Parent Survey Report

ASD Current Diagnosis, Therapies and their Perceived Effectiveness

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Report on an Internet Based Parent Survey –
Current ASD Diagnosis, Therapies and their Perceived Effectiveness

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Abstract

This study examines the reasons for the delay between a parent's first suspicions of autism and actually obtaining a diagnosis. It presents the main therapies being used by parents and their perceived effectiveness. The data were collected through an internet based survey. Of the 331 reponses received 261 (79%) were completed to varying degrees, of which approximately 215-235 were able to be used in the analysis. The results indicate a considerable degree of complacency and/or poor training in relation to autism among health professionals. Non-biomedical and biomedical therapies are examined for their perceived effectiveness. Speech and occupational therapies tend to work on a longer time scale than diet based therapies, which are found to provide rapid improvements in behaviour in 25-40% of the cases.
Recommendations are made with regard to the need for better training of health professionals, and the need to produce a series of biochemical based screening tests for detecting autism to replace the current tests which are psychological symptom and time dependant.

Keywords Autism, delayed diagnosis, therapies, diet, training.

Executive Summary

As far as the author is aware, there has never been an investigation into the delays in diagnosis of autism and the most frequently used therapies in either Australia or New Zealand. This report is based on the results of an internet based Parent Survey, aimed at obtaining a snap shot of autism diagnosis, therapy and perceived effectiveness. Owing to the fact that this is a private, independent project, and the difficulties in obtaining the cooperation of certain state based and national organisations, as well as the limitations in providing information placed on educational institutions, the survey responses were gathered mainly through informal networks. They are biased towards those parents who use biomedical therapies or interventions, as opposed to non-biomedical therapies in the approximate ratio of 4:1.

Despite the very limited number of responses to date, there are a number of conclusions that can be drawn, as follows:

1. The average delay between a parent's first suspicion of something being wrong with their child and actually obtaining a diagnosis is approximately 2 years. The main reason for this is GP, paediatric and health professional complacent reassurances that there is nothing wrong with their child and that "the delay is normal and nothing to worry about". Such comments accounted for just under 50% of the delays.

2. This in turn is due, at least in part, to the lack of adequate autism specific training in universities and other educational institutions. With the incidence of autism currently running between 1:100 and 1:160, there is an urgent need for GPs and other health professionals to be given autism specific training in its diagnosis and the range of therapies available.

3. Nearly 20% of parents were told their child was too young for assessment, and a further ~20% of the delays were due to not being able to get to see a psychologist for a diagnosis earlier.

4. The present delays are also in part due to the fact that to date, diagnosis is dependent primarily on psychological evaluation of the associated symptoms eg lack of speech, poor social and communicative skills, and these tend not to become apparent until the child reaches approximately two years of age (or later in the case of Asperger syndrome). These delays in obtaining a diagnosis are unacceptable and undermine the Early Intervention strategy being promoted by the Federal Government in Australia and the New Zealand Spectrum Disorder Guideline.

5. The most frequently used non-biomedical therapies were found to be speech and occupational (75.3% and 63.0%, n=219). ABA (Applied Behavioural Analysis) was also used by 34.7%. In this survey approximately 80% of parent had used, or were using, biomedical interventions such as dietary modification and supplements in addition to these other therapies. Those parents who were most influenced in choice of therapy by their GP or paediatrician used an average of 2.4 therapies (with a median of 2), whereas those parents most influenced by the internet, or a book they had read, used an average of 4.4 therapies (with a median of 3) on their children. None of the therapies listed in the Survey provided improvement in all children, indicating the great diversity of each child's individuality.

6. Approximately 50-60% of children on one of the commonly used diets (eg GF/CF=Gluten/Casein Free, GF/CF/SF=Gluten/Casein/Soy free, sugar removed, chocolate remove, salicylate free, SCD =Specific Carbohydrate Diet), showed a behavioural improvement within one month of starting. On the other hand around 20% showed no improvement after one month on diet.

7. Dietary therapies were found to bring about a more rapid improvement in behaviour within a month, than Speech and Occupational Therapy, ABA and Sensory Integration. There appears to be some slight advantage to using a combination of biomedical and speech therapy in order to speed up the rate of speech progress, though the precise nature of the biomedical therapy needs to be examined further.

8. The snapshot did not achieve its objective in terms of obtaining a broad overview of the Australian and New Zealand therapy situation in view

of the very small number of participants using only non-biomedical therapies. However those parents who are using biomedical therapies now have access to a reasonable yardstick as to the apparent effectiveness of the various diets and supplements being used by their community.

Recommendations arising from the conclusions concern the need for

1. substantial increased funding for education directed at the medical profession and allied health professionals, as well as parents and prospective parents, educators and the children (and adults) affected by ASD. This education needs to incorporate both the latest biochemical and psychological research into autism.

2. substantial increase in government and private funding to help establish research into the underlying biochemical causes of autism. At the present time, there is no one biochemical screening test which clearly identifies autism in the same way that a heel prick or Guthrie test will identify PKU. This report proposes the need to develop an array of tests which will at least identify any biochemical abnormalities in neonatal children, which in turn will enable early biomedical and other interventions, whether a child has autism, Crohn's, coeliac, or some other genetic, or environmentally induced condition. Such tests would help reduce the uncertainty associated with psychological testing and enable Early Intervention to be "Early". In depth biochemical screening of those children of parents who suspect something is not quite right with their child, would be a step in the right direction.

The Author

Dennis Crowley is an honours graduate in chemistry (Leeds University, 1966) and worked in laboratories, sales and marketing, and general management in the chemical industry in England, France, and Australia for nearly 40 years. He was CEO of ACNEM (The Australasian College of Nutritional and Environmental Medicine) in 2007 for a year before retiring (again) to devote more time to helping the autism community. He first became acquainted with autism in 2005 through a family connection, and has since become an active member of the Biomedical Autism Group. He was elected to the board of Autism Victoria in November 2008.

Vested Interest

Whereas the author admits to being in favour of biomedical therapy, among others, he has not sought, nor received funding from any company, and has not carried out the research on behalf of any company or organisation. His prime interest is to help bring relief to the families of ASD children.

Introduction

Autism is a condition affecting approximately 1 in 160 children and this rate appears to be increasing in countries where detailed surveys of its incidence have been carried out[1] [2] [3].

This survey, aimed primarily at the Australian and New Zealand ASD community, was prompted by a number of factors as follows:

1. many parent stories to the effect that their GP, or other health professional with whom they were in contact, suggested that there was nothing wrong with their child, and that boys were late developers, compared to girls.
2. a perceived insistence by psychologists that ABA (Applied Behavioural Analysis) was the only proven method to treat autism.
3. the apparent denial by most professional psychologists involved in treating autism that dietary regulation could be a useful tool in helping autistic children's behaviour.
4. the numerous anecdotes about the dramatic improvements obtained with some children following the application of dietary restrictions, primarily gluten and casein free (GF/CF) diet
5. the Autism Research Institute (ARI) Survey on Parent Ratings of Behavioural Effects of Biomedical Interventions[4]

As far as the author is aware, there have not been any surveys previously conducted within Australia and New Zealand to test any of the abovementioned factors 1-4 statistically. One internet survey in the USA conducted by The University of Texas at Austin in 2004[5] captured 552 usable responses in a 3 month period. This showed that speech therapy was the most commonly reported intervention (by 70%), followed by visual schedules, sensory integration and ABA (36%). 52% of parents were using at least one medication to treat their child, 27% were implementing special diets and 43% were using vitamin supplements.

Objectives

A key objective of the survey was to obtain a snapshot of the different types of treatments being used in Australia and New Zealand with a view to obtaining parent perspectives on their effectiveness.

Other objectives included:

1. An indication of the delay between the parents first suspicions of autism and diagnosis, and the reasons for the delay.
2. An indication of the effectiveness or otherwise of biomedical treatment.

Methodology

Using the internet as a contact medium is a cheap and easy means of obtaining information. According to the ABS (Australian Bureau of Statistics)

in 2006/7 64% of Australian Households had home internet access and 73% had access to a home computer. It was considered that similar percentages would pertain in New Zealand. Thus it was anticipated that an internet based survey should provide data from a good cross section of the population in each country.

Survey Development

The survey was based on offering multiple choice questions. The survey software used was Polldaddy and a specific URL was obtained as shown:

http://www.polldaddy.com/s/B208F0BA44AD4960/

There are 24 questions covering demographic data, delays in diagnosis and their reasons, who provided the diagnosis, and the therapies used. In order to encourage participation, none of the questions were made mandatory. One consequence of this policy was that a number of people clearly visited the URL just out of curiosity, while others answered some of the questions and not others.

Most questions had the opportunity to respond with “Other” answers where the reporter offered alternative options to those provided. Questions also covered the estimated costs,[#] and, in the case of biomedical treatment, the types of tests used. ([#]This information is not included in this paper).

The survey questionnaire was reviewed by two general practitioners and a professional statistician, and pilot tested with about 6 parents from the Melbourne branch of Biomedical Autism Group prior to launch.

Survey Distribution

It was expected that with the help of the state autism organisations, it would be easy to access the many thousands of families affected by ASD in both Australia and New Zealand. Regrettably, not all state based organisations in Australia were prepared to cooperate, and there was very limited response from the autism organisations in New Zealand. An autism specific school was also approached in Victoria, but the need to meet privacy and ethics requirements in dealing with it and any similar schools were overwhelming, and it became clear the project would not be able to proceed within the scheduled timeframe. Consequently the response to the survey has been smaller than anticipated, and very dependent on the good will of various parent support groups, internet forums, and those individuals who could see the value in such an exercise. A further consequence is that to date the responses have been predominantly from parents using biomedical therapy (plus other therapies) in the ratio of approximately 4:1 compared to those not using biomedical therapy. This is a much higher ratio than anticipated, given the anti-biomedical stance taken by many psychologists, health professionals and teachers. The literature suggests ratios in the order of 3:1 to 1:1 are probably more representative.[6 7 8] It is hoped that as the Survey is ongoing,

many more parents using only non-biomedical therapies will eventually agree to participate.

Results

Location

The results presented in this paper are based on those responses collected during the five month period from its launch at the Autism Victoria Research Forum 6 November 2008, to 6 April. By that time 331 responses were received, of which 79% were complete (n=261). 61% of the completed responses indicated they were from Australia, 20% did not provide any country address, 6% were from New Zealand. There were also 8 replies from Canada, Hong Kong, UK, and USA.

As expected, Victoria and NSW provided the most replies (95 and 57 respectively). Regrettably, there was minimal input from ACT, NT, Tasmania, WA families.

Child's Gender

82% were male and 18% were female, which figures are very broadly in line with previously published ratios of about 4:1.[9 10 11]

Child's first diagnosis

Parents were asked to indicate their child's first diagnosis and who provided it. The results are shown in Tables 1, 2, and 3

Table 1 Child's first diagnosis

First Diagnosis	N=230
Autism	132 (57.4%)
Asperger	35 (15.2%)
ADHD[#]	24 (10.4%)
PDD-NOS	19 (8.3%)
Epilepsy[#]	39 (1.7%)
Childhood Disintegrative Disorder	1 (0.4%)
Other	41 (17.9%)

ADHD and Epilepsy are not included in DSMIV Section 299 covering Autism.

Some parents cited more than one diagnosis.

Of the "Other' diagnoses, the main ones fitted into the following categories:

- 10 (4.3%) Global Development Delay (GDD) or developmental delay
- 5 ASD, provisional or possible
- 3 expressive or receptive language delay.

Table 2 Provider of child's first diagnosis

Practitioner	N=231
Paediatrician	100 (43.3%)
Psychologist	68 (29.4%)
GP	4 (1.7%)
Health visitor	1 (0.4%)
Naturopath	1 (0.4%)
Other	58 (25.1%)

Table 3 Main "Other" providers of diagnosis

Who diagnosed	N=231
Team of specialists	32 (13.9%)
Speech Pathologist	5 (2.2%)
Psychiatrist	4 (1.7%)
Pfeiffer or similar trained GP	3 (1.3%)
Occupational Therapist	2 (0.9%)

Thus the team approach ranks third behind the paediatrician and psychologist, these three accounting for 86.6% of all diagnoses. If the GP related diagnoses are added to this percentage then the data suggests that around 10% of all diagnoses are being made through other channels.

Delays in diagnosis

All childrens' dates of birth were given, and the median date was 2003, giving a median age of 5-6 years. (The oldest reported date of birth was 1983). In a number of cases, some of the reported dates of first suspecting the child was not developing typically, and the date of diagnosis were given only by the year, and not month/year. This may indicate the noted delays could be out by up to twentyfour months in some cases, and only one month in other cases. In order to minimise such potential discrepancies, the mid year was taken as the reference point for counting the number of months delay. Thus the average delay would be expected to be a reasonably representative indicator of the reality.

The average delay from all responses was found to be ~24.4 months (n=228), though with a very wide range (0-~132 months), and a median delay of ~17 months. Taking PDDNOS, Aspergers and ADHD[#] as three separate conditions, the overall result can be broken down as shown in Table 4:

Table 4 Average and median delays in diagnosis

Set/Subset	Ave age suspicion (months)	Ave age diagnosis (months)	Average delay (months)	Median delay (months)	Number
Autism (all responses)	27	51	24	17	(n=228)
PDDNOS	16	36	20	13	(n=13)^

Aspergers	42	82	40	36	(n=35)
ADHD[#]	33	76	43	41	(n=16)[##]

^ (1 male with delay of ~120 months excluded)
# Strictly speaking, ADHD is not classified as being on the Spectrum according to DSM IV (Diagnostic and Statistical Manual of Mental Disorders of the American Psychiatric Association). However, it was included in the Survey as some autistic children exhibit ADHD symptoms.
All male (1 female excluded)

Some parents reported multiple conditions eg Autism, ADHD, or Asperger, ADHD, in which case Autism or Asperger was taken as the prime condition.

With regard to the responses from parents of Asperger children, the average age of suspicion for males was 45 months while that for females was only 28 months. It is suspected that this may be due to a mother being able to sense there is something wrong quicker with a child of her own sex than with a boy. However, this hypothesis would require a much larger sample number to determine whether this is in fact correct. The delay in diagnosis is more than twice that for autism as a whole and nearly x3 that for PDDNOS.

Some other parents gave no diagnosis, which was either an oversight, or that they had not yet obtained one, or perhaps an indication that they preferred not to give their child a “label” of autism.

Bearing in mind the slight loss of accuracy in dates mentioned earlier, the above data regarding average age of suspicion appears to be in line with the findings that the vast majority of parents notice unusual characteristics in their ASD children within the first two years of life. De Giacomo and Fombonne[12] found that parents began to notice such symptoms at an average age of 19 months, with approximately 30% within the child’s first year. By the time a child had reached its second birthday, approximately 80% had begun to have concerns. A similar study in France[13] found the average age of recognition (AOR) was 17 months with 38% of parents being concerned about their child’s development at 12 months of age and 78% by 24 months.

Parents were asked to indicate which of the following statements best describe the reason (s) why there was a delay in diagnosis. The results are as shown in Table 5:

Table 5 Reasons for the delay in diagnosis

Delay Statement	**N=215**
GP advised just normal delay and nothing to worry about	61 (28.4%)
Paediatrician advised just normal delay and nothing to worry about	53 (24.7%)
Unable to get appointment with psychologist earlier	45 (20.9%)
Was told too young for assessment	40 (18.6%)
Never heard of autism before	33 (15.3%)
Not familiar with expected milestones	30 (14.0%)
Other	56 (26.0%)

There is some overlap in all the figures as 56 parents cited multiple reasons for the delay, the most significant overlap being that 22 parents cited both their GP and paediatrician indicated it was a “normal delay, and nothing to worry about”. This represents 10.2% of the responses. Overall, the GP or paediatric statements as shown in the table accounted for 40% of the cited delays. It is interesting to note that similar comments from health professionals were made in a survey carried out by La Trobe University researchers in 2002[14]

26.0% indicated there were “Other” reasons for the delay, and the two main features are summarised below:

- Reassurances from health professionals, including paediatricians, GPs, MCHNs (Maternal and Child Health Nurses) – 14 (6.5% of total responses)
- Reluctance to diagnose, or to accept a label of autism – 6 (2.8% of total responses).

Thus just under 50% (40%+ 6.5%) of the delays in diagnosis were due to reassurances from health professionals.

Given the research findings established in the literature referred to earlier[12 13], such results strongly suggest that the medical profession needs to become much more prepared to listen to parents concerns (and act on them in an appropriate manner), rather than just dismiss them as unnecessary worry.

The delays in getting to see a psychologist, which accounted for just over 20% of the responses are surprising given that Australia and New Zealand are generally held up as having excellent health systems.

Being “too young for assessment” (nearly 20% of the responses), serves to highlight the inadequacy of the present reliance on psychologically based diagnosis.

The Australian health system is such that parents need to obtain a referral from a GP before they can see a paediatrician or psychologist. Given the very low diagnosis by GPs (1.7%), it would appear there is an inherent delay built into the system, in obtaining a diagnosis. As they, along with MCHNs, are the first port of call for parents, it would seem appropriate that GPs and MCHNs should be properly trained in being able to recognise and diagnose autism at a very early age in order that parents, and other health professionals, may start applying early intervention. A similar system of referral applies in New Zealand, as well as in the UK. Such delays in the health system tend to be exacerbated in country areas where specialist expertise eg paediatricians and psychologists are in limited numbers, and quite widely dispersed, both in Australia and New Zealand.

A recent report by the National Audit Office in the UK[15] showed that 80% of GP’s responding to the survey “felt they required additional guidance and training to identify and manage patients with autism more effectively. In particular they mentioned a need for guidance on how to identify possible

autism, what referral protocols should be in place, (particularly for adults suspected of high functioning autism) and what services are or should be available locally". The present Survey appears to confirm similar findings in relation to the Australian, New Zealand situation, i.e. that training in identification and management appears to be inadequate, even though the proportion of doctors may not be of the same order.

Child's behaviour before diagnosis and after intervention

Overall 219 people responded to this multiple choice question relating to 75 behavioural characteristics which may be associated with autism. Parents were asked what the behaviour of their child was before diagnosis and after intervention (without specifying which therapies, or how long they had been employed), with the possibility of current behaviour ranking as "No better" "A little better", "Much better". The following data (Table 6) presents only the most common characteristics ie those for which >100 responses were obtained. They are ranked in order of number of observations with the percentages in the three right hand columns based on the "Before Diagnosis" figures.

Table 6 Child's behaviour before diagnosis and after therapy

Behaviour	Before Diagnosis (%N=219)	No Better	A Little Better	Much Better
Little or no eye contact	192 (87.7%)	16 (8.3%)	71 (37.0%)	106 (55.2%)
Poor sociability	189 (86.3%)	47 (24.9%)	87 (46.0%)	50 (26.5%)
No imaginary play	163 (74.4%)	37 (22.7%)	57 (35.0%)	71 (37.6%)
Fine motor delay (Tactile problems)	161 (73.5%)	24 (14.9%)	75 (46.6%)	61 (37.9%)
Limited span of attention	158 (72.1%)	41 (25.9%)	71 (44.9%)	46 (29.1%)
Sensitivity to noise	157 (71.7%)	39 (24.8%)	68 (43.3%)	51 (32.5%)
Fussy eater	155 (70.8%)	69 (44.5%)	49 (31.6%)	40 (25.8%)
Vacant looks	151 (68.9%)	17 (11.3%)	65 (43.0%)	70 (46.4%)
Delayed toilet training	148 (67.6%)	26 (17.6%)	32 (21.6%)	91 (61.5%)
Tantrums	146 (66.7%)	27 (18.5%)	59 (40.4%)	60 (41.1%)
Poor sleep patterns	140 (63.9%)	31 (22.1%)	39 (27.9%)	73 (52.1%)
Unwilling/unable to dress himself/herself	139 (63.5%)	20 (14.4%)	57 (41.0%)	65 (46.8%)
Does not follow pointed direction	137 (62.6%)	14 (10.2%)	61 (44.5%)	63 (46.0%)
Anxious/fearful	137 (62.6%)	38 (27.7%)	59 (43.1%)	44 (32.1%)
Lining things up	134 (61.2%)	19 (14.2%)	47 (35.1%)	66 (49.3%)
Gross motor delay	133 (60.7%)	23 (17.3%)	56 (42.1%)	52 (39.1%)

(clumsy)				
Does not look at animals or people	133 (60.7%)	9 (6.8%)	58 (43.6%)	70 (52.6%)
Does not show objects	129 (58.9%)	31 (24.0%)	31 (24.0%)	66 (51.2%)
Not pointing	126 (57.5%)	28 (22.2%)	39 (31.0%)	65 (51.6%)
Does not wave “bye bye”	123 (56.2%)	22 (17.9%)	34 (27.6%)	68 (55.3%)
Does not respond to his/her name	121 (55.3%)	3 (2.5%)	32 (26.4%)	89 (73.6%)
Delayed speech	119 (54.3%)	6 (5.0%)	33 (27.7%)	82 (68.9%)
Does not share	118 (53.9%)	28 (23.7%)	52 (18.6%)	40 (33.9%)
High pain threshold	115 (52.5%)	39 (33.9%)	48 (41.7%)	34 (29.6%)
Shouts/screams	115 (52.5%)	19 (16.5%)	44 (38.3%)	57 (49.6%)
Prefers to be left alone	113 (51.6%)	23 (20.4%)	51 (45.1%)	42 (37.2%)
Poor muscle tone	113 (51.6%)	24 (21.2%)	58 (51.3%)	33 (29.2%)
Rigid routines	111 (50.7%)	28 (25.2%)	53 (47.7%)	33 (29.7%)
Does not imitate	110 (50.2%)	20 (18.2%)	39 (35.5%)	52 (47.3%)
Flapping hands	107 (48.9%)	13 (12.1%)	36 (33.6%)	62 (57.9%)
Food sensitivities	106 (48.4%)	37 (34.9%)	48 (45.3%)	26 (24.5%)
Hyperactivity	101 (46.1%)	30 (29.7%)	45 (44.6%)	28 (27.7%)
Repetitive actions (stimming/rocking)	100 (45.7%)	23 (23.0%)	43 43.0%)	40 (40.0%)

It will be noticed that not all percentages add up to 100% owing to parent input errors.

Thus it is clear that therapy does bring about improvement over time in the majority of cases. As can be seen, the highest percentages where there was no improvement are:

- Fussy eater (44.5%)
- Food sensitivities (34.9%)
- High pain threshold (33.9%)
- Hyperactivity (29.7%)

Rather surprisingly, the above table does not contain a number of typical autistic features noted in the literature such as echolalia, speech loss. Table 7 lists those characteristics noted by 50-99 respondents, and it will be observed that it contains many of these typical autistic traits.

Table 7 Less common child behaviours before and after therapy

Behaviour	Before Diagnosis (%N=219)	No Better	A Little Better	Much Better
Unsteady walk or	94 (42.9%)	16 (17.0%)	33 (35.1%)	50 (53.2%)

toe walking				
Diarrhoea	93 (42.5%)	15 (16.1%)	25 (26.9%)	55 (59.1%)
Unhappy/crying	92 (42.0%)	14 (15.2%)	36 (39.1%)	51 (55.4%)
Little facial expression/smiling	92 (42.0%)	6 (6.5%)	40 (43.5%)	48 (52.2%)
Aggression towards others	91 (41.6%)	23 (25.3%)	42 (46.2%)	28 (30.8%)
Lack of affection	87 (39.7%)	10 (11.5%)	27 (31.0%)	51 (58.6%)
Mouthing objects	87 (39.7%)	22 (25.3%)	34 (39.1%)	36 (41.4%)
Ear infections	87 (39.7%)	8 (9.2%)	13 (14.9%)	67 (77.0%)
“Bags” or purple patches under eyes	82 (37.4%)	25 (30.5%)	32 (39.0%	32 (39.2%)
Constipation	81 (37.0%)	22 (27.2%)	23 (28.4%)	38 (46.9%)
Verbal stimming	79 (36.1%)	16 (20.3%)	38 (48.1%)	31 (39.2%)
Teeth grinding	79 (36.1%)	24 (30.4%)	33 (41.8%)	27 (34.2%)
Unable or unwilling to self feed	78 (35.6%)	9 (11.5%)	51 (65.4%)	22 (28.2%)
Unusual interest in spinning objects	77 (35.2%)	20 (26.0%)	23 (29.9%)	38 (49.4%)
Allergies	74 (33.8%)	28 (37.8%)	28 (37.8%)	21 (28.4%)
No speech	73 (33.3%)	6 (8.2%)	30 (41.1%)	44 (60.3%)
Unusual interest in switches/ electrical equipment	73 (33.3%)	15 (20.5%)	29 (39.7%)	35 (47.9%)
Obsessive speech	70 (32.0%)	16 (22.9%)	41 (58.6%)	21 (30.0%)
Speech loss	68 (31.1%)	13 (19.1%)	18 (26.5%)	31 (45.6%)
Unusual interest in water	68 (31.1%)	26 (38.2%)	30 (44.1%)	18 (26.5%)
Bed wetting	68 (31.1%)	28 (41.2%)	9 (13.2%)	32 (47.1%)
Destructive	66 (30.1%)	16 (24.2%)	29 (43.9%)	26 (39.4%)
Unusual interest in lights	63 (28.8%)	17 (27.0%)	21 (33.3%)	29 (46.0%)
Head banging	62 (28.3%)	8 (12.9%)	16 (25.8%)	42 (67.7%)
Eczema	62 (28.3%)	15 (24.2%)	21 (33.9%)	26 (41.9%)
Unusual interest in numbers	62 (28.3%)	21 (33.9%)	26 (41.9%)	18 29.0%)
Night sweats	59 (26.9%)	18 (30.5%)	26 (44.1%)	20 (33.9%)
Self injury other eg biting	58 (26.5%)	15 (25.9%)	28 (48.3%)	21 (36.2%)

From the above table it can be seen that the most intractable characteristics appear to be:

- Bed wetting (41.2%)
- Unusual interest in water (38.2%)
- Allergies (37.8%)

- Unusual interest in numbers (33.9%)
- Night sweats (30.5%)
- “Bags’ or purple patches under eyes (30.5%)
- Teeth grinding (30.4%)

All the above mentioned improvements are time dependent and it may well be that many of those parents who registered in the “No better “or “A little better” columns will eventually see some improvement.

The remaining conditions which attracted less than 50 responses in descending order were as follows:

Slow eater (48)
Fast eater (47)
Lethargy (47)
High pitched voice (39)
Rashes (37)
Pica (Eating abnormal products eg coal, paint) (34)
Asthma (27)
Rolling eyes (18)
Sick after eating (18)
Urinary tract infections (18)
Seizures (14)
Psoriasis (6)

The most commonly reported characteristics of Asperger children were as shown in Table 8

Table 8 Most commonly reported characteristics in Aspergers Syndrome

Behaviour	Male (N=27)	Female (N=8)	Total (% of N=35)
Little or no eye contact	18 (66.7%)	6 (75.0%)	24 (69)
Gross Motor (Clumsy)	17 (63.0%)	5 (62.5%)	22 (63)
Sensitivity to noise	21 (77.8%)	5 (62.5%)	26 (74)
Poor sleep	14 (51.9%)	7 (87.5%)	21 (60)
Fussy eater	17 (63.0%)	8 (100.0%)	25 (71)
Poor sociability	21 (77.8%)	4 (50.0%)	25 71)
Tantrums	16 (59.3%)	5 (62.5%)	21 (60)
Anxious/fearful	18 (66.7%)	5 (62.5%)	23 (66)

It is interesting to note that the ratio of male:female is ~4:1 as for the ASD population as a whole. Also noteworthy is the fact that all female Aspergers were fussy eaters, although this is based on an extremely small sample.

Therapies used in the treatment of ASD

For the purposes of this report, these therapies can be split into two categories:

- Non-biomedical
- Biomedical

Non-biomedical therapies tend to be those offered by psychologists based on behavioural research eg ABA as proposed by Ivar Lovaas[16 17], or some form of physical manipulation eg as in cranial osteopathy or sensory/auditory stimulation.

Biomedical therapies are those which involve dietary intervention, supplements and/or pharmaceuticals, and chelation (to remove heavy metals such as mercury and lead or other environmental toxins). The father of the biomedical approach was Dr Bernard Rimland[18 19], a psychologist with an autistic son. Such therapy is based on the evidence of biochemical imbalances obtained by testing blood, faeces, urine and hair, as well as genes. Many ASD children have co-morbidities which researchers are increasingly suggesting are indicators of the basic cause of autism.[20 21 22 23]

Both types of therapy have their uses, and in fact most parents using the biomedical approach also use non-biomedical therapies, especially speech and occupational therapy. So long as they see progressive improvements in their child, and their financial situation permits, they will generally continue with the therapies they believe are effective, and in fact may look around for more in order to achieve a particular behavioural or health benefit.

Non-Biomedical Therapies Used

Parents were asked to indicate which non-biomedical therapies their child had received, or were receiving. Non-biomedical therapy was defined as not involving any special diet, use of supplements or pharmaceuticals. This is another multiple choice question, with results as shown in Table 9. Details of "Other" therapies are provided in Table 10.

Note: Except where stated, the data and discussion provided under the following paragraphs relating to non-biomedical therapies apply to all parents who responded to the survey, and not just those who use only non-biomedical therapies.

Table 9 Non-biomedical therapies being used

Therapy	Using/used (N=219)
Speech	165 (75.3%)
Occupational	138 (63.0%)
ABA (Applied Behavioural Analysis)	76 (34.7%)
Sensory Integration	63 (28.8%)
Auditory Stimulation (Tomatis or	39 (17.8%)

other)	
Cranial Osteopathy	35 (16.0%)
Kinesiology	29 (13.2%)
Floortime	26 (11.9%)
NAET (Nambudripad's Allergy Elimination Techniques)	20 (9.1%)
Neurotherapy	14 (6.4%)
Vision (eg Irlen lenses)	7 (3.2%)
Son-Rise program	2 (0.9%)
Other	72 (32.9%)

Table 10 "Other" non-biomedical therapies being used

Main "Other" therapies	**Using/used (N=219)**
RDI® (Relationship Development Intervention)	20 (9.1%)
Miscellaneous applied psychology	18 (8.2%)
Biomedical intervention#	9 (4.1%)
Chiropractic	6 (2.7%)
Homeopathy#	6 (2.7%)

Parents indicated various biomedical and homeopathic interventions in this section which are covered later in the survey.
NB A few parents indicated they were not using any therapy.

41 parents reported using **only** non-biomedical therapies, of whom

- 82.9% used Speech Therapy (ST)
- 68.3% used Occupational Therapy (OT)
- 36.6% used ABA
- 22.0% used Sensory Integration.

The average number of therapies used per child was 2.4 (median 2) with ST and OT featuring predominantly.

Source of influence regarding therapy used

Parents were asked "Who or what influenced you to use any of the previously mentioned non-biomedical therapies?"

215 responses were received, the prime source of influence being the internet as shown in Table 11:

Table 11 Source of influence for use of non-biomedical therapies

Source of influence	**N=215**
Found out from the internet	92 (42.8%)
Paediatrician	86 (40.0%)
Read a book	68 (31.6%)

Friend or family other than grandparent	55 (25.6%)
Psychologist	49 (22.8%)
Article in a newspaper/journal	26 (12.1%)
General Practitioner	24 (11.2%)
Naturopath	20 (9.3%)
TV program	8 (3.7%)
Dietician	5 (2.3%)
Grandparent	3 (1.4%)
Pharmacist	1 (0.5%)
Other	57 (26.5%)

As this was a multiple choice question, many parents indicated several sources of influence. The lack of grandparent influence is quite remarkable, and may be attributed to the lack of any knowledge about autism in their days of child rearing, and also possibly such issues as the dispersed and diverse nature of families at the present time, compared with say, 30-40 years ago.

Analysis of the “Other” responses is as shown in the following Table 12 (main replies only)

Table 12 “Other” sources of influence – non-biomedical therapy use

Source of influence	**N=215**
Support groups/autism societies/Early Intervention centres	12 (5.6%)
School/kindergarten/teacher	8 (3.7%)
MCHN, Nurse	5 (2.3%)
Speech therapist/pathologist	4 (1.9%)

In terms of those parents using only non-biomedical therapies (N=41), the responses were as shown in Table 13 in descending order of importance.

Table 13 Sources of influence on parents using only non-biomedical therapies

Source of influence	**N=41**
Paediatrician	17 (41.5%)
Psychologist	11 (26.8%)
Found out from the internet	7 (17.1%)
Read a book	7 (17.1%)
Friend or family other than grandparent	4 (9.8%)
General Practitioner	3 (7.4%)
Article in a newspaper/journal	3 (7.4%)
TV program	1 (2.4%)
Naturopath	0
Grandparent	1 (2.4%)
Dietician	0

Pharmacist	0
Other[#]	10 (24.4%)

The main “Other” influences were support groups and Early Intervention programs. Others mentioned were occupational therapist, speech therapist, teacher, autism community seminars.

Length of time using therapies

Parents were asked how long they had been using non-biomedical therapies. The results are as shown in Table 14 in descending order of the numbers using the therapies. There were 211 responses. Figures are given in percentages except in the final column which is the number who replied.

Table 14 Length of time using non-biomedical therapies

Therapy	0-6 months	6-12 months	1-2 years	3-5 years	>5 years	Count
Speech	15.6	13.0	33.1	25.3	13.0	154
Occupational	20.3	18.0	25.8	25.8	10.2	128
ABA	23.4	15.6	26.0	27.3	7.8	77
Other	19.7	19.7	27.9	23.0	9.8	61
Sensory Int.	14.3	16.1	33.9	23.2	12.5	56
Auditory	44.7	18.4	23.7	13.2	0.0	38
Cranial Ost.	51.4	22.9	17.1	5.7	2.9	35
Kinesiology	53.3	13.3	16.7	16.7	0.0	30
Floortime	36.0	32.0	16.0	16.0	0.0	25
N.A.E.T	52.4	23.8	19.0	4.8	0.0	21
Neurotherapy	42.9	21.4	21.4	14.3	0.0	14
Vision	50.0	33.3	0.0	0.0	16.7	6
Son-Rise	60.0	40.0	0.0	0.0	0.0	5

The above statistics show a rather unusual pattern in that the speech, occupational, ABA, and auditory therapy usages for 0-6 months are much higher than for the 6-12 month period, but then pick up again in the 1-2 year period. On the other hand, the cranial, kinesiology, N.A.E.T, and neurotherapy treatments appear to drop off very steeply after 6 months, perhaps being a measure of their perceived or actual effectiveness (see table 13 below), and/or their cost. Speech, occupational, ABA, and sensory integration therapies tend to be used by about 50-60% of the respondents for between1-5 years with a suspected strong prospect of ongoing therapy after this period.

The length of time spent on a therapy will depend on many factors including the age of the child, the perceived effectiveness, the cost, whether other therapies appear on the market, support systems, perceived guilt factors. For example, ABA has been promoted for many years as the only evidence based therapy for autism, and therefore presented to parents as being the only therapy they should be using, even though, along with all the other therapies, (see Table 15 below[#]) it does not have a 100% success record. This subject

alone i.e. why parents continue to use some therapies and not others, would benefit from further study that is beyond the scope of the present paper.

(# RDI® figures, although indicating an apparent exception, are based on a very limited number of responses).

How helpful/effective have you found non-biomedical treatments to be?

Parents were asked to rate the treatments as one of the following:

- Not helpful/effective
- Mildly helpful/effective
- Moderately helpful/effective
- Very helpful/effective

The results (in percentages) are as shown in Table 15 where h/e = helpful/effective (N=213)

Table 15 Helpfulness or effectiveness of non-biomedical therapies

Therapy	Not h/e	Mildly h/e	Moderately h/e	Very h/e	Total
Speech	15 (9.5%)	36 (22.8%)	48 (30.4%)	59 (37.3%)	158
Occupational	9 (6.8%)	38 (28.6%)	39 (29.3%)	47 (35.3%)	133
ABA	6 (7.7%)	10 (12.8%)	26 (33.3%)	36 (46.2%)	78
Sensory Integration	7 (11.9%)	9 (15.3%)	20 (33.9%)	23 (39.0%)	59
Cranial Osteopathy	10 (26.3%)	13 (34.2%)	9 (23.7%)	6 (15.8%)	38
Auditory stimulation (Tomatis or other)	9 (25.0%)	7 (19.4%)	14 (38.9%)	6 (16.7%)	36
Kinesiology	11 (35.5%)	6 (19.4%)	6 (19.4%)	8 (25.8%)	31
Floortime	2 (7.7%)	9 (34.6%)	7 (26.9%)	8 (30.8%)	26
N.A.E.T.	11 (45.8%)	4 (16.7%)	7 (29.2%)	2 (8.3%)	24
Other (RDI only)	0.0	2(13.3%)	2 (13.3%)	11 (73.3%)	15#
Neurotherapy	3 (21.4%)	7 (50.0%)	1 (7.1%)	3 (21.4%)	14
Vision eg Irlen lenses	5 (71.4%)	2 (28.6%)	0.0	0.0	7
Son-Rise program	2 (66.7%)	0.0	0.0	1 (33.3%)	3

Of the 20 parents who gave RDI® as an “Other” therapy, four did not provide an answer to this question and one had indicated a number of (“Other”) therapies, and not just RDI®, so this response was not included. However, based on these extremely limited responses recorded, the figure of 73.3% for “Very Helpful/Effective” and 0% “Not helpful/remarkable,” is noteworthy. The

very limited numbers relating to the last four therapies in the list are not helpful from a statistical point of view.

Therapies may be compared by dividing their helpfulness/effectiveness (Moderate plus Very) and (Mildly+ Moderately + Very) percentages by the percentages in the Not Helpful/effective columns, the ratios are as shown in table 16:

Table 16 Comparative helpfulness/effectiveness non-biomedical therapies

Therapy	(Moderate+ Very)/Not	(Mild+ Moderate + Very)/Not	Count
Speech	7.1	9.5	158
Occupational	9.5	13.7	133
ABA	10.3	12.0	78
Sensory Integration	6.1	7.4	59
Cranial Osteopathy	1.5	2.8	38
Kinesiology	1.3	1.8	31
Auditory stimulation (Tomatis or other)	2.2	3.0	36
Floortime	7.5	12.0	26
N.A.E.T.	0.8	1.2	24

Thus it would appear that parents would do well, at least initially, to concentrate on Speech and Occupational therapies, ABA, Sensory Integration, and Floortime, although the data for Floortime are very limited.

Speed of Improvement using Non-Biomedical Therapies

Parents were asked how soon the above therapies were effective/helpful with regard to the child's behaviour? This question is important as parents will generally tend to continue using a therapy if they can see an early change in behaviour. 212 parents replied to this question (N=212)

The options offered were

- No apparent improvement after one month
- Some apparent improvement after one month
- Within improvement within 1-4 weeks
- Immediate improvement (within one week)

The data are presented in Table 17 as percentages of the total for each treatment.

Table 17 Speed of behavioural improvement of non-biomedical therapies

Therapy	None after 1 month	Some after 1 month	1-4 weeks	1 week	Total
Speech	44 (28.0%)	73 (46.5%)	31 (19.7%)	9 (5.7%)	157
Occupational	32 (25.4%)	63 (50.0%)	21 (16.7%)	10 (7.9%)	126
ABA	11 (13.9%)	36 (45.6%)	19 (24.1%)	13 (16.5%)	79
Sensory Integration	16 (26.7%)	22 (36.7%)	15 (25.0%)	7 (11.7%)	60
Cranial Osteopathy	8 (25.8%)	6 (19.4%)	7 (22.6%)	10 (32.3%)	31
Kinesiology	9 (34.6%)	7 (26.9%)	6 (23.1%)	4 (15.4%)	26
Auditory stimulation (Tomatis or other)	12 (34.3%)	6 (17.1%)	12 (34.3%)	5 (14.3%)	35
Floortime	4 (16.0%)	9 (36.0%)	10 (40.0%)	2 (8.0%)	25
N.A.E.T.	10 (50.0%)	4 (20.0%)	4 (20.0%)	2 (10.0%)	20
Other (RDI® only)	1 (5.9%)	5 (29.4%)	6 (35.3%)	5 (29.4%)	17
Neurotherapy	4 (28.6%)	5 (35.7%)	4 (28.6%)	1 (7.1%)	14
Vision eg Irlen lenses	6 (100.0%)	0.0	0.0	0.0	6
Son-Rise program	2 (50.0%)	0.0	0.0	2 (50.0%)	4

The speed of change in behaviour will depend very much on how much therapy is delivered each week, and this question (ie how much therapy/week) was not asked of the parents in order to try to keep the questionnaire as simple as possible. Speech and occupational therapy appear to be effective on a long term basis compared to ABA, but then they are probably not applied with the same intensity as ABA.

Comparing Tables 15 and 17, it is important to note the speed of improvement is not the same as the effectiveness or helpfulness.

Table 18 compares the apparent effectiveness (by adding the three columns to the left of the total in Table 16) with the apparent lack of effect after one month (the column to the right of the designated therapy).

Table 18 Comparative speed of effectiveness of non-biomedical therapies

Therapy	Ratio Apparent effect/No apparent effect, after one month	Number (N=212)
Speech	2.6	157
Occupational	2.9	126
ABA	6.2	79
Sensory Integration	2.8	60
Cranial Osteopathy	2.9	31
Kinesiology	1.9	26
Auditory stimulation (Tomatis or other)	1.9	35
Floortime	5.3	25
N.A.E.T.	1.0	20
Other (RDI® only)	15.9	17
Neurotherapy	2.5	14
Vision eg Irlen lenses	0.0	6
Son-Rise program	1.0	4

These ratios need to be viewed with caution, especially where <50 replies have been received. Of those with >50 replies, ABA stands out as being very effective. However, this may be due to the intense nature of the treatment which is normally recommended at a rate of at least 20 hrs/week, and sometimes up to 40 hrs/week. It is quite possible that many of the other therapies, particularly speech and occupational therapy would show similar improvements, if they too were being applied at this tempo. Perhaps the relevant therapists have been too complacent about the intensity of applying these therapies in the case of ASD children? Alternatively, if ABA were to be delivered for only 2-3 hours a week, as is typical of ST and OT, then perhaps it too would result in a lower ratio than indicated above.

There are insufficient data to draw any firm conclusions about the other therapies, although it would appear that cranial osteopathy, auditory stimulation, Floortime, and RDI® may offer noticeable improvements within one month. Much more data is required.

Another way of looking at these therapies is to examine whether any behavioural improvement is seen within a month by adding together only the first two columns to the left of the Total column in Table 17. The results are shown in Table 19

Table 19 Behavioural improvement within one month non-biomedical therapies

Therapy	% Improvement within one month	N
Speech	25.4	157
Occupational	24.6	126

ABA	40.6	79
Sensory Integration	36.7	60
Cranial Osteopathy	54.9	31
Kinesiology	38.5	26
Auditory stimulation (Tomatis or other)	48.6	35
Floortime	48.0	25
N.A.E.T.	30.0	20
Other (RDI® only)	94.7	17
Neurotherapy	35.7	14
Vision eg Irlen lenses	0.0	6
Son-Rise program	50.0	4

Again, for those therapies with >50 replies, the stand out therapy is ABA, with Sensory Integration not far behind, in terms of speed of improvement. Of those drawing 25 responses or more, all except kinesiology appear to provide noticeable improvement in about 45-55% of the cases, though the reported numbers are very low. Kinesiology would appear to be on a par with sensory integration, though more data are required. As a reminder, these data are based on responses from all parents, and not just those using only non-biomedical therapies.

Biomedical Treatment

For the purposes of the survey, parents were advised that biomedical treatment was to be understood as the intake or avoidance of specifically designated foods and/or supplements, and/or the removal of toxic metals, as well as the use of pharmaceuticals.

Before examining the nature of biomedical treatment in detail it is interesting to compare the parents' parallel use of non-biomedical therapies.

A total of 148 responses were received indicating a use of one or more non-biomedical therapy. The average number of biomedical therapies used (including the biomedical therapy itself) was 4.3 compared with 2.4 for those parent using only non-biomedical therapies. The median number was 3 cf 2 for the non-biomedical users. Table 20 compares the two populations in terms of percentages using each therapy:

Table 20 Percentages of parents using only non-biomedical therapy or a combination of non- and biomedical therapies

Therapy	Non-biomedical only (N=41)	Non-biomedical and biomedical therapies (N=148)
Speech	82.9	76.4
Occupational	68.3	64.2
ABA	36.6	35.8
Sensory	22.0	28.4

Floortime	7.3	13.5
Auditory	2.4	25.7
Kinesiology	3.3	17.6
Vision	0.0	2.0
Neurotherapy	0.0	6.8
Cranial Osteopathy	0.0	23.6
N.A.E.T.	0.0	13.5
Son-Rise	0.0	1.3
Biomedical	0.0	100.0

Notes

1. 3 biomedical parents indicated no non-biomedical therapies for their children. It is not known whether this was an oversight, or that they do not think it necessary.
2. 10.1% of parents using biomedical therapy also used RDI®.

The figures for speech therapy (82.9% and 76.4%) are broadly in line with the 70% found by Green et al.[5] as are those for ABA (36.6% and 35.8%) cf 36.4%. Occupational therapy was not included in the Green survey, so no comparison is possible. However, Green found 38.2% of respondents used sensory integration which is considerably higher than the figures in the present survey.

Clearly there is a significant difference between the two parent populations with biomedical parents investing much more in Floortime, Auditory therapy, Kinesiology, Neurotherapy, Cranial Osteopathy, and N.A.E.T., in addition to the biomedical therapy. Factors such as

- availability of services eg in the cities c.f. the country areas
- parental wealth
- parental education
- government funding
- acceptance of the health professionals (limited) recommendations (ie they know best)
- quality of health professionals' specific autism education

and no doubt many others play a part in the decision making process as to how parents can do the best to help their children.

Parents were asked who or what influenced them to try a biomedical approach. The results are as shown in Table 21:

Table 21 Source of influence for use of biomedical therapies

Source of influence	**N=165**
Internet information	95 (57.6%)
Read a book about biomedical therapy	64 (38.8%)
Friend or family other than	51 (30.9%)

grandparent	
Article in newspaper/journal	29 (17.8%)
Naturopath	25 (15.2%)
Paediatrician	20 (12.1%)
Psychologist	17 (10.3%)
General Practitioner	12 (7.3%)
Dietician	9 (5.5%)
TV programme	7 (4.2%)
Grandparent	6 (3.6%)
Pharmacist	1 (0.6%)
Other	30 (18.2%)

As with the non-biomedical question along the same lines, this was a multiple choice question so many parents gave more than one answer. With reference to the "Other" influences there were 6 references to other parents, or parent support groups, and 4 references to the MINDD# Conferences.

MINDD Metabolic Immunologic Neurologic Digestive Disorders (www.mindd.org)

Table 22 compares the influences (in percentage terms) impacting in those parents using only non- biomedical therapies with those who use biomedical and, though not necessarily, non-biomedical therapies.

Table 22 Comparison of sources of influence on parents using non-biomedical, both therapies or biomedical alone

Source of influence	Non-biomedical only (N=41)	Both types of therapies or biomedical alone (N=165)
Internet information	17.1	57.6
Read a book	17.1	38.8
Friend or family other than grandparent	9.8	30.9
Article in newspaper/journal	7.3	17.8
Naturopath	0.0	15.2
Paediatrician	41.5	12.1
Psychologist	26.8	10.3
General Practitioner	7.3	7.3
Dietician	0.0	5.5
TV programme	2.4	4.2
Grandparent	2.4	3.6
Pharmacist	0.0	0.6
Other	24.4	18.2

It is disappointing that the survey has reached so few parents using only non-biomedical therapies, which are believed to be in the majority in the community, as this makes statistically valid comparison of the influences

difficult. However, as can be seen, there are major differences in influence in such areas as sourcing information from the internet, reading books, paediatric and general practitioner advice.

Length of Time Receiving Biomedical Treatment

Parents were asked how long their child had been receiving biomedical treatment? This question is frequently asked in biomedical parent support meetings and chatrooms. The simple answer is that each child biomedical intervention depends on its biochemical makeup and speed of progress. 165 people replied. The results are as shown in Table 23:

Table 23 Length of time receiving biomedical treatment

Years/months	Number (%)
0-6 months	32 (19.4%)
6-12 months	21 (12.7%)
1-2 years	48 (29.1%)
3-5 years	49 (29.7%)
>5 years	15 (9.1%)

The higher percentage for the 0-6 month period may be explained by the fact that a number of parents try the biomedical approach, and when they do not see any immediate beneficial effect, they drop the treatment. The data also show that some parents just try one aspect such as a gluten free diet, or A2 milk and see no benefit. Some diets and supplements just do not result in any external signs of improvement, though they may well be providing internal beneficial effects.

Dietary Therapies

Parents were asked what types of diets they had tried or used, and their effectiveness (in terms of behavioural improvement)? The results are as shown in Table 24, bearing in mind that many parents try a number of different diets to find which one best suits their child:

Table 24 Dietary therapies and their effectiveness

Diet	No apparent effect after 1 month	Some apparent effect after 1 month	Some effect within 1-4 weeks	Immediate effect (within 1 week)	Total (N=167)
Casein Free (CF)	18 (21.7%)	17 (20.5%)	20 (24.1%)	28 (33.7%)	83
Gluten free (GF)	17 (20.2%)	28 (33.3%)	19 (22.6%)	20 (23.8%)	84
GF/CF	21 (21.9%)	19 (19.8%)	29 (30.2%)	27 (28.1%)	96
GF/CF/Soy free (SF)	12 (17.9%)	12 (17.9%)	16 (23.9%)	27 (40.3%)	67
GF/CF/SF/low oxalate	5 (22.7%)	5 (22.7%)	4 (18.2%)	8 (36.4%)	22

Low oxalate	6 (30%)	4 (20%)	7 (35%)	3 (15%)	20
Specific Carbohydrate diet (SCD)	6 (21.4%)	7 (25.0%)	7 (25.0%)	8 (28.6%)	28
Feingold[#]	5 (45.5%)	4 (36.4%)	2 (18.2%)	0 (0%)	11
Chocolate removed	10 (27.0%)	5 (13.5%)	8 (21.6%)	14 (37.8%)	37
Eggs removed	14 (48.3%)	4 (13.8%)	4 (13.8%)	7 (24.1%)	29
Rotation	4 (30.8%)	1 (7.7%)	6 (46.2%)	2 (15.4%)	13
Sugar removed	11 (19.3%)	8 (14.0%)	18 (31.6%)	20 (35.1%)	57
A2 milk	20 (54.1%)	6 (16.2%)	2 (5.4%)	9 (24.3%)	37
Non-allergenic	3 (12.5%)	5 (20.8%)	6 (25%)	10 (41.7%)	24
Salicylate free	7 (19.4%)	5 (13.9%)	11 (30.6%)	13 (36.1%)	36
Other	2 (7.7%)	5 (19.2%)	4 (15.4%)	15 (57.7%)	26

Feingold diet seeks to eliminate all artificial or synthetic colouring, flavouring, and preservatives, as well as aspartame as an artificial sweetener.[24] It is primarily directed at individuals with ADHD.

It is interesting to note, as with non-biomedical interventions, that in the population surveyed, none of these diets appear to provide any noticeable change in behaviour after a month for **all** ASD children. No one therapy fits all children's needs.

The above data may be presented in terms of ratios showing [apparent effect/no apparent effect] by taking the three columns to the left of the Total and dividing them by column to the right of the diet, in which no apparent effect was seen after one month. The results are shown in Table 25 in descending order of number of responses (except for "Other" – see below):

Table 25 Comparison of diet effectiveness vs no apparent effect

Diet	Apparent effect/no apparent effect	Number
GF/CF	3.56	96
Gluten free (GF)	3.95	84
Casein Free (CF)	3.61	83
GF/CF/Soy free (SF)	4.58	67
Sugar removed	4.18	57
Chocolate removed	2.70	37
A2 milk	0.85	37
Salicylate free	4.15	36
Eggs removed	1.07	29
Specific Carbohydrate diet (SCD)	3.67	28
Non-allergenic	7.00	24
GF/CF/SF/low oxalate	3.41	22
Low oxalate	2.33	20
Rotation	2.25	13
Feingold	1.20	11

Other[#]	11.99	26

The “Other” diets were not specified in the responses received, and so have no value for the purposes of this exercise.

Speed of change using non-biomedical and biomedical therapies.

There were not enough responses from parents using only non-biomedical intervention in order to come to any statistical conclusions about the real speed of change for individual therapies, except perhaps with regard to speech and occupational therapy. (For instance, there were only 15 people, or ~20% of the total number using ABA, using only non-biomedical therapies, and of those only 11 gave an indication of speed of improvement). The results are as shown in Table 26 in percentages (except for Count) where ST = Speech Therapy and OT= Occupational Therapy:

Table 26 Comparative speed of improvement in behaviour using speech and occupational therapy, with and without biomedical therapy

Therapy	None after 1 month	Some after 1 month	1-4 weeks	1 week	Count
ST (non-biomed)	41.4	44.8	10.3	3.4	29
ST (biomed)	32.8	46.6	17.6	3.1	131
OT (non-biomed)	37.5	41.7	12.5	8.3	24
OT (biomed)	27.2	46.5	19.3	7.0	114

The main differences between the two sets of results are that with the biomedical approach, both ST and OT appear to develop more rapidly within the first month - 20.7% vs 13.7% and 26.3% vs 20.8% respectively. Speech improvement is likely to be influenced by which particular biomedical therapy is being used. At the present time Methyl B_{12} injections are being promoted as an aid to speech by Dr James Neubrander[25]. 50% of the responses (n=36) (see later under section on supplements) from parents using Methyl B_{12} indicated a behavioural improvement within one month. A further 19.4% indicated some improvement after one month, while a similar percentage said there was no improvement, and 11.1% said their child got worse, though whether this was in terms of speech or some other behavioural issue, is not known. As nearly all parents apply multiple therapies, especially the biomedical parents, it is not possible to conclude from the broad data in this survey that Methyl B_{12} is in fact the key factor. As can be seen, speech therapy is usually a long term investment where approximately 80-90% of parents do not see any improvement within one month.

The differences in percentages for “None after 1 month” for both ST and OT in this table may be significant, but more data from the parents using only non-biomedical therapies is required.

Another way of looking at these results is to compare the apparent improvement in behaviour (by adding the three columns to the left of Count) with the “No apparent effect after 1 month” column as shown in Table 27

Table 27 Apparent effectiveness vs non-effectiveness after one month

Therapy	Ratio apparent effect/No apparent effect after 1 month	N
Speech (non-biomed)	1.4	29
Speech (biomed)	2.0	131
Occupational (non-biomed)	1.7	24
Occupational (biomed)	2.7	114

Comparison with ARI Survey Data

The above answers on the effectiveness in bringing about a change in a child’s behaviour show considerable differences to the data being collected by the Autism Research Institute in the USA since 1967[4] mentioned in the Introduction. Table 28 compares the two sets of results with behavioural data in percentage terms. Note the columns titled “No effect” may well be different as the Australian/NZ data refer to the “No apparent effect after one month” as shown in Table 24. The ARI survey does not specify a time limit, and is therefore probably not a valid comparison.

Table 28 Comparison dietary results with ARI Parent Ratings Survey

			USA					Aus/NZ	
Diet	**Got worse**	**No effect**	**Got better**	**Better/No effect**	**N_1**	**No effect**	**Got better**	**Better/No effect**	**N_2**
CF	2	46	52	1.1	6360	21.7	78.3	3.6	83
GF	2	47	51	1.1	3774	20.2	79.8	4.0	84
GF/CF	3	31	66	2.1	2561	21.9	78.1	3.6	96
SCD	7	24	69	2.9	278	21.4	78.6	3.7	28
Feingold	2	42	56	1.3	899	45.5	54.5	1.2	11
Chocolate free	2	47	51	1.1	2021	27.0	73.0	2.7	37
Egg free	2	56	41	0.7	1386	48.3	51.7	1.1	29
Rotation	2	46	51	1.1	938	30.8	69.2	2.3	13
Sugar free	2	48	50	1.0	4187	19.3	80.7	4.2	57

N_1 = Numbers of responses in USA
N_2 = Number of responses in Australia/New Zealand

It is interesting to note that in all cases except Feingold, the ratios for “Got better/No effect” are higher in Australia and New Zealand than in the USA. However, the Feingold (and Rotation) diet data for Australia and New Zealand are extremely low.

The range of ratios N_1/N_2 for each diet is between 26.7 for GF/CF diet and 81.7 for Feingold diet. The SCD ratio is very low at 9.9 suggesting that it is perhaps a more popular choice in Australia and New Zealand than Feingold.

Strictly speaking, the ARI survey reports on the basis of “Removed Milk Products/Dairy, Removed wheat”, which are not necessarily the same as the strictly gluten/casein free diets as generally understood and practised in Australia/New Zealand. Similarly “Removed chocolate, removed eggs, removed sugar” may mean different things to different parents in terms of whether products may contain these items, or whether it is just preventing the eating of chocolate, eggs and sugar as separate, clearly identifiable items. Despite these differences, and given that the ARI survey was one of the inspirations for the present project, it was thought worthwhile to include some of the findings in this report.

NB The ARI survey does not provide any information regarding soy free, low oxalate, non-allergenic, or A2 diets.

Considering these dietary interventions, the gluten, casein, and soy free, SCD diets, and the sugar removed diet, indicate an approximate 4:1 ratio of improvement to “no effect”. It would be surprising if such a ratio were explicable simply in terms of a placebo effect.

Effectiveness of supplements and other biomedical treatments in terms of significant behavioural improvement, whether in speech or other effects.

Dietary restriction eg to a gluten and casein free diet can lead to a deficiency in certain nutritional elements such as proteins and minerals. Consequently all parents using dietary therapies need to provide their children with supplements in order to compensate for such deficiencies. Many children also exhibit enzyme deficiencies thought to be due to the presence of heavy metals, such as mercury and lead, poisoning their biochemical systems, and leading to downstream anomalies which give rise to abnormal behaviours. These need to be treated using chelation or other means of encouraging their removal, eg by using the Pfeiffer protocol[26] which involves the use of zinc and other nutrients, followed by the gradual introduction of metallothionein (MT) promotion formulations.

A long list (81) of supplements and treatments was offered for parents to indicate which appeared to benefit the child after 1 week, 1-4 weeks, >1 month. They were also asked to indicate whether their child got worse, or showed no apparent benefit. Only those responses for which more than 25

replies were received are reported in Table 29 below in descending order of number of responses. All figures are percentages except for the Total column.

Table 29 Speed of behavioural improvement with supplements

Supplement or Treatment	Got worse	No apparent effect> 1 month	Some apparent effect >1 month	Some effect within 1-4 weeks	Immediate effect within 1 week	Total (N=160)
Zinc	3.3	11.1	27.8	28.9	28.9	90
Epsom salt baths	10.3	20.7	18.4	24.1	26.4	87
Cod liver oil	4.9	14.6	28.0	36.6	15.9	82
Probiotics	7.4	12.3	28.4	21.0	30.9	81
Fish oil	5.1	23.1	23.1	29.4	19.2	78
Magnesium	7.4	5.9	23.5	29.4	33.8	68
Enzymes	4.8	12.9	19.4	25.8	37.1	62
Essential Fatty acids (EFA/DHA)	3.2	19.4	25.8	32.3	19.4	62
Calcium	12.0	32.0	16.0	26.0	14.0	50
Multimineral supplements	12.2	8.2	26.5	26.5	26.5	49
Homeopathy	6.1	12.2	24.5	14.3	42.9	49
Vitamin B_6 (Pyridoxal)	14.9	14.9	31.9	21.3	17.0	47
Vitamin C	15.2	26.1	15.2	28.3	15.2	46
Pfeiffer protocol	14.0	11.6	32.6	20.9	20.9	43
Melatonin	14.0	9.3	4.7	7.0	65.1	43
Nilstat/Nystatin	14.3	28.6	9.5	23.8	23.8	42
Olive leaf extract	5.1	15.4	23.1	15.4	41.0	39
Methyl B_{12} injections	11.1	19.4	19.4	19.4	30.6	36
Dimethylglycine (DMG)	25.0	34.4	12.5	12.5	15.6	32
"Footsies" foot pads[#]	3.1	28.1	12.5	31.3	25.0	32
Coconut oil	12.9	35.5	29.0	12.9	9.7	31
Selenium	10.0	26.7	26.7	23.3	13.3	30
Vitamins other than A, B_6, C, B_{12}	10.3	10.3	17.2	37.9	24.1	29
Co Q10^	3.6	28.6	35.7	21.4	10.7	28
Vitamin A	3.6	21.4	21.4	39.3	14.3	28
Chelation DMSA oral	3.7	18.5	7.4	37.0	33.3	27
Saccharomyces boulardi	3.7	22.2	29.6	37.0	7.4	27
Biotin	3.8	19.2	15.4	46.2	15.4	26
MT Promotor	16.0	20.0	36.0	20.0	8.0	25
Taurine	0.0	12.0	32.0	36.0	20.0	25
Diflucan/Fluconazole	12.0	24.0	28.0	4.0	32.0	25

“Footsies” are detox foot patches certified as a therapeutic medical device in Australia (ARTG 151147)
^ Co Q10 is Co-Enzyme Q10

NB Many of the supplements may be provided in a variety of forms eg liquids, powders, capsules, and the metals in a variety of salts such as zinc sulphate, or picolinate, selenium methionate or sodium selenate, magnesium citrate or carbonate etc. For the sake of simplicity the exact chemical entities were not requested.

It is interesting to see that only three products gave a marked improvement noted by parents within one week, namely Homeopathy (no details requested or provided), at 42.9%, Melatonin (65.1%) a sleep regulating hormone and antioxidant, and Olive leaf extract (41%) said to be an antimicrobial and antioxidant. Note all three apply to <50 cases. On the other hand DMG, a methylating agent, produced the highest proportion (25%) of children who got worse out of the 32 cases reported. This is probably due to the child being an over-methylator. According to Dr William J Walsh[27] some 45% of autistic children are under-methylators and about 15% others are over-methylators. Overmethylation is generally accompanied by an overabundance of dopamine, epinephrine and nor-epinephrine, as well as low blood histamine. Over-methylators require folate and DMAE (dimethyl aminoethanol) among other supplements in order to help their biochemistry, whereas under-methylators benefit from DMG, SAMe (S-Adenosyl methionine) among others.

Note there were no adverse effects reported with taurine, a small sulphur containing amino acid with antioxidant properties. However, like many other supplements, there are not always any direct external signs that they are having an effect (good or bad) on the body’s metabolism as can be seen from the “No apparent effect after one month” column in this table.

Many parents use a number of supplements at the same time, so it is not always easy to determine which caused what change in behaviour. However, the results do show quite significant differences, suggesting that in many cases, they are indeed able to distinguish between products that affect a child’s behaviour and those that don’t.

The above data may be summarised in ratio format in a similar manner to the previous tables concerning diets. The following Table 30 illustrates the ratios (R:1) as indicated:

A $\frac{\text{Some effect> 1 month + some effect 1-4 weeks + Effect within 1 week}}{\text{Got worse}}$

B $\frac{\text{Some effect within 1-4 weeks + Effect within 1 week}}{\text{Got worse}}$

Table 30 Comparison of effectiveness of supplements over time

Supplement/Treatment	A	B	Total (N=160)
Zinc	25.9	17.5	90
Epsom salt baths	6.7	4.9	87
Cod liver oil	16.4	10.7	82
Probiotics	10.9	7.0	81
Fish oil	14.1	11.5	78
Magnesium	11.7	8.5	68
Enzymes	17.1	13.1	62
Essential Fatty acids (EFA/DHA)	24.2	16.2	62
Calcium	4.7	3.3	50
Multimineral supplements	6.5	4.7	49
Homeopathy	13.4	9.4	49
Vitamin B_6 (Pyridoxal)	4.7	2.6	47
Vitamin C	3.9	2.9	46
Pfeiffer protocol	5.3	3.0	43
Melatonin	5.5	5.2	43
Nilstat/Nystatin	4.0	3.3	42
Olive leaf extract	15.6	11.1	39
Methyl B_{12} injections	6.3	4.5	36
Dimethylglycine (DMG)	1.6	1.1	32
“Footsies” foot pads	22.2	18.2	32
Coconut oil	4.0	1.8	31
Selenium	6.3	3.7	30
Vitamins other than A, B_6, C, B_{12}	7.7	6.0	29
Co Q10	18.8	8.9	28
Vitamin A	20.8	14.9	28
Chelation DMSA oral	21.0	19.0	27
Saccharomyces boulardi	20.0	12.0	27
Biotin	20.3	16.2	26
MT Promotor	4.0	1.8	25
Taurine	#	##	25
Diflucan/Fluconazole	5.3	3.0	25

As indicated earlier, there were no reports of adverse effects with taurine.

Table 30 shows that the products with the highest ratios are as follows:

- Zinc
- Cod liver oil
- Fish oil
- Enzymes
- Essential Fatty acids (EFA/DHA)
- Olive leaf extract

- “Footsies” foot pads
- CoQ 10
- Vitamin A
- Chelation DMSA oral
- Saccharomyces boulardii
- Biotin
- Taurine

The remaining products on the list, with the number of responses, are as shown in Table 31 in alphabetical order.

Table 31 Other supplements or treatments used

Product	N	Product	N
Agiolax	1	Laxatives	15
ASDPlex	2	Lecithin	6
Authia crème (TTFD)^	4	Lithium	14
Bentonite	4	Manuka Honey	13
Bethanacol	13	Methyl B_{12} oral	17
Carnitine	16	Methyl B_{12} Nasal spray	8
Charcoal	13	Milk of Magnesia	7
Chelation ALA^^ oral	21	Movacol	8
Chelation ALA IV	0	Naltrexone	7
Chelation EDTA* oral	3	Neocate	5
Chelation DMPS** transdermal	3	Pioglitazones	0
Chelation DMPS suppositories	6	Prebiotics	17
Chelation DMSA*** (Suppositories)	3	Risperone/Risperdal/Ridal	22
Chelation DMSA transdermal	1	Ritalin/methylphenidate	11
Colostrum	15	SAMe[##]	9
Cultured veggies	11	Secretin IV	7
Flagyl/Metronidazole	8	Secretin transdermal	7
Folic acid	15	Slippery elm bark	9
Folinic acid	23	Spironolactone	2
Glutathione IV	11	Super Nu-thera	16
Glutathione oral	16	Tegretol/carbemazepine	1
Grapeseed extract	17	Transfer factor	9
HBOT[#]	9	Trimethylglycine (TMG)	20
Herbs	15	Zeolites	23
Kefir	10	Zoloft/Setraline	10

^ TTFD Thiamine tetrahydrofurfuryl disulphide
^^ AA Alpha lipoic acid

* EDTA Ethylene diamine tetraacetic acid
** DMPS Dimercaptopropanesulphonic acid
*** DMSA Dimercaptosuccinic acid
# Hyperbaric Oxygen Therapy
SAMe S-Adenosyl methionine

Therapies for Asperger Syndrome

The data from the Asperger responses is very limited. However, parents mentioned biomedical, speech, and occupational therapies as being the most frequently used or tried (17/35, 15/35 and 13/35 respectively). 14 children were reported as receiving no non-biomedical therapy, and 8 were reported as not receiving any therapy at all. Whether this was because the parent decided not to answer the question, or for some other reason is not known.

- 6/10 (60%) found that a gluten or casein free diet produced some improvement in behaviour over time.
- 13/14 (93%) indicated ST as being very, moderately or mildly helpful.
- 8/15 (53%) indicated OT as being very, moderately or mildly helpful.

Very few Asperger children appeared to be receiving supplements. However, when using fish oil, 3/6 showed some improvement within 1 week and 1/6 got worse. 3 out of 4 using melatonin showed some improvement within one week, and 1 got worse.

Comparison with ARI Survey Data

The same observations regarding the ARI Survey as were made earlier apply equally to the interpretation of the data presented in Table 32 (see p38). The Australian/ NZ data are taken from Table 29 with decimals rounded up to whole numbers

As can be seen, there are considerable discrepancies between the Better/No effect results for each geographic area. This is probably in part due to the fact that the ARI survey has been collecting data for a number of decades, whereas the present Parent Survey relates to more recent practices as indicated by the median age of 5-6 years ie with most children having been born since 2000. Again the Australian and New Zealand ratios ("Better/No effect") are much higher than those observed in the USA.

The range of ratios for N_1/N_2 for the above supplements is 2.4-181.5 with Vitamin B_6 (2.4), MT Promotor (2.4), Methyl B_{12} injections (4.7) being at the lower end and DMG at top of the range. The median ratio is 30.8. Given the very poor Better/No effect ratio for DMG in the USA at 0.8 (and only 1.2 in Australia/New Zealand) one wonders why the usage appears to be so high compared with that in Australia/New Zealand?

The stand out items (Ratio Better/No effect >2.0) in the USA are Detox (chelation), Methyl B_{12} (injection), and Melatonin. In Australia/New Zealand,

the stand out items (Ratio Better/No effect >5.0) are Magnesium, Melatonin, Zinc, Enzymes, and Cod liver oil.

Table 32 Comparison supplement effects with ARI Parent Ratings Survey

			USA					Aus/NZ		
Supplement	**Got worse**	**No effect**	**Got better**	**Better/No effect**	**N_1**	**Got worse**	**No effect**	**Got better**	**Better/No effect**	**N_2**
Cod Liver oil	4	45	51	1.1	1681	5	15	81	5.4	82
Detox (chelation)	3	23	74	3.2	803	4	19	78	4.1	27
Enzymes	3	39	58	1.5	1502	5	13	82	6.3	62
DMG	8	51	42	0.8	5807	25	34	41	1.2	32
Fatty Acids	2	41	56	1.4	1169	3	19	78	4.1	62
Magnesium	6	65	29	0.4	301	7	6	87	14.5	68
Melatonin	8	27	65	2.4	1105	14	9	77	8.6	43
Methyl B_{12} (injection)	7	26	67	2.6	170	11	19	69	3.6	36
MT Promotor	13	49	38	0.8	61	16	20	64	3.2	25
Vitamin B_6	12	37	51	1.4	529	15	15	70	4.7	47
Vitamin A	2	57	41	0.7	1127	4	21	75	3.6	28
Vitamin C	2	55	43	0.8	2397	15	26	59	2.3	46
Zinc	2	47	51	1.1	1989	3	11	86	7.8	90

N_1 = Numbers of responses in USA
N_2 = Number of responses in Australia/New Zealand

Pathology Testing to Assist Biochemical Therapy

Parents were asked to indicate which pathology tests they have used. The results are as shown below in Table 33 in descending order. 171 people replied.

Table 33 Pathology testing

Test	N=171
Hair analysis	97 (56.7%)
Faecal (stool)	96 (56.1%)
Blood elements (metals etc)	93 (54.4%)
Food allergy	83 (48.5%)
IgG	68 (39.8%)
Organic acids (OAT – urine)	65 (38.0%)
Amino acids	56 (32.7%)
Genetic	54 (31.6%)
Celiac	51 (29.8%)
IgE	49 (28.7%)
IgA	47 (27.5%)
Toxic metals (urine)	45 (26.3%)
Porphyrin	40 (23.4%)
Fatty acids	33 (19.3%)
Ferritin	31 (18.1%)
Homocysteine	30 (17.5%)
Vitamin D	30 (17.5%)
Skin prick	29 (17.0%)
Immune system	27 (15.8%)
Intestinal permeability	24 (14.0%)
Iodine	23 (13.5%)
Toxic metals (DMSA challenge)	12 (7.0%)
Renal function	11 (6.4%)
Testosterone	9 (5.3%)
Other[#]	30 (17.5%)

The “Other” tests are as shown in Table 34, of which kryptopyrroles, or urinary pyrroles, was by far the most frequently mentioned by 10 parents:

Table 34 Other pathology tests used

Antimyelin	Neuroimmunology
Bacterial	Oxalate spot and 24hr
Blood lactate	Oxidative Stress
Cholesterol	Plasma zinc
EEG	Purines and pyrimidines
Full blood count	Sulphocysteinuria
Histamine	Sweat test for cystic fibrosis
Kryptopyrrole	Syndrome X

KUB# X Ray	Thyroid function
Liver	Viral
MRI	Whole blood histamine

KUB = Kidney, ureter, bladder

Pharmaceutical Based Therapies

Very few responses received indicated pharmaceutical use in the treatment of autism. This is not surprising given that there is no known drug which will cure, or provide relief, for all autistic symptoms. However, as a number of pharmaceuticals were mentioned in the abovementioned list of 81 supplements and treatments, the responses are given in the following Table 35 for information only.

Table 35 Speed of behavioural improvements with pharmaceuticals

Product	Got Worse	No apparent effect >1 month	Some apparent effect >1 month	Some effect within 1-4 weeks	Immediate effect (within 1 week)	Total
Authia crème (TTFD)	0	4	0	0	0	4
Bethanecol	1	2	3	4	3	13
Diflucan (Fluconazole)	3	6	7	1	8	32
Flagyl (Metronidazole)	1	3	1	1	2	8
Naltrexone	2	2	3	0	0	7
Pioglitazones	0	0	0	0	0	0
Risperidine/Risperdal/Ridal	5	1	2	8	6	22
Ritalin (Methylphenidate)	4	0	1	3	3	11
Secretin IV	3	3	0	1	0	7
Secretin Transdermal	3	2	0	1	1	7
Tegretol/Carbamazepine	1	0	0	0	0	1
Zoloft/Sertraline	6	1	0	1	2	10

Conclusions and Recommendations

The number of people who responded to the Survey during the first 4 months, was rather disappointing. However it does provide some very broad indication of the issues facing parents at the present time, and the following initial conclusions and recommendations to be made. It is anticipated more detailed studies into the sociological and biochemical aspects of autism will provide additional support for these findings.

Diagnosis Conclusions

It is clear from the limited data and parent comments (not included in this paper) that diagnosis is a major concern. The median age of the children in the Survey was in the order of 5-6 years.

Overall, the GP or paediatric statements to parents accounted for 40% of the cited delays between a parent's first suspicion of something not being quite right with their child and actually getting an official diagnosis. Just under 50% of the delays in diagnosis were due to reassurances from health professionals (GPs, Paediatricians, MCHNs). Nearly 20% were unable to obtain an immediate appointment with a psychologist and a further ~20% were due to being told the child was too young for assessment.

As a result, the average delay for all children surveyed was approximately 2 years, with a median delay of 17 months (N=228), while Asperger children had a diagnosis delay of 38 months, with a median of 36 months (N=32). The delay and median data for ADHD were 43 months and 41 months (N=16), and for PDDNOS, 20 months and 13 respectively (N=13).

Whilst the data numbers for Aspergers, ADHD, and PDDNOS are very low, such long average and median delays for these conditions, as well as those for autism, suggest that:

1. there is a degree of complacency towards autism in the medical profession which results in unnecessary delays in diagnosis.
2. there is a lack of proper training in the recognition of autism by the front line health professionals such as GPs and MCHNs.
3. the current psychiatric testing is inadequate in that the criteria are not sufficiently specific to identify many cases of autism and so paediatricians and psychologists tend to advise the parents to " have another look at him/her in 6 months' time".
4. at the present time, psychological testing is considered not possible until a child reaches the age of about 18-24 months, by which time the characteristics which tend to form the basis of testing become more apparent. This results in an inherent delay in obtaining a diagnosis.
5. there is a second inbuilt delay in diagnosis in the health system arising from the referral system.
6. the present diagnostic system is not coping with the numbers of parents trying to get appointments with psychologists.

With regard to the principle characteristics of autism, the Survey shows that the main issues observed by parents (N=219) are

- little or no eye contact 87.6%
- poor sociability 86.3%
- lack of imaginary play 74.4%
- fine motor delay (tactile problems) 73.5%
- a limited span of attention 72.1%

The main physiological characteristics were

- sensitivity to noise 71.7%
- being fussy eaters 70.8%
- delayed toilet training 67.6%
- poor sleep patterns 63.9%

Diagnosis Recommendations

Delays in diagnosis defeat the whole purpose of Early Intervention.

1. The response by GPs and MCHNs to an anxious parent should be to err on the side of caution, rather than to dismiss the parent as having exaggerated fears about their child's behaviour or development. The New Zealand Guideline is at least a step in the right direction when it recommends "valuing and addressing parental concerns about their child's development". The abovementioned characteristics, as observed by parents, particularly the "little or no eye contact", should be used to help in their diagnosis.

2. There is an urgent need to train GPs and MCHNs, the front line health professionals, in the early recognition of autism, and to be able to give a diagnosis which avoids the need for referral to a paediatrician or psychologist and consequent further delay in obtaining early intervention. Training should include current psychological testing as well as undergraduate education in basic human biochemistry, specifically in relation to autism, but also other similar conditions resulting from genetic and environmental susceptibility.

3. There is an urgent short term need for more psychologists to be trained specifically in autism, including the underlying biomedical aspects.

4. A biochemical screening test, or array of tests, is urgently needed for all neonates to take some of the guesswork out of the psychological testing and to enable **real** early intervention to proceed. The USA Government has recently taken steps to investigate early risk factors for Autism Spectrum Disorders (ASD). The network, called the Early Autism Risk Longitudinal Investigation (EARLI), will follow a cohort of up to 1,200 pregnant women who already have a child with autism[28]. The study is considered one of the best-equipped to discover biological markers and environmental risk factors for autism due to its elevated autism risk pregnancy cohort, wide ranging data collection with extensive bio-sampling, length of time it follows pregnant women and their babies, and multi-disciplinary team of expert investigators. The EARLI Study is one of eleven National Institutes of Health Autism Centers of Excellence projects nationwide. Australia and New Zealand would do well to see whether they would be able to participate, or even set up a similar project with their Asian neighbours. Every child diagnosed with autism should at least be investigated for biochemical imbalances, in order to build up a database which is to be used as a source of information for research into biochemical treatment.

Therapy Conclusions

41 parents advised they used only non-biomedical therapies, while 148 advised they used biomedical therapies, most of whom also used one or more

non-biomedical therapy. The average number of therapies used by each of the non-biomedically inclined parents was 2.4 with a median number of 2, while the average number used by the biochemically oriented parents was 4.3 with a median of 3.

Parents using only non-biomedical therapies are primarily influenced by paediatricians (41.5%) and psychologists (26.8%). Those parents using both biomedical and non-biomedical therapies are more influenced in their choice by the internet (57.6%), reading a book (38.8%) and a friend or family member (30.9%) (N=165). The two key non-biomedical therapies employed by the majority of parents surveyed (N=219) are speech (75.3%) and occupational (63.0%). The next most frequently used therapies are ABA and Sensory Integration used by 34.7% and 28.8% respectively. Very few parents use either no therapy or only one therapy.

The percentages of parent using speech, occupational therapy, ABA and sensory integration are broadly in line for those parents using biomedical and non-biomedical approaches. The major differences appear in the biomedical group using much more floortime, auditory therapy, kinesiology, neuropathy, cranial osteopathy and N.A.E.T, as well as the overall biomedical therapy. Factors such as

- availability of services eg in the cities c.f. the country areas
- parental wealth
- parental education
- government funding
- acceptance of the health professionals' (sometimes limited) recommendations (ie they know best)
- quality of health professionals' specific autism education

are thought to be involved, and this is clearly an area that requires much further investigation.

ABA appears to be an effective therapy, though whether this is simply due to the intensity of its application compared to others is no known.

Overall speech and occupational therapies, ABA and sensory integration tend to produce some beneficial effects in behaviour within a month for approximately 25-40% of the children. On the other hand approximately 15-30% show no improvement in behaviour after a month of these therapies. 65-75% of parents found these four therapies helpful.

The figures for the number of parents using speech therapy (82.9% and 76.4%) are broadly in line with the 70% found by Green et al[5]., as are those for ABA (36.6% and 35.8%) cf 36.4% where the first figures in brackets refer to those using only non-biomedical therapies, and the second figure refers to those using non-biomedical and biomedical therapies. Occupational therapy was not included in the Green survey, so no comparison is possible. However, Green found 38.2% of respondents used sensory integration which

is considerably higher than the figures in the present survey (22.0% and 28.4%).

Speech and occupational therapies, ABA, sensory integration, and biomedical therapy are being used for periods up to 5 years in many cases, and beyond 5 years by about 10% of those who responded.

Approximately 50-60% of children on one of the commonly used diets (eg GF/CF=Gluten/Casein Free, GF/CF/SF=Gluten/Casein/Soy free, sugar removed, chocolate remove, salicylate free, SCD =Specific Carbohydrate Diet), show a behavioural improvement within one month of starting. On the other hand around 20% show no improvement after one month on the diet.

Dietary therapies were found to bring about a more rapid improvement in behaviour within a month, than speech and occupational therapy, ABA, and sensory integration. There appears to be some slight advantage to using a combination of biomedical and speech therapy in order to speed up the rate of speech progress, though the precise nature of the biomedical therapy needs to be examined further.

With regard to supplements it is interesting to see that only three products gave a marked improvement noted by parents within one week, namely Homeopathy (no details requested or provided), at 42.9%, melatonin (65.1%) a sleep regulating hormone and antioxidant, and olive leaf extract (41%) said to be an antimicrobial and antioxidant. On the other hand DMG (dimethylglycine), a methylating agent, produced the highest proportion (25%) of children who got worse out of the 32 cases reported. This is possibly related to the child being an over-methylator, and it is preferable that parents find out whether their child has this condition before using such a product.

The highest ratios for apparent effectiveness (improvement in behaviour/worse behaviour) of supplements/treatments were found for the following products:

- Zinc
- Cod liver oil
- Fish oil
- Enzymes
- Essential Fatty acids (EFA/DHA)
- Olive leaf extract
- “Footsies” foot pads
- CoQ 10
- Vitamin A
- Chelation DMSA oral
- Saccharomyces boulardii
- Biotin
- Taurine

The stand out items in terms of the child's behaviour getting better, compared with not having any effect, were magnesium (as in Epsom salts), melatonin, zinc (as in zinc salts), enzymes, and cod liver oil.

Therapy Discussion

With regard to non-biomedical therapies, it would appear that, from a perspective of helpfulness and effectiveness, parents would do well, at least initially, to concentrate on speech and occupational therapies, ABA, sensory integration, and floortime, although the data for floortime are very limited. The choice from within these therapies will of course depend very much on the child's individual needs. Other therapies may be useful where the above methods are not producing the required results.

With regard to biomedical therapy, this needs to be targeted to each individual's particular biochemistry, and this is why substantial pathology testing may be required in order to expose the underlying disorders. The ten tests most frequently carried out on the children in descending order were as follows (N=171):

- Hair analysis (56.7%)
- Faecal (stool) (56.1%)
- Blood elements (metals etc) (54.4%)
- Food allergy (48.5%)
- IgG (39.8%)
- Organic acids (OAT – urine) (38.0%)
- Amino acids (32.7%)
- Genetic (31.6%)
- Coeliac (29.8%)
- IgE (28.7%)

Generally speaking, it is necessary to carry out more than the standard blood and urine tests. Blood tests expose the presence of mercury and lead over only a short period and not over a longer period as can be obtained using a standard hair analysis. The present standard urine test does not provide any indication of organic acid deficiencies or excess, or the presence of heavy metals. Furthermore, except for the genetic test, many of these tests are usually carried out at regular intervals in order to establish trends in relation to treatment given.

Biomedical therapy alone is most unlikely to bring back a child's speech, which is after all the crucial factor in being able to communicate with the child, but it may well provide the biochemical environment within the brain (and the gut!) such that it is able to pick up speech signals it receives in a cohesive manner, thus facilitating the production of a rational thought and possible answer to a question.

Educating the educators is a key issue in making sure that those involved in autism and its treatment are fully aware of the latest research into autism and

have an open mind to investigating new ideas. ABA was first proposed by Lovaas over 20 years ago, and since then there have been a number of refinements or developments which have led to other therapies such as Floortime, Son-Rise, RDI®, etc. In a similar manner, the discovery by Dr Bernard Rimland of the effectiveness of Vitamin B_6 and magnesium in the 1960s has led to an enormous amount of research into the biochemistry of autism, and the development of dietary and other protocols such as GF/CF diet, Pfeiffer protocol, Methyl B_{12} injections, HBOT, to produce improved outcomes.

The insistence by the medical profession that these developments need to be subjected to double blind placebo cross over trials (The Gold Standard of proof) has meant that these therapies have received no promotion by the vast majority of doctors, and in fact have been downplayed by both the medical profession and the psychologists. However, as can be seen from the results of this pilot study, many parents do find behavioural improvement in their children, which is hardly surprising, given that autism has its origins in the basic genetics and biochemistry of the body, most likely as a result of an environmental insult. There is a dichotomy in terms of standards of proof between psychologists' findings in the treatment of autism that are accepted just on the basis of using a control group, whereas the general practitioners require not only a control group, but also a cross over situation, both parts of which must be run blind, before they will accept that a benefit may exist. It is practically impossible to run such trials because of ethical considerations. The products used in the biomedical treatment of autism are for the most part innocuous eg dietary modification, pre- and pro-biotics, zinc salts etc, except for the synthetic chelating agents used to extract heavy metals. The benefits of dietary intervention have been clearly demonstrated in dealing with such conditions as PKU, coeliac disease, diabetes etc. and the same needs to be applied in the case of autism. It may well not result in improved behaviour in all children, but the present study indicates that it should provide benefit in about 80% of them.

Autism is thought to be a biochemical condition arising from a genetic susceptibility to an environmental insult. Biochemical research will undoubtedly bring about advances in the therapeutic treatment of autism in the same way as it has been used to help people with Syndrome X, coeliac disease, diabetes, phenylketonuria (PKU), and other metabolic disorders.

Further Research

This Survey has uncovered a number of areas where further research is required. These include the need

1. to survey GPs, paediatricians, psychologists in the region on how well they feel equipped to correctly identify and manage autism along the lines of the UK survey.
2. to find an agreed array of biochemical/pathology tests which will enable GPs to determine rapidly and with maximum precision those children at risk of autism and other similar conditions.

3. to obtain more input from those parents not using biomedical therapies.
4. to explore the relationship between the medical profession, internet, parental finance, education, and choice of therapies.
5. to explore why parents continue or discontinue therapies
6. to explore exactly how much therapy children do in fact receive
7. to evaluate dietary and other biochemical interventions to determine their effectiveness in controlled trial conditions.
8. to research the annual cost to parents for looking after their ASD children both financially and psychologically.
9. to obtain a more detailed investigation into the speed of effectiveness of therapies in relation to specific suitability for Autism, Aspergers, PDDNOS, CDD and gender, so that cost effectiveness can be determined.
10. to survey universities and other relevant educational institutions to establish the extent of specific training of undergraduate doctors and nurses in autism recognition and management.
11. to investigate the claim by Dr James Neubrander regarding the impact of Methyl B_{12} injections on speech development.

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