Autism Spectrum Disorders (ASD) Diagnosis, Therapies and their Perceived Effectiveness

- extract from a report of a parent survey

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ABSTRACT

This study examines the reasons for 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. Data was collected through an internet-based survey. Of the 331 responses received, 261 (79%) were completed to varying degrees, of which between 215 and 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 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, ASD, 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 snapshot 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 limitations on providing information from educational institutions, the survey responses were gathered mainly through informal networks. Responses are biased towards those parents who use biomedical therapies or interventions, as opposed to non-biomedical therapies in an estimated 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 two years. The main reason for this is GP, paediatric and health professional 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 may be 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 see a psychologist for a diagnosis earlier.*

4. *The present delays may also be in part due to the fact that diagnosis is primarily dependent 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 approaches were found to be Speech and Occupational Therapies (75.3% and 63.0% respectively, n=219). Applied Behavioural Analysis (ABA) was also used by 34.7% of respondents. In this survey approximately 80% of parents had used, or were using, biomedical interventions such as dietary modification and supplements in addition to 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) on their children, 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). None of the therapies listed in the survey provided improvement in all children, indicating each child's individuality.*

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

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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 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 include 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 Guthrie test will identify Phenylketonuria (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.*

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:

1. *Many parent stories, indicating 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. *An 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. *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 factors 1-4 statistically. One internet survey in the USA conducted by The University of Texas at Austin in 2004[5] received 552 usable responses in a 3 month period. This showed that speech therapy was the most commonly reported intervention (70%), followed by visual schedules, Sensory Integration and ABA (36%). Half (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 parent's first suspicions of Autism and diagnosis, and the reasons for the delay.*

2. *An indication of the effectiveness or otherwise of biomedical treatment.*

ANALYSIS AND RESULTS

The full analysis (approximately 30 pages) is not included here but is available on request from the author.

DISCUSSION, CONCLUSIONS AND RECOMMENDATIONS

The number of people who responded to the survey during the first four months was disappointing. However it does provide some 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 Discussion and 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 including GPs, Paediatricians and Maternal & Child Health Nurses (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 for ADHD children were 43 months and 41 months respectively (N=16), and for Pervasive Developmental Disorder Not Otherwise Specified (PDDNOS), 20 months and 13 respectively (N=13).

Whilst the participant numbers for Aspergers, ADHD, and PDDNOS are very low, 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 six 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) were:

Little or no eye contact	87.6%
Poor sociability	86.3%
Lack of imaginary play	74.4%
Fine motor delay (tactile problems)	73.5%
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 Spectrum Disorder Guideline is 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, "little or no eye contact", should be used to help in 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 US Government has recently taken steps to investigate early risk factors for Autism Spectrum Disorders. Called the Early Autism Risk Longitudinal Investigation (EARLI), the study will follow a cohort of up to 1,200 pregnant women who already have a child with Autism[6]. 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 will follow pregnant women and their babies, and multi-disciplinary team of expert investigators. The EARLI Study is one of eleven National Institutes of Health Autism Centres of Excellence projects nationwide. Australia and New Zealand would do well to participate in, or set up a similar project with our Asian neighbours. Every child diagnosed with Autism should at least be investigated for biochemical imbalances, in order to build up a database which can be used as a source of information for research into biochemical treatment.*

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Therapy Discussion and Conclusions

The use of only non-biomedical therapies was reported by 41 parents, 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 were primarily influenced by paediatricians (41.5%) and psychologists (26.8%). Those parents using both biomedical and non-biomedical therapies were 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) were Speech (75.3%) and Occupational (63.0%) therapies. The next most frequently used therapies were ABA and Sensory Integration used by 34.7% and 28.8% respectively. Very few parents used either no therapy or only one therapy.

The proportion of parents using Speech, Occupational Therapy, ABA and Sensory Integration was similar between parents using only non-biomedical therapies and those also using biomedical therapies. The major differences appeared in the biomedical group using much more 'Floor Time', auditory therapy, kinesiology, neuropathy, cranial osteopathy and N.A.E.T, as well as the overall biomedical therapy. Other factors thought to be involved and requiring further investigation were:

Availability of services, eg: in metropolitan areas compared with rural 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

ABA appears to be an effective therapy, though whether this is simply due to the intensity of its application compared to others is not known.

Overall, Speech and Occupational Therapies, ABA and Sensory Integration tended 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. About two-thirds (65-75%) of parents found these four therapies helpful.

The proportion of parents using speech therapy (82.9% using only non-biomedical and 76.4% using both biomedical and non-biomedical) is broadly in line with the 70% found by Green et al[5], as are those for ABA (36.6% and 35.8% respectively) compared with 36.4% found by Green et al. Occupational Therapy was not included in the Green study, so direct comparison is not possible, however, Green found 38.2% of respondents used Sensory Integration which is considerably higher than in the present survey (22.0% and 28.4% respectively).

Speech and Occupational Therapies, ABA, Sensory Integration, and biomedical therapy were being used for periods up to five years in many cases, and beyond five years by about 10% of those who responded.

Approximately 50-60% of children on one of the commonly used diets, eg: Gluten/Casein Free, Gluten/Casein/Soy free, sugar removed, chocolate removed, salicylate free, Specific Carbohydrate Diet), show a behavioural improvement within one month of starting, however around 20% showed 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
CoQ10
Vitamin A
Chelation DMSA oral
Saccharomyces boulardii
Biotin
Taurine

The stand out products in terms of the child's behaviour improving, were magnesium (as in Epsom salts), melatonin, zinc (as in zinc salts), enzymes, and cod liver oil.

Therapy Recommendations

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 Floor Time, although the data for Floor Time was 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 (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 he/she is able to pick up speech signals received in a cohesive manner, thus facilitating the production of rational thought and a 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 Floor Time, 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 and HBOT, to produce improved outcomes.

The reliance of the medical profession on double blind placebo controlled cross over trials (the 'Gold Standard') for evidence of efficacy has meant that these biochemical therapies receive little promotion by the vast majority of doctors, and in fact have been downplayed by both the medical profession and psychologists. It is practically impossible to run such trials because of ethical considerations. 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. 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 not result in improved behaviour in all children, but the present study suggests that it should provide benefit in about 80% of cases.

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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, PKU and other metabolic disorders.

Further research

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

1. *Survey GPs, paediatricians and psychologists on how well they feel equipped to correctly identify and manage Autism along the lines of the UK survey.*
2. *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. *Obtain more input from those parents not using biomedical therapies.*
4. *Explore the relationship between the medical profession, internet, parental finance, education, and choice of therapies.*
5. *Explore why parents continue or discontinue therapies*
6. *Explore exactly how much therapy children do in fact receive*
7. *Evaluate dietary and other biochemical interventions to determine their effectiveness in controlled trial conditions.*
8. *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.*
9. *Survey universities and other relevant educational institutions to establish the extent of specific training of undergraduate doctors and nurses in Autism recognition and management.*

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The Author

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