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Issue 1

Diagnosis of Asperger Syndrome – Our Right to Know

Conference paper, 2006 World Autism Congress and Exhibition, South Africa

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Asperger Syndrome. It is a label that invokes strong responses, or complete ignorance. Everyone who knows about it has their pet theories, mostly gained by reading other people's interpretations of unusual behaviours or interpreting unusual behaviours according to theories of normal development. There is a resource for information about Asperger's which is rarely considered. I am referring to people like me. We have largely lived in fear of being found out. We have often felt like aliens in a hostile environment. Now many of us are liberated from fear of discovery of our difference. We have been liberated by the label. Liberation for me means knowledge of who and what I am. It means that at 50 years old I found a peer group; people who understand me without the need to justify my perceptions of life. The thought of others like me having to experience the isolation and fear of not knowing about their diagnosis of Asperger Syndrome is appalling, especially since so many of us are struggling to be heard on the internet, in families, workplaces and communities around the world. Hold that thought, because I would like to explain to you what diagnosis means to many people on the autism spectrum.

First, you may see me refer to myself as autistic. I, and many others, do not use the politically correct term of being with autism. I think it was Wendy Lawson who said she does not have autism walking beside her like a dog. I agree. Our expression of autism is as intrinsically a part of us as gender. I am not with femininity. That would be nonsense. I am short. I am dark. I am also autistic. If that is distressing or offensive, I am sorry, but I will be referring to myself and my peers as autistic.

A diagnosis of an autism spectrum disorder is a strange thing. Today I was assured that for a parent, it signifies a lifetime of grieving for the loss of a perfect child. Another interpretation is that parental grief is about loss of dreams and rage that the parents cannot die as they are responsible for a lifelong dependent. No wonder the "A" word is often avoided.

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Another common argument is that the diagnosis of an autism spectrum disorder is too hard for a parent to face. However, these parents are already facing autism. They are facing it without the skills and knowledge required to bring up an emotionally healthy child. Without a diagnosis, they do not have access to information about specific parenting skills which will improve family life. Without the support of others who share the experience of parenting an autistic child, parents may blame themselves. They may feel very much alone and despair of being able to help this child who is so different. Above all, for parents, as for their children, the unknown is always worse than the known.

There is another perspective. Many autistics are proud of their personal characteristics. . Autism can certainly present difficulties, many of which are caused by other people but many of our characteristics are advantageous. For example, autism allows me to concentrate for very long hours on topics of interest. I have therefore developed a considerable body of knowledge in some areas which are useful in my work. Rather than introduce parents to Asperger Syndrome as a tragedy, it could be pointed out that we exist. Many of us are high achievers and it is possible to have families and relationships. The important thing to understand is that a “normal” life could be quite unpleasant for an autistic person. If we are permitted to develop our potential and find an appropriate niche, an autistic niche in the world, our lives are not tragic at all. They may just be different.

Back to the “A” word. I sometimes hear of parents who are told that their child may have an autism spectrum disorder, but the diagnostician feels that it is unnecessary for a formal diagnosis because the child is doing well. The parents are told that it would be better not to label the child and it would be a waste of time anyway as no services are available. While I understand very well the stigma of a label, in my experience, this view reflects a misunderstanding of the importance of a diagnosis for people who have autism spectrum disorders.

Children who have an autism spectrum disorder are usually aware of difference from an early age. I knew at 5 that I was not like the other children. It was a lonely and terrifying realization. I spent hours watching children and trying to work out why I was not acceptable. I never did find a reason, but in playing with magnets and iron filings, I noted that the filings that were far from the magnet did not do what all the other filings did. In a strange way, I had come to the crux of autism. I knew that in some way, I was like the distant filings, too far from a certain influence to follow regulated patterns. By the age of seven, I believed that the reason for that was that I was mad, a concept based on playground gossip about strait jackets and asylums. I was very afraid of being taken away and locked up for having a strange perception of life and spent years trying to ensure that others did not find out that I was mad. An example of this was my terrible fear of entering rooms with closed doors. As a child I was afraid of highly patterned curtains and did not want to enter strange rooms if I could not pass by the room, checking curtains with quick, oblique glances. As an adult, I was amazed to discover that most of you do not experience nausea when exposed to certain colours. Very few of you see contrasting colours as ebbing and surging waves. My experience of the vivid colours and patterns of the fifties and sixties was that curtains and carpets could rush towards me provoking waves of nausea. I was under attack. I screamed and ran away. My explanations and pleas to leave the area led to labels. My labels were spoiled, manipulative and attention seeking. I prefer the “A” word.

I have communicated with many autistic adults, both in real life and on the internet. Most experienced deep depression and anxiety in trying to understand why they are so disliked. “Be yourself”. This is advice which is commonly given to people who are shy and awkward. If you are “yourself”, people will like you. The hard lesson to be learned by people with autism is that for us, “be yourself” is not the true message. Without self knowledge, the message from parents and teachers may become “be like me”. And we may try very hard to do this. Without knowledge, we are denied the opportunity to develop a personal identity. It is easy to see why many develop depression and anxiety disorders.

In order to counteract the harm done by ignorance, I believe that autism should be explained in the same way as adoption.

Explanations should start as early as possible. They should focus on the positive aspects of autism as well as the idea that there are times when everyone needs help. The children need to know that they are not alone and that there are many people just like them. They need to know that they can have successful careers and good lives. They need to know that when they are older, they can choose to meet their peers and that this may be a source of friends. I have one exception to this. Some adolescents may be too vulnerable. I do not believe that they should be kept ignorant in case the news is too depressing. They should be told briefly about autism or Asperger syndrome so that the knowledge is there when the

person is ready to explore his/her difference. If the young person becomes distressed, I recognize that it is not appropriate to try to force self acceptance, but the label provides a lead for the person to follow in developing self awareness at a personally appropriate time.

Educationally, withholding information is not justified either. Often it is said that the child is doing well, so a label is not necessary. This is a myth. Even well adjusted autistic children do experience communication difficulties. Although one teacher may address these, another may decide that the child is wilful and punish social infringements. While the child may be successful at school, there is no guarantee that this will continue. Educators need to be aware of potential problems. Proactive education strategies may ensure that positive education experiences continue. I believe that it is negligent to wait until a young person experiences academic failure, extreme emotional pain, depression and anxiety before attempting to inform teachers of difficulties. I often use the analogy of visual impairment. Nobody would ever try to hide the fact that a person has a visual impairment. I have not heard of the notion of addressing the characteristic and not the label in this case. The idea of a parent being told that his/her child has difficulty negotiating large objects and is textually challenged would be laughable. The label is given as it provides instant access to understanding, educational and environmental supports.

I saw an article in which it was argued that adults should not be told of diagnosis. The reasoning was that they were likely to indulge in the diagnosis and behave in a more autistic manner. The article described behaviours in which the adult sinks into a morass of autism, refusing to communicate and spending long hours on the internet. Some people do this. I certainly did it for some time. I think it is understandable. With diagnosis, there can be a period of grieving. In my case, I had always hoped that I would find a pill which would fix everything. Diagnosis dashed the hope I had for a good life. I spent hours on the internet communicating with other autistic people. The relief of chatting to people who shared an emerging culture and who instantly understood and may even have shared my experiences and perceptions was indescribable. After a while, I started to see possibilities in helping others. One thing I was able to do that was positive was to help monitor an autistic children's chat line. I found that the way to helping myself, was of course helping others. As grief healed I became more confident, far more than at any other stage of life. By the way, I was wrong about being sentenced to misery by that diagnosis. Knowledge has given me a new world, a world acknowledging autism. It is good to be alive.

Diagnosticians who deny the label are forgetting that autism is a pervasive developmental difference. There are lifelong implications to that. If diagnosis is withheld, there is a possibility that a person may never access information required for good health. When we chat online, my peers and I compare information. We have found many interesting and useful trends. Often, females attend university at around the age of 35. If your autistic daughter does not succeed at university at 18, it is not the end of the world. It could be the beginning of her world for she has many years in which to reach her potential.

Many women are diagnosed with at least one auto immune disease when we are in our thirties. If parents had that information, they would have the opportunity to ensure that the child learned about preventative health care at an early age.

Aging is of concern. The lifespan for institutionalized adults in Australia has been quoted as forty seven. What is the lifespan for people who live independently? Does the depression and anxiety experienced by most, predispose us to suicide? Do autoimmune diseases cut short our lives? What is the outlook for someone who may not be able to tolerate communal living as experienced in nursing homes or residential care? We have many questions to explore.

Diagnosis can help people address issues which have often resulted in social injustice. Young men, in particular may experience problems with the law. These often relate to a poor understanding of appropriate behaviour when forming relationships. They may be offences committed in pursuit of special interests. Appropriate counselling rather than punishment is effective in promoting appropriate behaviours. Without diagnosis, social justice may be denied.

Social isolation is a major problem for people on the autism spectrum. While some develop social contacts based on special interests e.g. train spotters, ornithologists and computer groups, others enjoy contact on the internet, finding a source of information, peer support and political activism. They find a medium for belonging and sharing as an autism culture develops.

Many of us have relationships. We often need to share information required to sustain those relationships. Our needs are not the same as our neurotypical peers so it is very empowering to have the

support of other people on the autism spectrum. In the medium of cyberspace where nonverbal communication is simplified, we are able to achieve the information sharing, peer support and relationships we were unable to access in adolescence. In cyberspace we compare experiences without fear that our most personal thoughts e.g. sexuality enhanced or complicated by sensory sensitivities, being distorted or pathologised.

Adults on the autism spectrum understand autism in a very different way than that experienced by observers. Often we find our experiences discounted by people who see us merely as defective. We have a great deal to offer in promoting a useful understanding of Autism Spectrum Difference. For example, there are aspects of autism which are rarely discussed in the literature. Parents and teachers often complain that the child is impossible to motivate, perhaps even lazy. They describe children who begin tasks but refuse to complete them. I could tell you a lot about that. I should know. I have experienced the distress of being shouted at for a behaviour I dare not try to explain for fear of derision. There are many reasons for this block in motivation, but for me a common reason relates to the fairly typical cognitive profile of autism. In some ways, I function at a very high level. In others, I struggle. At times, particularly during more complex tasks (and remember the things that are easy to you may be complex to me and vice versa) the various layers of thinking abilities are not able to merge. I am stuck. I have a physical sensation of ramming into a barrier and there is nothing I can do. Picture a brick wall with an abyss behind it. I try to batter that wall down, but there is nothing beyond it. No matter how often I try to complete the task, I run into the same problems. Prior to diagnosis, I would try again and again. Now I know that when I have that brick wall experience it is time to stop and assess the situation. It is time to break the task into small chunks and identify my strengths. I can often find a way around difficulties and for the first time in my life, at the age of 50, I was able to learn to ask for help.

Far from being a sentence, the “A” word has power. The label of Asperger Syndrome opens doors to appropriate education, training and employment. During the course of this conference we hear about enabling supports and accommodations for individuals on the autism spectrum. Apart from personal distress, the waste of human resources due to disability discrimination is being recognized at last. Educators are developing understandings of autism and appropriate teaching. Employers are being educated about the need to adapt workplaces to suit individuals with different abilities. The “A” word may now open doors to opportunity.

Diagnosis is a process which also tells the individual about his/her strengths and needs. This knowledge is essential for developing the ability to be proactive in facing life’s challenges. It enables people to influence policy and to help change community attitudes. Knowledge gives us the power to determine our futures. In Australia, autistic adults are now taking their places on autism society management committees. We participate in decision making. We increasingly participate in advocacy with a view to influencing government policies pertaining to autism. We cannot trust that others will value our rights enough to fight battles such as these.

Knowledge is power and this applies to understanding ourselves better. If you can get formally diagnosed it's a good idea. Knowing that you have AS and learning to understand that and the way that it impacts your relating, relationships, and overall functioning and way of relating to the world in general is a very valuable thing that can only add to your self-acceptance and self-understanding in time, in ways that will enable you to find more peace and contentment in life.
Ms. A.J. Mahari 2004

Not all adults who discover that they may have Asperger Syndrome choose to pursue diagnosis, but that opportunity to be empowered should be theirs. For both children and adults, a diagnosis of Asperger Syndrome is not a sentence. It is a signpost to a rich and varied way of being a person. Diagnosis represents our right to fulfil our potential.

Convenor's message

Dear A4 member,

I feel like there is a lot happening around ASD at present.

A result from the National Autism Forum in 2005 has emerged (see *Autism treatments: New guide to help parents* below).

The Senate Inquiry into the CSTDA has produced its report. It highlights the chronic unmet need for disability services generally. Since the report is a bipartisan report, government should accept many of its recommendations.

Much of the report talks about substantial unmet need and calls for more resources in all areas of disability services. Unfortunately, it does not seem to appreciate the needs of people with ASD for services that provide for them as individuals meeting their needs for ASD-specific services and supports.

The only section of the report that recognises ASD as a distinct disability relates to the need for early intervention for children with autism. You can download a PDF version of the report from http://www.apf.gov.au/senate/committee/clac_ctte/cstda/report/report.pdf to see how A4's lobbying efforts influenced this report.

I was told the Health Minister, The Hon. Tony Abbot MHR, wrote to the Prime Minister, The Hon. John Howard MHR, asking him to decide who was responsible for autism/ASD. Such a decision should have some input from the ASD community. I wrote a letter about some of the issues at the federal level and how I suggest they fit into various government responsibilities. If you would like to see what I said, please download the letter and take a look. The URL is www.a4.org.au/documents/JH061215-A4.doc

Mr Howard has not sent me a response yet. There may be time for you to have a say as well.

Autism/ASD does not get onto the Prime Minister's agenda very often. We should make the best of this opportunity. I believe you will be most effective if you keep to the issues of who should be responsible at the federal level for which ASD-related issue, and how the government can meet the needs of people with ASD. He will be more interested if you suggest solutions to problems.

Please, if you have a view about which federal ministers should be responsible for issues affecting people with ASD, or if you either agree or disagree with what I said, please write to the Prime Minister yourself. He has a website where you fill in a form, rather than sending him an email. The URL is <http://www.pm.gov.au/contact/index.cfm> then click on "Continue" and fill in the required information ... and your view.

I also wrote to the Parliamentary Friends of People with a Disability (PFPD) asking for a chance to present to them (see <http://www.a4.org.au/documents/PFPD070116-A4.doc>). Unfortunately, this group is too busy to meet A4's representative(s) for some time. The A4 Steering Committee is preparing written information to send to the group members before the coming election.

I am sorry that A4 missed an opportunity to put our case to another Parliamentary Committee late last year. Fortunately, the AEIOU team from Qld provided a submission. You can download and read it at <http://www.apf.gov.au/house/committee/fhs/workandfamily/subs/sub222.pdf>

While the government seems to be taking some notice of lobbying efforts, especially in relation to early intervention services, A4 has raised numerous other concerns with government. For example my recent letter to John Howard expresses concerns about the CSTDA generally, education, respite, accommodation, health, family/carer support, the law and human rights.

If you have concerns that you want A4 to raise with government, please let the A4 Steering Committee know. Email me or the Secretary (email addresses can be found in the Contacts section below) so we can work out how to include your concerns in our lobbying efforts.

Quite some time ago, a number of A4 members wrote their stories for a journal called "The Clinician" published by the Department of Psychological Medicine of the Children's Hospital at Westmead in NSW. I recently received a large edition of the "The Clinician" containing numerous stories of people and families affected by ASD. If you provided a story, you may wish to contact the Department to get a copy.

In overseas news, the US Centre for Disease Control released a new report on the prevalence of autism spectrum disorders in the USA. I have a separate comment on this below.

The A4 Steering Committee had a small discussion of issues associated with the **Combating Autism Act of 2006**, Pub. Law No. 109-416, an Act of the US Congress (Senate Bill 843) that was signed into law by President George W. Bush on December 19, 2006. There is an item on Wikipedia (see http://en.wikipedia.org/wiki/Combating_Autism_Act).

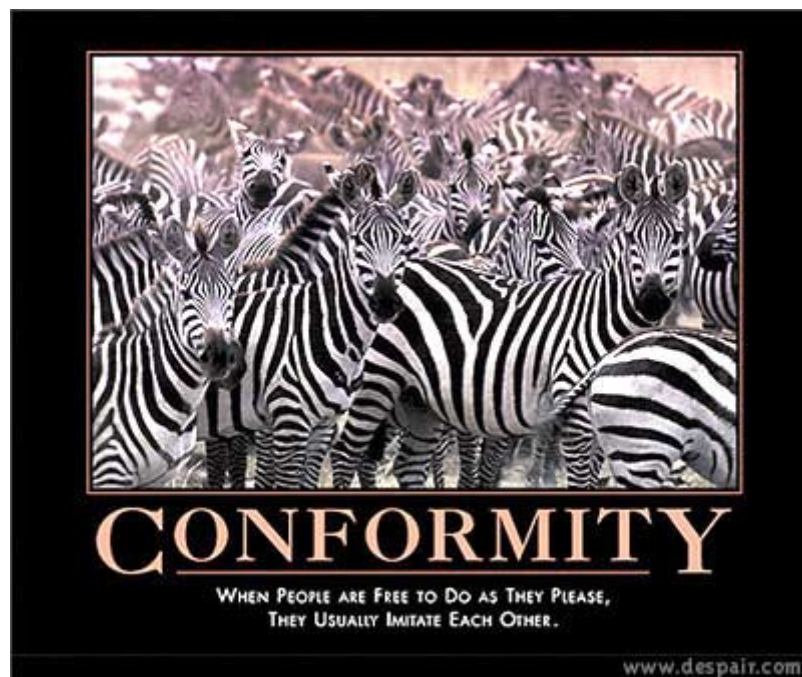
The Wikipedia article on the US Combating Autism Act notes there is an autism rights movement that opposes efforts to cure autism, with claims that the activity is genocide or eugenics.

Following are my own views, not the views of A4 or its Steering Committee.

The opponents presume "cure" means eradicating everything that might relate to autism. If that was what a "cure for autism" meant, I too would oppose it. But they are mistaken.

Any cure, that is an effective treatment, for ASD would overcome the "severe and pervasive disorder" that are ASD. A cure for ASD would address dysfunction. It would seek to eliminate or replace behaviour that is severely dysfunctional. Any effort directed at unusual but functional behaviour is not treating or "curing" autism.

In other words, treating ASD is about treating a person's severe and pervasive disorders and dysfunctions. It is not about changing a person's personality or about making people "normal".



Some parents say they want a "normal" child. This attitude is not limited to parents of children with ASD. Plenty of parents regard their children as unusual or different. But in the end, they still love their child; and most parents learn to accept their child for who they are.

In my experience, most parents of children diagnosed with ASD are relieved if their child's disorder, or some part of it, is reduced or overcome. Most parents are grateful when their child's disability is reduced; but they don't expect to make everything including personality "normal" ... whatever that means. If there are parents who, following successful treatment of the disordered and dysfunctional parts of their child's behaviour, remain severely distressed over their child's residual unusual but functional behaviour then these people need counselling.

I often see written down that "there is no cure for autism". If that means no person with ASD can have their disorders treated effectively, then I reject this claim. Treatments that reduce or overcome disorder can contribute to a "cure". I have met people whose dysfunctions have been treated effectively, and who no longer meet the diagnostic criteria for ASD. Usually, they remain "different" or unusual but they no longer meet the criteria required for an ASD diagnosis.

I accept that no one particular treatment achieves a cure in all cases ... or even in a majority of cases. There may even be some forms of ASD that cannot be treated effectively ... this would be difficult to prove and we certainly do not know that yet. But if people mean "some people have ASD that do not respond to a particular treatment approach" when they say "there is no cure for autism", then they should be much clearer and less misleading. This truism applies generally: one could say "there is no cure for cancer" but many cancers can be treated effectively and a range of approaches are needed for treating different types of cancers. In my experience, individuals with ASD need individual programs and all the credible approaches to treating ASD provide this.

Some research aims to find genetic variations that increase an individual's risk of developing ASD¹. I understand that researchers are already confident ASD are due to a combination of gene variations. There is a long way to go before we know most of the relevant gene variations, and how different combinations of those gene variations may affect individuals.

Some ASD research has complex ethical questions associated with it. Our leaders may face issues around DNA technology that can estimate the risk an individual embryo would grow to develop severe autism or, on the other hand, major genius such as Einstein, Newton, etc. People who want to influence our leaders and to make an effective contribution to community discussions around DNA sequence technologies will not include inaccurate and inflammatory terms like "genocide" and "eugenics".

It seems to me that treatment based on gene-related technology is a long way away ... and could take many different forms. Some of the possibilities would not be acceptable to me. Generally, I reserve my judgement: there is still a long way to go.

I will be at the national conference in mid-march. If you see me around, please feel free to say "hello".

Regards
Bob Buckley
3/3/2007

¹ Some gene anomalies cause disorders. For example, in individuals with "Fragile X", there is a mutation in one end of the gene (the 5' untranslated region), consisting of an amplification of a CGG repeat. Patients with fragile X syndrome have 200 or more copies of the CGG motif.

It seems that once discovered disorders that are due to known mutations, like Fragile X, Angelman's syndrome, Prada-Willi syndrome, etc., are no longer classed as a mental disorder in the DSM. This may soon happen to Rhett's syndrome.

Family studies suggest the risk of autism is a genetic phenomenon, but twin studies suggest autism is not due entirely to genes.

Australian Advisory Board on Autism Spectrum Disorders

formerly the Autism Council of Australia

MEDIA RELEASE

MARCH 5, 2007

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FIRST AUTISM PREVALENCE STUDY FOR AUSTRALIA

An exhaustive three year study commissioned by the Australian Advisory Board on Autism Spectrum Disorders into the prevalence of autism, led by Perth paediatrician Dr John Wray, has concluded that one in 160 Australian children aged between 6 and 12 years have an autism spectrum disorder (ASD) – that is over 10,000 Australian children in that age group.

The finding is consistent with the latest overseas research on the prevalence of autism spectrum disorders.

The report's finding could be extrapolated to suggest that as many as 125,000 people may have some form of ASD in Australia. Given the difficulties faced by many families, then half a million Australians could be impacted by ASD.

"This study sets clear benchmarks for early intervention planning and other services," Advisory Board spokesman Mick Clark said today. "The Advisory Board on Autism Spectrum Disorders will seek discussions with governments at an early opportunity to better plan and fund early intervention, education and support services."

The report bears out the need for a national protocol of no more than 3 months waiting time for a diagnosis and assessment by multidisciplinary teams who are funded to provide these services. Further, no family should experience a waiting period of more than 3 months between diagnosis and early intervention service provision.

"The report reveals that in some parts of Australia, diagnosis and intervention can take up to two years – this is far too long," Mr Clark said.

The Advisory Board commissioned this important study with funding from the Commonwealth Department of Family & Community Services and Indigenous Affairs (FaCSIA) as there was no accurate and reliable figure on ASD prevalence in Australia. Researchers took great care in ensuring an accurate national figure was extracted from many sources including the Commonwealth Government's own statistics.

"The important thing was to get an accurate sounding, for the first time, on how prevalent the disorder is.

"We should act promptly as a community to tackle ASD after diagnosis, to give those who have an autism spectrum disorder the best chance in life. In most cases, early intervention followed by schooling that uses autism-specific interventions can bring real improvement," Mr Clark said.

The report is also a useful snapshot of what services are available nationally, and where strengths and weaknesses lie in diagnosis and intervention.

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Download the report from <http://www.autismaus.com.au/aca/pdfs/PrevalenceReport.pdf>

Autism treatments: New guide to help parents

Press release:

A new brochure, available from today, will help parents of children with autism match up the best treatment for their child's condition.

"Early and effective treatment is crucial in getting positive results for children with autism, so parents need more information on the best treatments available," the Assistant Minister for Health and Ageing, Christopher Pyne, said when launching *Early Intervention for Children with Autism Spectrum Disorders: A Guide For Parents*.

Mr Pyne said the Australian Government produced the new brochure as a guide to help parents find the most appropriate treatment for autism to suit their child's particular condition.

"Autism is a complex disorder. There is no known cure," Mr Pyne said.

"But there are treatments that can help. Many different treatments are available - with varying levels of evidence for their effectiveness.

"This brochure, which has been developed by experts in the field, summarises the research available about different types of treatments and it provides information and contact details for programs available in Australia," Mr Pyne said.

Further information: the brochure, and a more comprehensive report "A Review of the Research to Identify the Most Effective Models of Practice in Early Intervention for Children with Autism Spectrum Disorders", can be found at: www.health.gov.au/internet/wcms/publishing.nsf/Content/mental-child-aut.

Comment

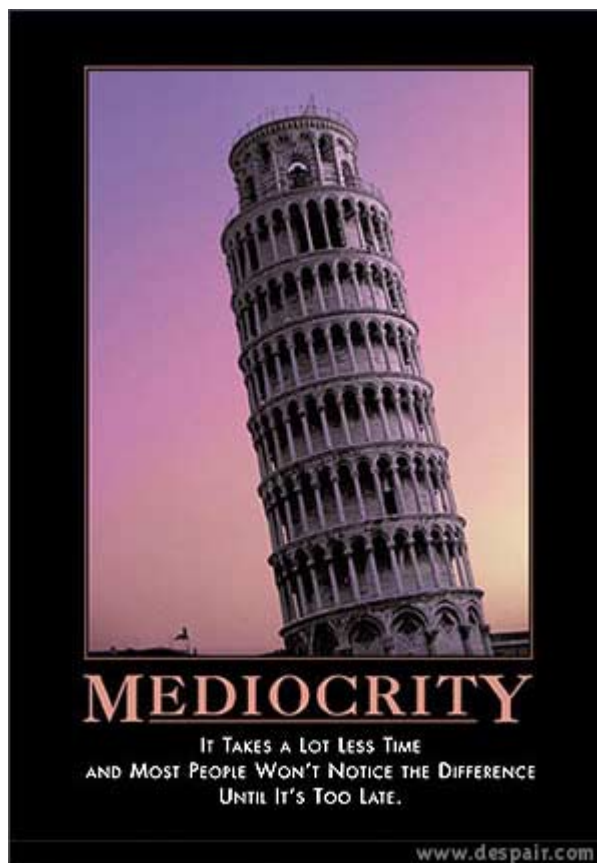
The brochure *Early Intervention for Children with Autism Spectrum Disorders: A Guide For Parents* (download from [http://www.health.gov.au/internet/wcms/publishing.nsf/Content/D9F44B55D7698467CA257280007A98BD/\\$File/autbro.pdf](http://www.health.gov.au/internet/wcms/publishing.nsf/Content/D9F44B55D7698467CA257280007A98BD/$File/autbro.pdf)) summarises and presents views from the federal Department of Health about early intervention for autism.

This is a big step forward for the federal Department of Health and Ageing. It admits that many children diagnosed with autism need effective early intervention. And it recognises that the early intervention they need may consist predominantly of specialist clinical services.

But it does not really guide parents.

The brochure describes various elements and aspects of "best practice" in early intervention for ASD. And it lists service providers. Unfortunately, none of the Government funded early intervention services in Australia provides what the government's brochure describes as "best practice" early intervention for ASD... early intervention that governments offer children with autism/ASD is mediocre at best.

Our governments really need to take a good look at the long-term cost of mediocrity in these circumstances. My observation is that it is incredibly expensive for everyone.



If the early intervention your child receives, or received, was not best practice according to the description in the brochure, you might like to write to your local member of parliament, at both a federal and state level, letting them know you are disappointed that government funded services provided for your child fall/fell short of what the federal government describes as best practice.

The report, *A review of the research to identify the most effective models of practice in early intervention of children with autism spectrum disorders* (download from [http://www.health.gov.au/internet/wcms/publishing.nsf/Content/846804F6D67F34F3CA257280007853DE/\\$File/autrev.pdf](http://www.health.gov.au/internet/wcms/publishing.nsf/Content/846804F6D67F34F3CA257280007853DE/$File/autrev.pdf)), does not “identify the most effective models of practice in early intervention” as its title suggests. Parents hoping to use this report “to identify the most effective models of practice in early intervention” may be concerned that it says “For the majority of interventions, further research is required...” (p8).

Some of the big problems for parents are:

1. advice given to parents following an early diagnosis is unlikely to resemble what this report describes as “the most effective models of practice in early intervention”.
2. parents who ask a number of professionals what specific approach(es) to early intervention would be best for their child usually get different and conflicting answers from each professional.
3. most parents cannot access services for their child that even remotely resembles “the most effective models of practice in early intervention”.
4. parents are left to case manage a complex array of services.

It is a big step forward for government to recognise these needs of children with ASD. The next step, to ensure families can access these services if and when they need them, is crucial.

ASD Prevalence. Again!

The US Centre for Disease Control (CDC), a US Government agency, recently revised its ASD prevalence estimate (see <http://www.cdc.gov/od/oc/media/pressrel/2007/r070208.htm>, <http://www.cdc.gov/od/oc/media/pressrel/2007/f070208.htm> and <http://www.cdc.gov/ncbddd/autism/documents/AutismCommunityReport.pdf>). The report describes a study that counted children aged 8 years who have been diagnosed with ASD. It says:

The average ASD prevalence was 6.7 per 1,000 in 2000 and 6.6 per 1,000 in 2002, or approximately 1 in 150 children.

This is a 10% increase over the CDC's previous position on prevalence.

These figures are consistent with the prevalence figures I presented to the 2004 Biennial Australian Autism Conference (the peer reviewed paper can be downloaded from http://autism.anu.edu.au/pdf_files/buckley_submit2.pdf).

The analysis of Centrelink data in the last A4 Update told a similar story.

The most important message from this is ...

"Finally, we can end the debate on the prevalence of autism in our nation and focus on getting the services and supports the families need," said Lee Grossman, Chief Executive Officer of the Autism Society of America.

See <http://www.medscape.com/viewarticle/551907>

Autism prevalence is not a single number. Some people with ASD will be diagnosed after the age of 8 years. So ASD prevalence will rise higher in this slice of the population as they get older.

One feature of both the US figures and the recent Centrelink data is that diagnosis rates (observed prevalence) varies significantly between states. Possibly, government policy significantly affects diagnosis rates. Diagnosis rates may be high in states that demand a formal diagnosis of a clinical disorder (such as autism) in order to get support in education settings. There may be high levels of co-morbid intellectual disability with autism where an Education Department does not provide essential support for children with autism but provides services and support for children with an intellectual disability. States that do not cover the cost of a PDD-NOS diagnosis may have very few PDD-NOS diagnoses.

New medicines subsidised for cancer, arthritis and autism

The Hon Tony Abbott MHR, Minister for Health and Ageing.

Extract from media release:

Patients with prostate cancer, arthritis and autism-related behavioural problems will benefit from three medicines that will be subsidised from 1 March 2007 through the Pharmaceutical Benefits Scheme.

The treatment of severe behavioural disturbances associated with autism in children and adolescents will be assisted by the inclusion of RISPERDAL QUICKLET® (risperidone) on the PBS. This will benefit 3,165 children and adolescents, at a cost to the Government of about \$1 million a year.

<http://www.health.gov.au/internet/ministers/publishing.nsf/Content/mr-yr07-ta-abb018.htm>

Medicare and communicating health issues

Bob Buckley, 4/3/2007

The federal government introduced “a new Medicare rebate for people with an intellectual disability” (see www.health.gov.au/internet/ministers/publishing.nsf/Content/mr-yr07-cp-pyn006.htm). The press release said “the new [Medicare] item recognised that people with an intellectual disability had complex health needs that were difficult to adequately assess because of the patient’s inability to recognise and communicate symptoms”. Hopefully, people with both an autism spectrum disorder (ASD) and an intellectual disability will benefit from the new Medicare item.

But many people with ASD could miss out. Many people with autism/ASD have complex health needs. Many of them have sensory issues that make it difficult for them to recognise their symptoms. And they are diagnosed with a severe communication disorder that makes it difficult for them to communicate their symptoms.

It seems from the purpose of this Medicare item, as described in the Assistant Minister’s press release, that the government intends to help people such as people with autism, not just people with an intellectual disability. Many people with ASD do not have an intellectual disability, but they do have complex health needs that are difficult to assess due to their communication disorder and sensory issues.

If this Medicare item is only available for people with an intellectual disability, then many people with autism who should benefit from the initiative will be excluded. Without access to this or a similar scheme, many people with ASD will continue to suffer because their health care does not get the attention and treatment it needs.

Some years ago, researchers told the AIHW that people with developmental delay have worse health outcomes than Australia’s indigenous population (whose health is a national disgrace). Adults with developmental delay have on average 5.2 major health disorders, of those two were undiagnosed.

The head of AIHW at the time told those present that the AIHW would investigate and report on this issue. As yet, there is no report.

Limiting access to this Medicare scheme to people with an intellectual disability continues to deny many people with autism/ASD access to care that is essential and should be a human right. Such a policy discriminates against some of our most vulnerable and disadvantaged citizens.

A4 raised this with the Assistant Minister’s Office. You can download his response from www.a4.org.au/documents/CP070207response.tif. The letter refers only to “patients who have an intellectual disability” and omits any reference to “complex needs” and “the patient’s inability to recognise and communicate symptoms”. The policy decision to restrict access to the Medicare item to those with intellectual disability may already be in place.

The Assistant Minister’s letter says “Eligibility criteria are yet to be finalised. This will be undertaken as part of the formal consultative process...”. Is this just about deciding the IQ cut off for eligible intellectual disability?

The letter says “Your comments will be put forward as part of this process for consideration”. While it is good that some input from A4 may be considered, this is not an adequate consultative process. The ASD community has not been consulted or given a chance to properly prepare its comments on this issue.

Disability Discrimination Commissioner Graeme Innes AM put out a press release that congratulates the government unreservedly (see http://www.hreoc.gov.au/media_releases/2007/8_07.html). Unfortunately, the Disability Discrimination Commissioner is oblivious to or condones the discriminatory nature of the eligibility criteria proposed for this new Medicare item.

The HREOC press release says ...

“This decision has occurred following lengthy negotiations between the Government, the Royal Australian College of General Practitioners and the disability sector.”

The ASD sector was not consulted... **as usual.**

A legal complaint against such a discriminatory policy could not succeed. Section 45 of the federal *Disability Discrimination Act 1992* fully protects a “special measure” intended to benefit one group of people with a disability, such as people with intellectual disability, while excluding others irrespective of their need for and inability to access any such “special measure”. It does not matter that the exclusion criteria may violate central government policies such as prioritising services on the basis of “relative need”.

The new Medicare item may benefit people with both an autism spectrum disorder and intellectual disability. The rest of us will have to wait and see whether comments from the ASD sector have a beneficial effect.

Letters / Emails

Please send letters to edit@a4.org.au. Letters sent to the editor may be published unless they are clearly marked “not for publication”. Normally, they will appear with your full name and state unless you mark them clearly “anonymous” or “first name only”.

Bernard Rimland's Autism Increase Opinion

Keri Waldron 5Feb2007

I thought you might like to read a reprint of Bernard Rimland’s testimony “The Autism Increase” at the US House of Representative Government Hearings - April 2000

<http://curezone.com/art/read.asp?ID=79&db=2&C0=1>

From later videos etc, it seems he only became more convinced of his facts.

The DAN doctors and Pfeiffer doctors believe likewise.

The damage done by vaccines goes far further than autism, ADHD/ODD etc. There's SIDS, CFS, Anaphylactic allergic reactions, sixfold increase in asthma, MS, Guillaume Barre and other chronic auto-immune disorders. We are systematically poisoning our kid’s immune systems (brains, guts etc)

I think the "clincher" for me was that after the overwhelming science I was hearing at conferences I finally read BigPharma's own vaccine "package inserts"!

All these conditions are listed there, BUT as supposedly "rare" side-effects - i.e. 1/1,000,000.

[Well, they said incest was 1/1,000,000 too up until the 1970s when they found out it was more like 1/25 (paternal) or 1/4 (molested).

I believe the serious damage from vaccines is "out" by the same factor.

Investigation into Mood and Stress Problems in Adults With Asperger Syndrome

6Feb2007

Many people with Asperger syndrome and autism report experiencing mood and stress difficulties and other problems in coping with everyday life. Many people feel happy most of the time, but others sometimes feel stressed or unhappy.

Dr Jane McGillivray and Dr David Hamilton from the School of Psychology at Deakin University are conducting a study looking at the way people who have autism or Asperger syndrome feel about themselves and what they think about themselves and their lives. We also want to determine whether these thoughts and feelings can be measured by a self-report questionnaire.

We are seeking adults who have Asperger syndrome or high functioning autism who would be willing to participate in this study. Participants will be required to complete an anonymous questionnaire which will take approximately 35 minutes. The questionnaire would be posted out and then returned to us in a pre-paid envelope.

The study has been approved by the Deakin University Ethics Committee.

If you would like to be involved, or would like further information, please contact:

Dr David Hamilton on (03) 9244 6139 or e-mail david.hamilton@deakin.edu.au or
Dr Jane McGillivray on (03) 9244 6426 or e-mail jane.mcgillivray@deakin.edu.au

Event Professor Tony Attwood, Sydney 14-15 June 2007

7Feb2007

Autism and Aspergers Support Group Inc

The Autism and Aspergers Support Group Inc are proud to present Prof Tony Attwood. Prof Attwood is considered to be one of the world's experts on Autism Spectrum Disorders and travels the world extensively to educate parents and professionals on Autism Spectrum Disorders.

DAY ONE - Thursday, 14 June 2007 aimed at an audience of parents: Managing Feelings; Making Friends.

DAY TWO - Friday, 15 June 2007 aimed at an audience of professionals: Cognitive Abilities; Special Interests.

The Richmond Club
Cnr East Market & Francis Streets
Richmond, Sydney NSW

For more information see www.autismsupport.org.au or call the support group's mobile number - 0425 380 575.

Pfeiffer Outreach Clinic Sydney April 2007

Medical Practitioners Training Program & Patient Assessments 16th-24th of April 2007. For more information see <http://www.biobalance.org.au/events/>

Spectrum Parenting Magazine - February 2007 edition

The February edition of Spectrum Parenting Magazine is now available to download at <http://www.autisminfo.org.au/spectrumparenting.htm>

A4 Contacts

A4 is a grassroots organisation. All A4 activity, such as publishing the Updates (newsletters), is done by volunteers. Please understand that A4 volunteers may have no training or qualifications for their various roles. They do the best they can for people with ASD, their families and associates. A4 welcomes assistance and constructive criticism.

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