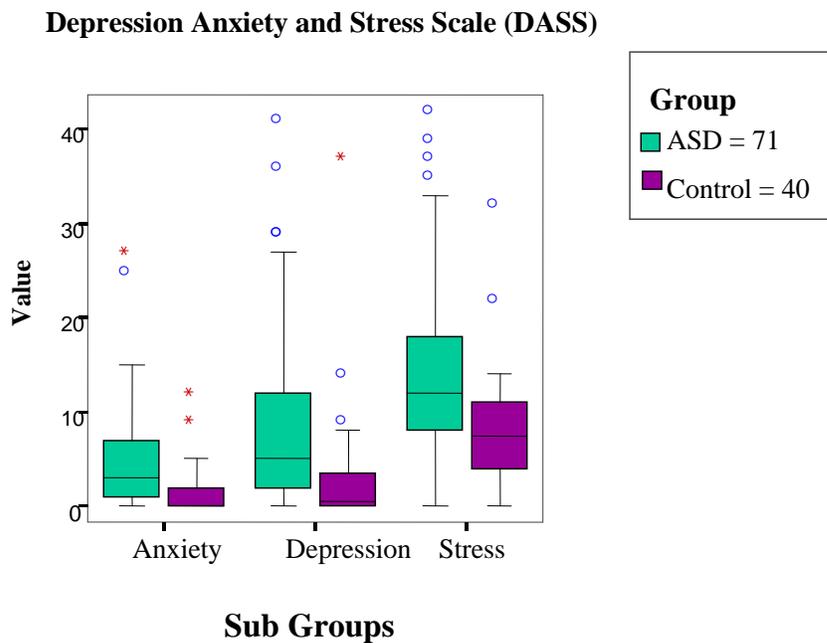
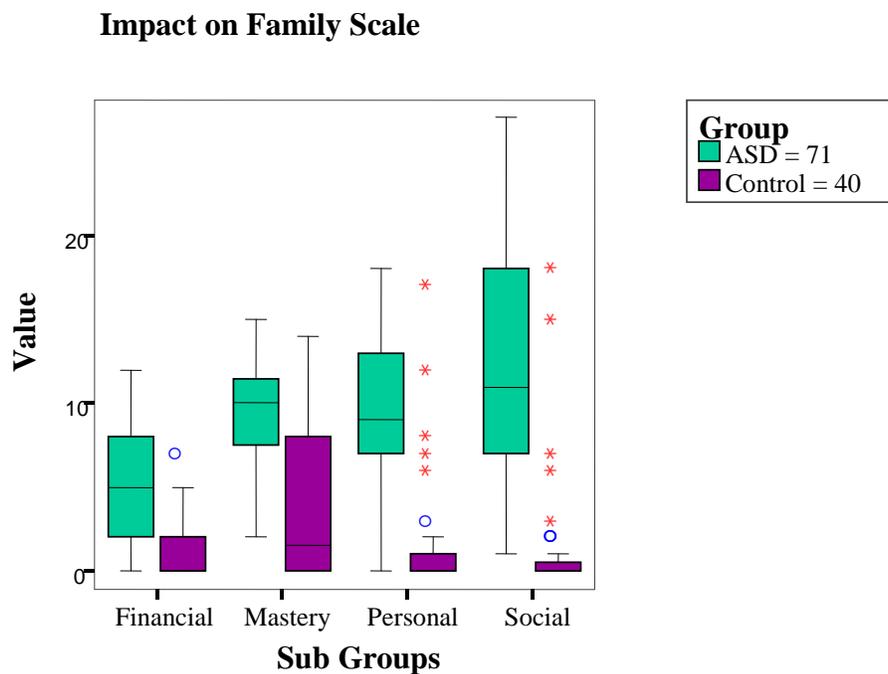


Figure 3, clearly identifies having a child with ASD has a large impact on the family. Social and personal domains exhibit the greatest impact, with mastery and finance rating only slightly behind. Within the social and personal domains for control, there are several extremes. The domain of social shows great variation within responses. It can be seen for this variable of ASD, there is great variation in responses. Figure 3 shows ASD children have a significant impact on their families', however; personal and social domains are the most affected.

Figure 3: Box Plot Representation for the Means Score of the IFS



Results from the tests of normality (Shapiro-Wilk) confirmed the variables to be not normally distributed. Table 5 (Appendix 7) confirms the listed variables do differ from a normal distribution as $p < 0.05$.

As data was found to be significantly different, non-parametric tests were carried out. These results can be found in Appendix 7 (table 6). Results indicate all except conduct and psychosomatic, variables were indeed significantly different ($p < 0.05$) within the cohorts. However, the association between control and ASD samples for the

psychosomatic and conduct variables did not show to have a statistical difference as $p > 0.05$.

Tables 7 to 21 (Appendix 7) contain the regression results for ASD on the DASS mental status outcomes assessed using the Conners' and IFS scales. Each table indicates the Adjusted R squared, partial correlation and significant value. Adjusted R squared was used to reflect the "goodness of fit" of the variable in the sample. The closer the value of Adjusted R squared and partial correlation is to 1, the better the dependant variable can be explained. A p-value of < 0.05 indicated the variable does a good job of explaining the variation in the dependant variable. Alternatively, if $p > 0.05$, it does not do a good job of explaining the variation. Significance is indicated in each table when there is a significant change in adjusted R squared, which is explained by each new 'step' in the equation. The significance of the partial r is differs between steps (i.e. models), the first represent the level of significance for the variable upon entry into the equation, while the remaining indicates the significance of the variable/s at the final step/s, once all variables have been entered.

With respect to the results obtained, when the variables social and personal were entered into the step equation, it showed great significance ($p < 0.05$), and for all aspects of the DAS, can explain to a certain degree, the poor mental status of ASD parents. Table 1 summarises the results obtained from the tests, and shows the representation that the personal and social variables have on depression, anxiety and stress.

Table 22: Summary from Step-Regression Results for variables of significance

Dependant Variable	Independent Variable	Adjusted R Sq	Partial r	Sig Value
Depression	Social	.155	.409	.001
	Personal	.116	.371	.000
Anxiety	Social	.089	.320	.007
	Personal	.032	.240	.045
Stress	Social	.166	.422	.000
	Personal	.121	.365	.002

It can be seen from table 22 that the partial r value for depression and stress are the highest for social, with personal only slightly less. The adjusted R squared values for

social and personal can be thought to represent between 12-16% of stress and depression. While the social and personal adjusted R square's for the anxiety are not as high, they still represent a large amount. Their partial r values are also relatively high. It can also be seen that all variables are statistically significant. While other variables definitely could contribute to the elevated levels of depression, anxiety and stress amongst the sample, personal and social variable were the most common. The remaining variables of interest in some regression tests reduced the partial r and significant value, however were still not seen as significant. It was of surprise that the variables of learning, conduct and hyperactivity did not predict depression anxiety and stress to a greater level. It can be clearly noted that the levels of depression, anxiety and stress among the ASD sample can be definitely attributed to personal and social aspects.

It is evident through the results obtained by the statistical analysis of the questionnaires that there is defiantly an elevated level of stress and depression, and to a lesser extent anxiety, for parents of children with ASD. The influencing factors for stress, depression and anxiety were all largely related to the social and personal issues, with some behavioural factors slightly influencing the predictors of stress, anxiety and depression. Previous studies have acknowledged the increased stress levels amongst parents and families of ASD children, however, to date, none have specifically focussed on the indicators of such stress, anxiety and depression. This study, while not able to completely identify all indicators was successful in identifying significant sources within families, which contribute to such high levels of stress, depression and anxiety. While the questionnaires identified specific sources, the focus groups (to follow), expanded on similar sources while also revealing other indicators which the questionnaires did not reveal.

Focus Groups

Six focus groups were conducted, and the purpose of using both the questionnaires and focus groups was to investigate further where the origins of stress anxiety and depression lie. 45% of the ASD cohort had been recruited to take part. However, at completion of the 6 sessions, 27% of the cohort had taken part. While the parents each had their own unique experiences, many common factors emerged, and despite the focus groups representing only 27%, the saturation point was defiantly met. The focus groups complemented the questionnaires, and gave a greater insight into the lives of such families. The focus groups enabled us to probe for further information on specific points, which was unable to be achieved in the questionnaires. Hence, it was desirable to obtain qualitative insights as well as quantitative, as they pertain specifically to the stress, depression and anxiety of parents of ASD children, the specific area of interest to the current research.

Main findings from the focus groups included the following broad areas;

1. The impact on the family of an ASD child and the main stresses within the family
2. The impact that diet plays and issues relating to food
3. Health Profession Experience
4. Wish List

1. The Impact on the Family of an ASD child and the Main Stresses within the Family

A common term by many of the families used to describe the child's behaviour was 'meltdown'. When asked why this word all parents agreed it completely summed up the extent of their child's behaviour.

"The behaviours are like a nuclear reactor, when she is in that situation you can't reason with her, and it's very difficult to stop".

"They just get to a point where it all of a sudden switches, you just don't know when they will stop".

The IFS revealed that the impact of having a child with ASD is quite significant on the family. The focus groups reinforced this result, and also revealed the varying degrees of

impact. When participants were asked what the impact was of having a child with ASD on the family, five common factors were revealed:

- 1.1 Social impact
- 1.2 Behavioural impact
- 1.3 Impact on siblings
- 1.4 Financial implications
- 1.5 Emotional impact

1.1 Social Impact

The unpredictable behaviour and fear of the child having a meltdown has resulted in the majority of families ceasing their social lives and becoming isolated within their own familiar environment. In addition, respite services for these families do not exist, and so families find themselves not venturing outside of their own homes.

“I guess socially there’s a lot of things you can’t do whether it’s because your child is going to be put in danger or there is the problem of tantrums. Not being able to do things that normal families do. Family outings are really restricted; we have a few friends who understand where we are coming from.”

“We don’t have a baby sitter that we can rely on. So you kind of become isolated. You become just the four of you – which is fine. But you do miss a little bit of socialisation and the socialisation becomes a bit harder because of the instability of his behaviour.”

“ASD limits your social life a lot. You tend not to go anywhere else but home very much and I guess you tend to stick to families who are in a similar situation because they understand, and you don’t feel like you have to be apologising for it all the time”.

“A lot of criticism, and non support from family members who think ‘he just needs discipline’ all that sort of thing. We don’t have support from family members”.

1.2 Behavioural Impact

The *unpredictable* behaviour and fear of a meltdown for many of the parents had a large impact on the family. The child's behaviour is a main reason for the lack of social activities, as the unpredictability and extent of the meltdowns is a fear for many families.

"Its their unpredictability of what's going to happen – not knowing exactly what is going to happen, and it keeps you very stressed through out the day and throughout most of anytime in a situation".

"Not knowing what mood he's going to be in. if it's a good one then everybody's happy. If he's in an aggressive kind of mood then your whole day starts out terrible and you get into stressful situations. It's that unpredictability of he can just turn".

Routine for many parents was an issue hard to deal with. Life revolving around the child and lack of spontaneity was a stressful factor.

"The family has to plan things around him – everything revolves around him"

"Its just that's nothing is spontaneous. Everything is routine, and it almost becomes stressful for me if I know that the routine is going to change because I know he won't cope with that".

The child's sense of withdrawnness from the world, and lack of communication skills was a behavioural aspect that created many frustrations for parents.

"I couldn't reach her and she couldn't reach me. It was like she was in a bubble. You couldn't get into her world she was just happy to be by herself.... It was like she was intoxicated".

"For a long time our son was known as the bubble boy – he was in his own little world. If I tried to get into his space without him inviting me then that was the end of the world and we'd have screaming and biting"

1.3 Impact on Siblings

The impact on siblings was a great concern for many parents, and was not revealed in the questionnaires. There seems to be many sacrifices made by siblings, and many parents worry they will not experience a ‘normal’ childhood. Questions from the siblings with respect to wanting to know why he can’t have a “normal brother” or the pressure from friends from school asking “what’s wrong with your brother, why did he do that?” brought strain into many families.

“He communicates with his sister by hair pulling. She might be asleep in the bedroom, he’ll walk in unbeknown to us and we will hear a shriek, he has gone in and dragged her out of bed by her hair”

“We do get concerns for our daughter and how this might impact on her. She has to make a lot of concessions and sacrifices because of our son. It can be really difficult to try and divide your attention and give them both equal times with one or either parent alone”.

“We are just starting to get to the stage where my daughter understands that our family is different from others. But there’s things we do to try and help her cope with that, and for her sake try and avoid situations where it’s going to be embarrassing for her”

In addition, there many requests by parents for a support service for siblings, as a respite for them, to have time out from their home lives.

“I know that my other daughter finds it very hard. I’d like to see more help for siblings of autistic kids because they have their own special needs”

1.4 Financial implication

While the issue of finance was not largely significant in the questionnaire results, financial implications arose throughout the focus groups. Raising a child with ASD is a full time job and in many of the families, at least one parent had given up work to look after the child. The various ‘special’ foods and diets were a source of financial strain as was the constant doctors and specialist appointments. Special schooling and home

schooling, early interventions, speech therapy and behaviour programs all rated as large financial strains on the family.

“I gave up work when he was diagnosed and everything has just become too stressful to work with that. So financially it has an impact. Therapy which is extremely expensive, financially it’s stressful”.

“My husband is my bank. He doesn’t come to appointments or research with me, but he pays for it all”.

“My life is so full on. Looking after my daughter is my full time job. This is more than parents can bear”.

1.5 Emotional impact

The mental status of the parents of ASD children is affected greatly by the emotional impact. Previous studies have reported that the stress and depression from these parents are associated with the demands they experience from a child with ASD (Hastings and Johnson 2001).

“For my husband it was very hard to deal with the diagnosis. For our marriage it was very difficult because my husband felt it was because I was a bad mother”.

“It’s all very stressful on our marriage. I’m largely the one who has managed the situation, all the research, appointments, intervention, everything. My husband is supportive, but it’s largely my problem”

Parents were reluctant and also scared to introduce new aspects to their ASD child, in the fear they would turn it into an obsession.

“You don’t know if you are having the right impact and if you’re doing things the right way - because things stick with them, we don’t want to stall or start anything as another obsession, and that makes it really hard because mentally that’s tiring”.

2 The Impact that Diet plays on ASD and Issues relating to food

The main themes that emerged from diet's impact on ASD and issues they experience relating to food were:

- 2.1 Food Fussiness and Meal Time Behaviour
- 2.2 Diet Modification and Implementation
- 2.3 The Effect of Diet on Behaviour

2.1 Food Fussiness and Meal Time Behaviour

Some parents found their children would only eat a very limited diet consisting of very limited foods in both colour and texture, with many concerned about this fussiness leading to malnutrition. In some instances, force feeding was tried, in the attempt to prevent starvation or nutrient deprivation.

“Feeding time was the struggle. I had to go away from home. My husband would feed her, and unfortunately sometimes it was force feeding, other wise she would starve to death”

The concept of food fussiness revealed the issues of food texture and colour. Some children would eat only certain colours; others didn't care, while some wouldn't eat a food if it had been near a particular colour. While there was a varying degree of food fussiness within the six groups and each child, the fussiness typically occurred around the same age, about 1.5-2.5 years, where sometimes the child may have a favourite food and suddenly refuse to eat it.

“She wanted chocolate mousse so I made her some up and put into a certain container, a different one to last time. When she went to get it she said she didn't want it anymore and couldn't eat it out of that container. I spooned it out into a little glass dish and she wouldn't eat it because we spooned it out and it wasn't set in it originally”.

“All of a sudden he stopped eating certain things and now he's very restrictive in his food choices. He won't eat anything green, orange or yellow. He will only eat potatoes. He can't have anything with sauce on it. If you dish up the dinner and little bit of gravy has

gone on a piece of meat or something, the whole plate is no good. We have to start again”.

2.2 Diet Modification and Implementation

It is an interesting concept to ask why the parents think that these children have such fussy eating habits. When asked, many thought that the foods react with the children and give them some of their behaviours. However, since many of the children have been following a very white and basic diet, enormous improvements have been noted by parents. Many of the children due to their fussiness had pretty much chosen their own diets.

“My daughter has had a feeding problem since birth, and has more or less chosen her own diet. If I had listened to her instead of to doctors we’d probably be better of”

“It took a little while to completely adjust to the foods he was eating, and he was very limited. Since being on the diet he asks for food. His range has changed. He wears different clothes. He even led the football team out with 300 screaming people, which was a major achievement. His meltdowns are down from 1-2 hours to about 10 minutes. His language has come on. The mental fog just seems to be lifting”.

While some have seen fantastic results from eliminating certain foods from the children’s diet, others find the whole idea very stressful and hard to deal with putting it into place.

“I think I am frightened of the whole diet issue. I’ve been sticking to what people have suggested but knowing that it isn’t really in my son’s interest not to investigate further, or try just a bit harder. I’m worried about the impact it’s going to have on the whole family, that extra step, it’s a scary thought”.

2.3 The Effect of Diet on Behaviour

The majority of parents could pin point certain foods that their children would react to. Such foods included dairy, salicylates, and some wheat products. Most parents who had tried to implement some form of a gluten and/or casein free diet saw huge changes in their child’s behaviours. There was a noticeable improvement in concentration,

aggressiveness, and language and communication levels. For many parents, they had a new child.

“The gluten and casein free diet has made a huge difference. He adjusted very well to the diet, he pretty much took himself off dairy, but we stepped it up to wheat and gluten. I’ve noticed a huge difference. We also took him off salicylates - he was eating a lot of these and we could see he had an aggressive behaviour from them. His communication opened up, his language too. He became a nicer boy from it. He has become less aggressive with anything”.

“If he has apple juice he just loses control completely. He gets upset, and cant calm himself down. He’ll go into a huddle on the floor and not move. It will take hours for him to calm down again”.

“He was an absolute milk addict. We had heard how eliminating milk might help with autistic kids, so we thought we would give it a try. We found that it made a difference. He just calmed down. The meltdown lessened. The mental fog seemed to lift. His language was improving, his receptive skills were better; he was more responsive, just overall things improved”.

3. Health Professional Experience

It became clear parents were disappointed with the lack of support and knowledge from the medical profession, however for certain teachers, schools and associations, parents were very grateful for their help. It became apparent that parents want Drs to be able to educate families on ASD and various techniques for management. However, until the medical profession learn more about ASD, they are unable to successfully deal with it. It would greatly benefit not only the family, but ultimately the children with ASD for education on the disorder to become more available and accessible. Many parents noted various sectors of the medical profession were not willing to explore diet as a management option, and in fact discouraged dietary interventions. Despite some parents noticing fantastic results in their child, certain Doctors are not convinced diet plays a part.

“Everything that you learn you mostly pick up from parents. The information resources are not very good”

“The general medical body needs to listen to what parents are saying - because we know our kids. They tell us to go home and the child’s ok, they’re just being naughty. It’s the challenge of ignorance”

“I found it hard to get a referral to go and see a dietitian. Even though I felt quite strongly that my child was having serious reactions to foods. It took me three times with my GP to get a referral to come here. The GP still isn’t sold on the idea of diet in spite of the fantastic results you can see”.

“I would like the medical profession to support people earlier on – we could have put ourselves where we are now earlier. I’d like to see paediatricians and the GPs referring people sooner rather than later and not using diet as a last resort”.

4. Wish List

It was clear that parents seek more education with respect to diet. While it is recognised a miracle cure does not exist, there is the knowledge that their children may function better. Many times medical professional are reluctant to explore diet as it is seen in the alternative light, and is often overlooked (Apel; Levy et al). Many parents would ultimately like to have access to services in one centre where all management techniques can be explored. A comprehensive centre which provides information and various pathway options they can follow.

“It just seems to me there are so many people out there who are just burnt out. After a while you kind of keep saying ‘I need help with this or can somebody help me’ and there is nothing there to point you in the right direction if you don’t know the right question to ask. That is what is really frustrating”.

In addition, despite the increasing numbers of diagnosis, there is a very limited range of support programs for parents and also siblings of ASD children. Many of the parents

attending the focus group did so in the hope that they would meet people in a similar situation. A larger body of support services defiantly needs to be created. In addition, respite services for ASD families need to be made available. However, this cannot be put into place until there is a greater level of awareness of ASD within the community.

In combination with the quantitative findings, the current findings using qualitative techniques support the theory of ASD parents experiencing significantly higher levels of stress due to personal and social factors. In addition, some interesting new relationships were identified not previously discussed in the quantitative part of the study. The introduction of the impact which siblings experience is an important factor not previously explored in this study.

CONCLUSIONS AND FUTURE DIRECTION

It can be seen that qualitative research provides a wealth of possible avenues to explore further. The focus groups conducted in this study were highly successful in not only exploring indicators of stress identified in the questionnaires, but also to introduce new indicators not previously obtained from the questionnaires. The combining of results from quantitative and qualitative investigations provided a more complete, holistic understanding of the impact on the family and the stress, depression and anxiety felt by such families, with which will help to guide treatment and management interventions in the future. It can be concluded, parents of ASD children experience far greater levels of stress, depression and anxiety than parents of children without ASD.

From this study, it can be concluded that:

- Children with Autistic Spectrum Disorder show significant learning and behavioural problems
- Primary causes of stress, anxiety and depression are social and personal factors
- A strong desire for social support and the opportunity to interact with other families exists among parents
- Support systems to be put into place for siblings of autistic child
- There is a need for community wide education programs to be put into place to educate people on the disorder.

As it was revealed that siblings of ASD children experience a different childhood to many other children, it would be beneficial for a future study to focus on the impact the sibling's encounter.

The large amount of dropout participants in the focus groups could be due to the increased levels of stress such families encounter on a daily basis and the interruptions to a daily routine which cannot occur. Although time constraints prevented it from being done, but it would be an interesting comparison to find the mastery values for the parents who came to the focus groups, who had intended to attend but didn't, and who did not intend to, and see what influence the scores had on attending.

More research needs to be conducted on where the behaviours of ASD children begin. If this can partly be understood, then various management techniques could be introduced to control these. Many medical professionals are not up to date and are partly ignorant on the various management programs for ASD children, including diet. Such professionals need to be aware and educated on the array of services available for families of ASD children, and if are, and then will be able to pass on this to the families in the initial stages of diagnosis. This may include training for people studying education (teachers and the like), so more respite services are available, and a wider sector of the community understands the disorder.

Due to the large demand of support services requested by the parents, and the need to be able to talk to other people in a similar situation, the staff at RPAH Allergy Unit is considering to put a service group in place for the area of Central Sydney to be a part of. This would give parents of ASD children the chance to have time out from their daily routines.

This research has quite clearly reinforced to a great extent the levels of stress, depression and anxiety that parents of ASD children deal with, as well as the impact which is has on the family. In addition, it has not only identified, but given supporting evidence for the key indicators of such levels. The elevated levels are of concern, and future studies should also include strategies to help alleviate such levels.

REFERENCES

1. American Psychiatric Association, Diagnostic and Statistical Manual of Mental Disorder (DSM-IV), (1994) 4th edition. American Psychiatric Association.
2. Andonopoulos, M. (2003). Social Impact on ASD Families and Alternative Treatments. University of Wollongong.
3. Apel, L. (2002). Summarising alternative treatments for autism and other developmental disorders. *New Doctor, Journal of Doctors*. Vol 65, p24-25.
4. Autism Association of New South Wales. What is Autism? Available URL: <http://autismnsw.com.au/about%20autism/whatis.asp> [Accessed 25/05/04].
5. Boyd, B. (2002). Examining the relationship between stress and lack of social support in mothers of children with autism. *Focus on Autism and Other Developmental Disabilities*. Vol 17, Issue 4.
6. College of Saint Benedict, Physics Department. Available URL: www.physics.csbsju.edu/stats [Accessed 10/10/04]
7. Conners, C.K. (1997) Conners' Rating Scales- Revisited. Multi-Health Systems Inc.
8. Dunn, M.E., Burbine, T., Bowers, C.A., Tantleff-Dunn, S. (2001). Moderators of Stress in Parents of Children with Autism. *Community Mental Health Journal*. Vol 37, Issue 1.
9. Gillberg, C., Wing, L. (1999). Autism: no an extremely rare disorder. *Acta Psychiatrica Scandinavia*. Vol 99, Issue 6.
10. Hastings, R.P. And Johnson, E. (2001). Stress in UK Families Conducting Intensive Home-Based Behavioural Intervention for Their Young Child with Autism. *Journal of Autism and Developmental Disorders*. Vol 31, Issue 3.
11. Hastings, R.P. (2003). Child behaviour problems and partner mental health as correlates of stress in mothers and fathers of children with autism
12. Hewson, P., Icasiano, I., Machet, P., Cooper, C. (2003). Family Difficulties in Children with Autism Spectrum Disorder (ASD). *Journal of Paediatric Childs Health*. Vol 39.
13. Hudson, P., Aranda, S. and McMurray, N. (2002). Intervention development for enhanced lay palliative caregiver support – the use of focus groups. *European Journal of Cancer Care*. Vol 11.

14. Ives, M. and Munro, N. (2003). Caring for a Child with Autism. *Journal of Applied Research in Intellectual Disabilities*. Vol 16.
15. Kidd, P.M. (2003). An Approach to the Nutritional Management of Autism. *Alternative Therapies in Health and Medicine*. Vol 9, Issue 5.
16. Kitzinger, J. (1994). The methodology of focus groups: the importance of interaction between research participants. *Sociology of Health and Illness*. Vol 16, Issue 1.
17. Kubizniak, M. (1999). Food Induced Anaphylaxis: A needs assessment. University of Wollongong.
18. Levy, S.E. and Hyman, S.L. (2003). Use of Complementary and alternative treatments for children with autistic spectrum disorders is increasing. *Paediatric Annals*. Vol 32, Issue 10.
19. Lovibond, S.H. And Lovibond, P.F. (1995). Manual for Depression Anxiety Stress Scales. 2nd Edition. School of Psychology, University of New South Wales.
20. May, J. and Waterhouse, P.J. (2003). Dental erosion and soft drinks: a qualitative assessment of knowledge, attitude and behaviour using focus groups of school children. A preliminary study. *International Journal of Paediatric Dentistry*. Vol 13
21. Murphy, M., Bolton, P.F., Pickles, A., Fombonne, E., Piven, J. and Rutter, M. (2000). Personality Traits of Relatives of Autistic Probands. *Psychological Medicine*. Vol 30, Issue 6.
22. National Institute of Mental Health (NIMH). Autism Spectrum Disorders Research Fact Sheet (2004). Available: <http://www.nimh.nih.gov> [Accessed 06/10/04]
23. Olsson, M.B. And Hwang, C.P. (2001). Depression in mothers and fathers of children with intellectual disability. *Journal of Intellectual Disability Research*. Vol 45, part 6.
24. Reichelt, K.L., Ekre, J., Scott, H. (1990). Gluten, Milk Proteins and Autism: Dietary Intervention effects on behaviour and peptide secretion. *Journal of Applied Nutrition*. Vol 42, Issue 1.
25. Smeardon, L. (1998). *The Autistic Spectrum – A Handbook*. National Autistic Society, London.

26. Stein, R.E.K. and Jessop, D.J. (2003). The Impact on Family Scale Revisited: Further Psychometric Data. *Developmental and Behavioural Paediatrics*. Vol 24 Issue 1.
27. The Australian Brain Foundation. Autism. Available URL: http://www.brainaustralia.org.au/AZ_of_Brain_Disorders/autism [Accessed: 25/05/04].
28. Williams, K.R., Wishart, J.G. (2003). The Son-Rise Program intervention for autism: an investigation into family experiences. *Journal of Intellectual Disability Research*. Vol 47, Issue 4-5.

APPENDIX 1

3 Sections of the questionnaire used in this research

- DASS
- IFS
- Child's Conners'

APPENDIX 2

FOCUS GROUP LETTER

APPENDIX 3

Focus Group Discussion Guide

1. What has been the impact on the family of having a child with ASD?
2. What do you think are the main sources of stress in families of children with ASD?
3. Do you think diet has any role in ASD, and if so in what way?
4. How much do you think that food issues such as pressure to look at diet or following a limited diet are a source of stress or dysfunctional family behaviour?
5. What dietary modifications have you found helpful or harmful and in what way?
6. What if any supplements have you found helpful and in what way?
7. What is the most important aspect about diet in ASD and your own experience that you would like research to address?

APPENDIX 4

INFORMATION SHEET

(To be read out at the beginning of each Focus Group)

Thank you for taking the time to come to this session today. We are interested in discussing with you, your experiences and concern in the management of a child with Autistic Spectrum Disorder.

All discussions today will be kept confidential, and the results from today's discussion will be recorded in a report which will remain confidential, and accessible only to the relevant people from RPAH. At the end of the discussion, we will set aside time to answer any questions you may have.

Your participation is completely voluntary, and if you do not wish to participate in the discussion now, or if at any time you wish to stop participation in the discussion, feel free to leave.

Is there anyone who does not understand or who is not happy with this, and would prefer to not stay and participate?

Are there any questions?

Finally, we need to ask for your permission for taking notes and tape recording the discussion. The purpose of this is so we can analyse in further detail what was said today at a later date. On completion of the research, the tape as well as any notes made from the discussion will be kept in a secure place for a period of five years.

Is everyone happy for us to do this?

Focus Group Rules

- You can leave at any time
- All members of the focus group will be given the opportunity to speak

- Please do not speak at the same time or over one another
- There is no such thing as a right or wrong answer
- Please say what you think, and not what you think someone wants to hear
- Not everybody needs to agree, as we are interested in obtaining a range of opinions
- No names will be used for identification of comments at any stage
- Any information obtained in the focus group session will be limited to the staff from the RPA Allergy Unit

APPENDIX 5

THANKYOU LETTER

APPENDIX 6

Coding Frame for Focus Group Discussions

1. The Impact on the Family of an ASD Child and the Main Stresses Within the Family

1.1 Social Impact

- 1.1.1 Social life is limited
- 1.1.2 Social life doesn't exist anymore
- 1.1.3 Not many friends
- 1.1.4 Restricted from outings
- 1.1.5 Defiantly notice the difference when you step outside your home
- 1.1.6 Unable to do things 'normal' families do
- 1.1.7 Sense of isolation
- 1.1.8 No respite available to have a break
- 1.1.9 Behaviours impact on where we can go
- 1.1.10 Lack of support from family
- 1.1.11 Stressful to go out in public
- 1.1.12 Stressful trying to keep everyone calm
- 1.1.13 Meltdown behaviour
- 1.1.14 Unpredictable behaviour prevents going out

1.2 Behavioural Impact

- 1.2.1 Unpredictable behaviour
- 1.2.2 Child can all of a sudden turn
- 1.2.3 Everything is so routine
- 1.2.4 Life is not spontaneous anymore
- 1.2.5 Withdrawn behaviour from children
- 1.2.6 Don't know if it's just a child's behaviour or if it is autism
- 1.2.7 In their own world
- 1.2.8 Can't get into their world
- 1.2.9 The bubble boy
- 1.2.10 Need to be invited to their world, cant just go in, or aggression occurs
- 1.2.11 Stressful not knowing when the child will suddenly turn

1.3 Impact on siblings

- 1.3.1 Concerns as the siblings don't have a normal life

- 1.3.2 Sense of embarrassment
- 1.3.3 Try not to put the siblings in an embarrassing situation
- 1.3.4 May suffer the violent streak from the autistic sibling
- 1.3.5 Different treatment and rules
- 1.3.6 Make a lot of sacrifices
- 1.3.7 Worried unequal time is spent, more time and focus is on the autistic child
- 1.3.8 Need a sibling service
- 1.3.9 Why can't I have a normal brother?
- 1.4 Financial Implications
 - 1.4.1 Financial strain
 - 1.4.2 Full time job of raising the child
 - 1.4.3 Many don't work
 - 1.4.5 Different treatments appointments, Drs, foods all expensive and add up
 - 1.4.6 Special schooling and transport is expensive
- 1.5 Emotional Impact
 - 1.5.1 Tiring, frustrating, exhausting
 - 1.5.2 Mentally and physically tiring
 - 1.5.3 Relationship strain, strain on marriage
 - 1.5.4 Changed our lives
 - 1.5.5 Life revolves around the child
 - 1.5.6 Scared to teach new things in case they keep hold of it
 - 1.5.7 Constantly thinking
 - 1.5.8 Feeling of hopelessness
- 2. The Impact that Diet Plays and Issues Relating to Food
 - 2.1 Food Fussiness and Meal time behaviour
 - 2.1.1 Feeding problems have increased as child has become older
 - 2.1.2 Limited range of foods for some
 - 2.1.3 Texture and colour is important
 - 2.1.4 Force feeding
 - 2.1.5 Issues surrounding use of cutlery and sitting at table to eat
 - 2.1.6 Child prefers to eat away from everyone

- 2.1.7 Had favourite foods then suddenly stopped eating them and refused them
- 2.1.8 Food familiarity
- 2.1.9 Have to eat things out of certain containers or drinks from certain cups
- 2.1.10 Will eat everything
- 2.1.11 Loves milk
- 2.2 Diet Modification and Implementation
 - 2.2.1 Know certain foods cause child to react
 - 2.2.2 Expensive to implement gluten and casein free diet
 - 2.2.3 Many have heard of the gluten and casein free diet concept
 - 2.2.4 Scared to try something new in case child stops eating all together
 - 2.2.5 Where diet has been modified, have a new child
 - 2.2.6 Stressful to implement diets
 - 2.2.7 Can't understand how good foods like broccoli and oranges can harm the child
 - 2.2.8 Try to hide foods within foods eg vegetables
 - 2.2.9 Child can smell and taste things so much clearer
- 2.3 The Effect of Diet on Behaviour
 - 2.3.1 Can pin point certain food the child reacts to
 - 2.3.2 Dairy cause gut problems
 - 2.3.3 Fruits send the child off
 - 2.3.4 Huge behaviour change when foods from diet are eliminated
 - 2.3.5 Increase in concentration. Language, communication levels
 - 2.3.6 Decrease in autistic behaviours such as aggressiveness
 - 2.3.7 Fog has lifted when diet has changed
 - 2.3.8 Very gut sensitive
- 3. The Key Issues and Wish List
 - 3.1 Lack of help from medical bodies
 - 3.2 Conflicting advice
 - 3.3 Nothing central to gain information from
 - 3.4 Get most of the information from reading, internet, talking to other parents
 - 3.5 Medical profession needs to listen to the parents, we know our kids best

- 3.6 Ignorance from medical bodies
- 3.7 Hard to get referrals for dietitians
- 3.8 Get support earlier on
- 3.9 Frustrating that non one will help

APPENDIX 7

Table 1: Comparisons of Means between Control and ASD for the Child's Conners'

	Conduct	Learning	Psychosomatic	Impulsive Hyper	Anxiety	Hyperactivity
ASD	51.40	75.91	56.61	61.44	57.49	68.29
Control	50.30	48.90	61.47	48.03	47.55	47.65

Table 2: Comparison of Means between Control and ASD for the DASS

	Depression	Anxiety	Stress
ASD	8.03	4.42	14.06
Control	2.93	1.30	7.68

Table 3: Comparison of Means between Control and ASD for the Impact on Family

	Financial	Social	Personal	Mastery
ASD	5.27	12.54	9.80	9.39
Control	1.05	1.43	1.50	4.13

Table 4: Results from analysis of independent sample t-test statistical significance difference of the mean scores between the ASD and control cohorts for all variables.

Variable	p-value	Interpretation
DASS		
Depression	.002	Significant
Anxiety	.001	Significant
Stress	.000	Significant
IFS		
Financial	.000	Significant
Social	.000	Significant
Personal	.000	Significant
Mastery	.000	Significant
Conners'		
Conduct	.909	Not significant
Learning	.000	Significant
Psychosomatic	.195	Not significant
Impulsive-Hyper	.000	Significant
Anxiety	.018	Significant
Hyperactivity	.000	significant

Significance is at $p < 0.05$

Table 5: Results from the Tests of Normality. Shapiro-Wilk Value noted. Interpretation given

Shapiro-Wilk		
Variable	p-Value	Interpretation
Depression	.000	Significant
Anxiety	.000	Significant
Stress	.000	Significant
Financial	.000	Significant
Social	.000	Significant
Personal	.000	Significant
Mastery	.000	Significant
Leaning	.000	Significant
Impulsive-Hyper	.001	Significant
Anxiety	.000	Significant
Hyperactivity	.044	Significant
Conduct	.000	Significant
Psychosomatic	.000	Significant

Table 6: Results from the Mann-Whitney non parametric test for all subgroups, in comparison with the ASD and control groups

Variable	p-Value	Interpretation
Depression	.000	Significant
Anxiety	.000	Significant
Stress	.000	Significant
Financial	.000	Significant
Social	.000	Significant
Personal	.000	Significant
Mastery	.000	Significant
Leaning	.000	Significant
Impulsive-Hyper	.000	Significant
Anxiety	.000	Significant
Hyperactivity	.000	Significant
Conduct	.159	Not Significant
Psychosomatic	.431	Not Significant

Tables 7 – 21: Step-wise Regression Results for ASD Sample. Depression, Stress and Anxiety as the Dependant Variables.

Table 7: Step-Wise Regression Results for ASD Sample – Depression as the Dependant Variable

<i>Model</i>	<i>Adjusted R Sq</i>	<i>Partial r</i>	<i>Sig. value</i>
1 Personal	.125	.371	.001
2 Personal Mastery	.116	.371 -.070	.002 .562
3 Personal Mastery Conduct	.105	.373 -.070 -.042	.002 .567 .735

Significance for sig. is indicated when $p < 0.05$

Table 8: Step-Wise Regression Results for ASD sample – Depression as the Dependant Variable

<i>Model</i>	<i>Adjusted R Sq</i>	<i>Partial r</i>	<i>Sig. value</i>
1 Social	.155	.409	.000
2 Social Learning	.154	.418 -.115	.000 .344
3 Social Learning Financial	.147	.378 -.114 -.082	.001 .350 .502

Significance for sig. is indicated when $p < 0.05$

Table 9: Step-Wise Regression Results for ASD sample – Depression as the Dependant Variable

<i>Model</i>	<i>Adjusted R Sq</i>	<i>Partial r</i>	<i>Sig. value</i>
1 Hyperactivity	-.012	-.052	.668
2 Hyperactivity Conduct	-.021	-.089 .076	.462 .530

Significance for sig. is indicated when $p < 0.05$

Table 10: Step-Wise Regression Results for ASD sample – Depression as the Dependant Variable

	<i>Model</i>	<i>Adjusted R Sq</i>	<i>Partial r</i>	<i>Sig. value</i>
1	Social	.155	.409	.000
2	Social Psychosomatic	.169	.435 -.174	.000 .149
3	Social Psychosomatic Anxiety	.157	.435 -.145 -.029	.000 .233 .812

Significance for sig. is indicated when $p < 0.05$

Table 11: Step-Wise Regression Results for ASD sample – Depression as the Dependant Variable

	<i>Model</i>	<i>Adjusted R Sq</i>	<i>Partial r</i>	<i>Sig. value</i>
1	Mastery	-.010	-.067	.580
2	Mastery Impulsive-Hyperactivity	-.021	-.068 -.057	.575 .637

Significance for sig. is indicated when $p < 0.05$

Table 12: Step-Wise Regression Results for ASD sample – **Stress** as the Dependant Variable

	<i>Model</i>	<i>Adjusted R Sq</i>	<i>Partial r</i>	<i>Sig. value</i>
1	Personal	.121	.365	.002
2	Personal Learning	.140	.382 -.190	.001 .116
3	Personal Learning Financial	.143	.386 -.186 -.134	.001 .125 .273

Significance for sig. is indicated when $p < 0.05$

Table 13: Step-Wise Regression Results for ASD sample – **Stress** as the Dependant Variable

	<i>Model</i>	<i>Adjusted R Sq</i>	<i>Partial r</i>	<i>Sig. value</i>
1	Personal	.121	.365	.002
2	Personal Hyperactivity	.122	.378 -.125	.001 .301

Significance for sig. is indicated when $p < 0.05$

Table 14: Step-Wise Regression Results for ASD sample – **Stress** as the Dependant Variable

<i>Model</i>	<i>Adjusted R Sq</i>	<i>Partial r</i>	<i>Sig. value</i>
1 Impulsive-Hyper	-.009	-.074	.539
2 Impulsive-Hyper Mastery	-.024	-.074 -.007	.541 .952

Significance for sig. is indicated when $p < 0.05$

Table 15: Step-Wise Regression Results for ASD sample – **Stress** as the Dependant Variable

<i>Model</i>	<i>Adjusted R Sq</i>	<i>Partial r</i>	<i>Sig. value</i>
1 Financial	-.002	.110	.362
2 Financial Anxiety	-.005	.126 -.108	.297 .374

Significance for sig. is indicated when $p < 0.05$

Table 16: Step-Wise Regression Results for ASD sample – **Stress** as the Dependant Variable

<i>Model</i>	<i>Adjusted R Sq</i>	<i>Partial r</i>	<i>Sig. value</i>
1 Social	.166	.422	.000
2 Social Conduct	.154	.422 -.027	.000 .826

Significance for sig. is indicated when $p < 0.05$

Table 17: Step-Wise Regression Results for ASD sample – **Anxiety** as the Dependant Variable

<i>Model</i>	<i>Adjusted R Sq</i>	<i>Partial r</i>	<i>Sig. value</i>
1 Financial	.000	.119	.325
2 Financial Social	.089	-.119 .320	.326 .007

Significance for sig. is indicated when $p < 0.05$

Table 18: Step-Wise Regression Results for ASD sample – Anxiety as the Dependant Variable

<i>Model</i>	<i>Adjusted R Sq</i>	<i>Partial r</i>	<i>Sig. value</i>
1 Impulsive- Hyper	-.012	-.050	.677
2 Impulsive-Hyper Personal	.032	-.117 .240	.333 .045

Significance for sig. is indicated when $p < 0.05$

Table 19: Step-Wise Regression Results for ASD sample – Anxiety as the Dependant Variable

<i>Model</i>	<i>Adjusted R Sq</i>	<i>Partial r</i>	<i>Sig. value</i>
1 Conduct	.006	.143	.234
2 Conduct Learning	.101	.188 -.134	.118 .268

Significance for sig. is indicated when $p < 0.05$

Table 20: Step-Wise Regression Results for ASD sample – Anxiety as the Dependant Variable

<i>Model</i>	<i>Adjusted R Sq</i>	<i>Partial r</i>	<i>Sig. value</i>
1 Anxiety	-.009	.071	.557
2 Anxiety Hyperactivity	-.021	.091 -.058	.454 .632

Significance for sig. is indicated when $p < 0.05$

Table 21: Step-Wise Regression Results for ASD sample – Anxiety as the Dependant Variable

<i>Model</i>	<i>Adjusted R Sq</i>	<i>Partial r</i>	<i>Sig. value</i>
1 Social	.089	.320	.007
2 Social Mastery	.076	.319 .005	.007 .968