A4 Autism Aspergers Advocacy Australia

UPDATE

November 03
Issue 10

Feature

Why Speaking Up Means Speaking Out

By Karen Mackie

Misplaced comments, a sideways glance, or a sweeping generalization - I am sure many of us have all felt the unthinking actions of sometimes well meaning people. Irrespective of what legislation exists to protect our children and our families, we are still vulnerable to the ignorance of others. More often that not that very ignorance equates to down right discrimination. This is one of the main reasons I chose to become an active member of A4, working with other families to educate, enlighten and at times correct public perceptions of a person living on the ASD spectrum.

Recently, A4 bought to task the ABC, for airing a program depicting Asperger’s as a disorder characterized by aggressive behaviours. In fact the inference was so strong that any one living on the spectrum could be reasonably viewed as a potential physical threat to anyone with whom they came in contact. As we are all well aware, aggressive behaviour can stem from a multitude of sources, but is not reliant on a diagnosis of an ASD. As one member described it ..”it is as ludicrous proposition as suggesting all people with blonde hair are aggressive personalities”. Unfortunately viewing such programs, forms public opinion, and once an issue is out there no matter how ill informed, “it sticks”.

This was clearly demonstrated to me when not long after this program aired my ex husband phoned me coughing and spluttering and crying foul. He had applied for a rental property and was signing up the final documents with the owner of the property. He told him of our arrangement for my ex husband to have the three children every second weekend, which was fine. In the further course of conversation he mentioned that our son, who is nearly six is Autistic. The owner then withdrew his offer of the property saying that “."he did not want someone like THAT around his home. " he felt ASD behaviour was too erratic and too disruptive. One wonders where someone with no experience of ASD would have been able to draw that conclusion. The Disability Discrimination Act 1995 exists to give us a vehicle through which my ex husband may pursue this matter, but it doesn’t act as an effective deterrent when the national broadcasting authority is seen to be not only presenting such concepts as fact, but further when challenged continues to refuse to withdraw the comment.

So what is all the fuss about? Autism Aspergers Advocacy Australia, are pursuing comments made during a segment ‘Callous Unemotional’ which aired in August on the ABC’s *The Health Report*. The segment featured a discussion with Professor Mark Dadds from the University of New South Wales School of Psychology. Professor Dadds, at the time, was involved in researching a measurable trait in children called ‘callous unemotional’. This was just one of the comments by Dr Norman Swan (both a paediatrician and a broadcaster)

“Although they say that the true Aspergers is quite an aggressive person and often the Aspergers are mislabelled as the kid who’s got mildly autistic behaviour and not showing much emotionality or receptivity to others. Often a really nice kid who does well, and they’re often mislabelled Aspergers. And true Aspergers are often quite aggressive people.”

BobBuckley on behalf of A4 wrote to the ABC and indicated that Dr Swan had made unsubstantiated ‘utterances’ on a number of points:

1. Children are mislabelled autism spectrum disorder
2. People are often mislabelled Aspergers
3. True Aspergers are often quite aggressive people.

Prior discussion on the topic had included inflammatory references to Martin Bryant with the inference that he fitted the profile of Aggressive Aspergers. It would not be unreasonable therefore to expect viewers to carry forth the image of a person with Aspergers as a gun wielding unemotional and unrepentant mad man. Further, they single handedly minimalised the diagnosis of Autism Spectrum Disorder to be the result of hysterical parents pushing professionals into “labeling their child”. I had thought we were all over the “refrigerator mother syndrome” but according to Dr Swan we are still to blame.

Allowing these comments to stand uncorrected is not simply unjust it's dangerous. Our children have a difficult enough time as it is without being unfairly judged against Dr Swan's criteria for ASD and Aspergers. A4 will continue to pursue the ABC in this matter on behalf of all our families until such time as the comments are withdrawn or corrected. Speaking out collectively against such comments helps to not only educate the general public as to what an ASD is, but will help the "professionals" to learn to listen to the families who are after all the experts on the topic. It's not about being difficult or destructive advocacy is about enriching all our lives.

While my son is sometimes difficult, he is no more so than any other six-year-old boy. He is a bright, funny, astoundingly articulate little boy. Oh what the world will miss out on if they are allowed to view him in the guise of his ABC inferred aggression. By speaking up and speaking out we can all make a difference.

Inside This Issue

NOTE

With Christmas fast approaching … December 9 is the deadline for reader's contributions for the next Update issue. All contributions are welcome.

From the Convenor

Dear A4 member

I write hoping you can reflect positively on your year. Mine was a challenge.

Looking forward and thinking about the coming school year for my son, I find there is a long way to go to meet his special needs so we are chasing down immediate issues and concerns as fast as we can.

The Government responded to Senator Allison's questions. I find the answers disappointing. I suggest A4's most immediate challenge is to get the Government and the opposition alike to admit ASD may be a matter of concern. The Government, it seems, believes since it hasn't established an ASD register, there cannot be a problem. It says the view of Professor Stanley, noted epidemiologist and Australian of the Year, is 'no evidence'. Having initially referred to ABS data, the Government is now backing away from surveys using self=reporting (such surveys include the National Census). The Government did admit it has done nothing.

The Federal Government wants us to believe all the ASD-related issues are state issues. I don't think that it is right. Australia has international obligations to its children. Our allies acknowledged the challenge and are targeting autism; our government is unwilling to 'join the coalition of the willing' in addressing autism. We need to change their mind.

Earlier on during the year, I formally complained to the ABC about a statement made on the Health Report. I received some sort of a result after pursuing the complaint through the process. Briefly, the ABC obtained an 'independent review' from the Monash Institute of Health Services

Research (MIHSR). The review found: *There was a lack of high-quality evidence to either support or refute the association between Asperger's Syndrome and aggressive behaviour.*

Three comparative studies suggest that aggressive tendencies may be present, but the research was often conducted on small groups or on special populations. There was no examination of the extent or severity of these behaviours, nor whether these aggressive behaviours were qualitatively different from general population samples.

The full response may be downloaded from www.a4.org.au/documents/ABCHR030918.doc. I believe the subject of the complaint is contrary to the ABC's Code of Practice. My letter to the ABA is also available at www.a4.org.au/documents/ABASwan031118.doc.

Furthermore, whatever happened to the presumption of innocence? In this instance, social and justice conventions make it appropriate to say 'there is no evidence supporting an association'.

The issue of Thiomersal also got some recent attention. Medical authorities say ' there is no evidence of any link' in relation to ASD and MMR/Thiomersal. A more appropriate phrase would be 'the lack of evidence to either support or refute…'. The language of science around ASD is far from neutral.

On a more disturbing note, this month A4 received a number of reports of alleged ASD professionals portraying parents and other (sympathetic) professionals particularly poorly. We have responded to the appropriate bodies regarding these allegations and are waiting for responses at this time.

Bob Buckley

Convenor

Editorial

Format

Since taking on the editorial 'job' we have looked at a number of ways that the format and content could be changed to reflect the growing interest and involvement that our members are having. You may notice that this update looks a little different from the last as we continue to develop a style that we hope will be reader friendly, informative and interesting.

We are aware that some members would prefer to receive notice of the edition of the Updates by way of an email containing a link; and also that many would prefer to receive the Update in PDF. The Updates are available to download in either word or PDF from the A4 website. We welcome your feedback about the format that members would prefer, and indeed any other issue.

Congratulations

A4 would like to congratulate one of our keenest members, Dorothy Lewis-Heselwood of Gladstone (Queensland). Dorothy has ASD herself and has a number of children also diagnosed with ASD. Dorothy is a terrific person. She is always keen to do more on the advocacy front. Dorothy recently wrote an article called **'Do Conference Create Opportunities?'** with reference to the Melbourne World Congress and submitted this to the international website www.autismarts.com taking out 4th prize for last years awards. The link is: http://www.autismarts.com/subpage.html8.html

Job Vacancies

We are still looking for members to be our state correspondents from **SA, WA, QLD, NSW and NT** for the A4 Update. This would involve a monthly roundup state related ASD issues. This is a great way to become more involved in A4. If you are interested please contact us at edit@A4.org.au for further information.

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Letters to the editor

The A4 Update team want your feedback!!!

We want your praise (of course!), your criticism, your input, your ideas, your wants, your thoughts, etc. Tell us what you want more information about or what you want less of. Email us at edit@A4.org.au with ‘your say’.

Dear A4

I would just like to send a word of encouragement and congratulations to you and your team at A4. I am a mother of two beautiful boys, one of which has ASD. Both provide challenges for my husband and I as parents but with our eldest being ASD we find your website information invaluable. The unique situations and problems we often face in this area require the support your website and organisation offers to keep us sane - just as the advice from other parents for our other child keeps us equally sane. To know we are not alone in itself is comforting and encouraging as we often gather strength from the stories and advice from others facing similar situations. Again your sacrifice of time and effort is not wasted and I’m sure many beautiful children benefit from the time and energy you invest in this area.

From our hearts we say …
Thank you ...

The Seamer Family (by email)

Dear A4

Thanks for the work you do at A4. I enjoy receiving the Update and generally find it very informative. It does however take a lot of space in my inbox and I wonder if it would be possible to get a link to it instead?

Robbie D (by email)

Dear Bob and A4 team

My wife and I look forward to the newsletters. One problem that we have is that the word document is very large to receive and takes a long time to download. I have noticed that you have the PDF version on the website. Is it possible to mail out the PDF version instead of the long one?

JD and PH (by email)

National/State Roundup

National

Commonwealth Carers Allowance

The Commonwealth government is conducting a review of the lists of recognised disabilities, and submissions are invited from interested parties.

This matter is of considerable importance because it may provide an avenue for Asperger's to be listed.

Information about the review - including a discussion paper can be found at: http://www.facs.gov.au/internet/facsinternet.nsf/aboutfacs/programs/lord.htm

New South Wales

Dyslexic boy says authorities failed him

By Kelly Burke, Education Reporter

November 18, 2003

A year 12 student has taken his case against a northern suburbs school and the Department of Education to the Human Rights and Equal Opportunity Commission, arguing that he was discriminated against on the basis of his learning disability.

The 17-year-old Asquith Boys High student, who was diagnosed with dyslexia at age five, is arguing that his performance in the HSC and preceding assessments was severely compromised by the school's unwillingness to meet his special learning needs. The Board of Studies' refusal to allow him extra time and a writer to complete the HSC exams was also discriminatory, he claims.

In the complaint lodged with the commission, the student alleges the school and the Education Department have failed to appreciate the seriousness of his disability, or the impact it has had on his capacity to learn or access the visually based school curriculum.

The complaint is something of a test case in NSW, because dyslexia, under both state and Commonwealth anti-discrimination legislation, is recognised as a disability under the "disorder or malfunction" category.

But under the NSW Department of Education's criteria, dyslexia is simply categorized as a "learning difficulty", and not as an intellectual, sensory or physical disability. Consequently, children suffering from dyslexia are not eligible for the State Government's funding support program for disabled students.

Dyslexia awareness campaigner Jim Bond, who is acting for the student, says should the commission uphold the complaint, it would be a landmark decision in favour of the estimated 14 per cent of students with learning difficulties who are subsequently diagnosed with dyslexia.

"The [Education] Department's consistent refusal to recognise dyslexia as a disability is all about funding," he said. "If you don't have a recognised disability under their definition, then you can't access the appropriate funding to get help."

A spokesman for the Board of Studies said dyslexic students had a range of special examination needs.

He said special examination provisions were determined "on an individual case-by-case basis by a panel including specialist pediatricians and learning difficulty specialists". The board was unable to comment on individual cases.

The principal of Asquith Boys High, David Short, declined to comment.

This story was found at: http://www.smh.com.au/articles/2003/11/17/1069027048348.html

Victoria

By Meredith Ward

There has been a lot of activity in the area of early childhood intervention in Victoria since the release of Autism in Victoria (see update no. 9 for full details).

Since then, the Dept. of Human Services announced a new funding model for early childhood intervention services. The “Output” model will redistribute funding around the state so that every early Childhood Intervention Service (E.C.I.S) provider will be funded at about $4350.00 per child/family p.a. These changes to funding are not needs based, or evidenced based, but are a Treasury directive.

Some service providers will be forced to increase the number of families they provide services to, hence reducing the level of their services to families. Other service providers will need to reduce the number of children/families that they provide a service to, (despite their long waiting lists), so that they can increase the level of service to their families, to meet the new requirements.

In order to make funding more “equitable” across the state, Treasury has chosen to force some providers to “cut” their levels of service. Treasury could have chosen to increase the early intervention budget so that all service providers would be brought up to the same level. ~ why didn’t they?

The new “equitable” funding model does not consider complex needs of children with ASD and disadvantages specialist services providers like Irabina Early Childhood Autism Services, and Mansfield Autistic Centre & Travelling Teacher services who provide services only to children/families with ASD. Irabina and Mansfield TT will not have the flexibility to offer “a sliding scale of service” because 100% of their clients have complex high needs. However, generalist service providers will be able to offer some families a service that costs say $2000.00 and others a service that costs say $6000.00.

The “Output” funding model would be significantly improved if consultation included all stakeholders and all available data. Excluded from the process to formulate the new funding model were the results from “Autism in Victoria”, the Dept. of Human Services project that investigated Prevalence, Results of current evidence based research, Current diagnostic tools and processes for assessment and Program design and practice for children with ASD under 6. Autism Victoria, was also excluded from the process.

Problems with historical funding, Sharper focus on individual needs, more transparent and equitable, and Dept. of Treasury and Finance requirement are the reasons stated for needing a new funding model. Treasury deems this model to be equitable because every service provider will soon receive the same amount of funding per child/family. In reality the “Output” model is an over simplistic formula for sharing increasingly inadequate resources. It seems to be designed to avoid discovering how much service is needed and how much it actually costs.

Families still wait up to a year to access a diagnostic team and then up to 2 years to access E.C.I. services. The average group size of 6 used in the new costing formula does not consider those children whose needs require them to be in a small group of 3.

But, having a costing model is a starting point. It is far from perfect but it is a beginning. It now gives Victorian advocates the opportunity to say to Treasury, you have a model, and you now know what a service costs you. It’s now time to meet the needs of those receiving a service and address the waiting list issues.

Angry and upset Parents from Irabina Childhood Autism Services, Bayswater and Kalparrin Early Intervention Program, Greensborough have been actively lobbying the State Government in recent months as their service levels will be drastically cut to meet the new requirements under the Output based funding model.

The “Your Say” section of the Herald Sun has seen a steady stream for three weeks of letters regarding inadequate early childhood intervention services. These resulted after Irabina parent, Yvonne Lee had apiece published in the “My Say” section. It explained that Yvonne and Warren decided to leave Victoria to move to Queensland so their son Mackenzie could receive more funding under the Qld. education system than he would have received here in Victoria when he starts school next year.

Another major event in Victoria was the launch of the Early Childhood Intervention Services (ECIS) vision and key priorities document released recently. This vision seems to advocate a world where early childhood intervention services, rebadged as "specialist services" will become "specialist supports" and delivered "within the universal platform of services" i.e. day care centre, kinder, maternal child health centre and family support services.

The Vision statement says:- "Families caring for a child with a disability or developmental delay are able to access flexible and responsive specialist supports within the universal platform of services, to support them in raising their child within the family and community and enabling them to achieve their developmental, social and emotional potential." (available at www.ecis.vic.gov.au)

Quality early childhood intervention service (ECI) providers already support children at their local kinder and day care centre. Some provide reverse kinder integration models where children with and without disabilities attend kinder together, incorporating specialist intervention provided by the ECI program.

Does the new ECIS vision mean that the services currently delivered at a centre by ECI providers will in future be based in the community; that 100% of their services are to be delivered through the day care centre, the kinder, the maternal child health centre and family support services, in a world void of separate early childhood intervention centres?

We agree that families of children with a disability especially those with ASD, need equity of access to both specialist services and universal services. But where exactly should the line be drawn in terms of what percentage of specialist services should be delivered through universal services V's delivery through a separate centre? And how will specialist therapy services like Psychology, Speech and OT that are paramount to improving the outcomes of autistic children be delivered?

Will our ASD diagnostic specific providers (like Irabina Childhood Autism Services and Mansfield Travelling Teacher Services) , and ASD specific programs delivered through generic programs be able to continue in their current format?

Quality ASD programs promote a child's best possible outcome whereby the individual is successfully included into society to the best of their ability. The benefits of quality, appropriate early childhood intervention are maximized because they are delivered in both universal services and through ASD specific programs. These programs utilize a multi-disciplinary team in a safe, secure environment with a professional to child ratio of about 1 : 2. They also have a family focus where parent education/information forms a large part of the program.

Is it the ultimate intention of this Government to phase out all the individual centres throughout Victoria where ECI services are currently provided and roll the funds used for early childhood intervention services into the "Children's Centres" as described by the Government's Children First policy? (available at www.vic.alp.org.au)

This is certainly something for Victorian members and advocacy groups to seek clarification and answers to these and more questions.

A4 member in Bairnsdale, East Gippsland, Tim Bull recently met with leader of the State Opposition, Robert Doyle for a discussion on a range of issues relating to early intervention and special needs children in the education system.

One of the major topics was the suggestion of a "catch up day" for special needs children attending Kindergartens.

Children in receipt of special needs funding packages in schools have an annual "catch up day" (February 28) when kids that do not have appropriate packages or assistance are identified and dealt with. The level of the packages are not always to the satisfaction of parents, but nevertheless it is a day to make sure that all children get some level of service and do not slip through the system.

In kindergartens in East Gippsland however, relief catch up packages were not provided until July this year for kids that initially missed out altogether!. While Tim was unsure in how many other areas this scenario, it is a totally unacceptable arrangement.

Tim and Mr Doyle had discussions on introduction of a "catch up day" for the kindergarten system on the same day as primary schools. Mr Doyle was extremely receptive to the idea and has promised to pursue the issue in Parliament when it resumes.

We will keep you informed of the outcomes to this and other issues in Victoria as they happen.

Tasmania

By Geraldine Robertson

Autism Tasmania employs Rose Clark in the position of Family Support Co-coordinator. In addition toinhome support, Rose co-ordinates regional support groups. She also accompanies parents to meetings with schools and various support services. Rose frequently addresses schools and service organizations regarding autism. Her presentations are always very well received.

Tasmania des have and advocacy organization, Speak Out. This is a generic service, and although one of their staff has an autistic child, systemic problems affecting people with disabilities in Tasmania have been identified. These affect autistic people profoundly, as there is a lack of choice of services resulting in a low quality of life for many. Amongst these are a lack of employment options, support for families and difficulties accessing generic services.

In addition to this, many are involved in promoting an understanding of Autism throughout the state. I have noticed an interest in Autism from diverse groups, with all reporting that they are experiencing an unprecedented demand from autistic people. Recently I met with a representative from Family Planning to talk about sexuality issues for high functioning adults. I have also addressed Disability Support workers on counseling adults with Asperger's Syndrome. Recently I was invited to address paediatric nurses on supporting children with Asperger's Syndrome in hospital. I would recommend that these groups be targeted in all states, as they can make a profound difference in the quality of life for autistic people.

Geraldine has kindly agreed to be our State Correspondent for Tasmania and will keep us informed of the news in that state. We look forward to reading her contributions.

In The News

Recent review of ASD in The Lancet

Fred R Volkmar, David Pauls (Oct 4, 2003) Autism, The Lancet, pp1133-1141

Abstract: Autism is a disorder characterised by severe difficulties in social interaction and communication, and with unusual behaviours. Once thought of as rare, autism is now recognised as being common. The role of CNS factors in pathogenesis is suggested by high rates of seizure disorder; research has highlighted the role of several specific brain regions in syndrome pathogenesis. Autism is a strongly genetic disorder and probably arises because of multiple genes; recurrence rates in families with one child are high. Early intervention with various techniques is helpful in many cases. Some pharmacological agents may help with certain problematic behaviours but do not address the underlying cause of the disorder.

It is a "seminar" that could be considered to update some of the standard texts and references. It summarises a considerable set of research works. The views it contains would be regarded by most as conservative. This may be a useful reference in some advocacy situations.

Is Autism Ultra-Maleness?

Source:

THE SCIENCE SHOW

Saturday 1 November, 12.10pm, Radio National

http://www.respitewest.infoxchange.net.au/group/noticeboard/items/20031205006b.shtml

Babies only 24-hours-old differ in their reaction to people: boys respond to machines and girls to faces. This finding by a Cambridge Professor is just one reason he sees autism as extreme male behaviour. But a London Professor has taken a different tack and followed those who cannot recognise fear in others. He too has found a gender link.

Click here for more information

Autism , Testosterone & X

Broadcast Saturday 01/11/2003

http://www.abc.net.au/rn/science/ss/stories/s975521.htm

Summary: Neurophysiologist Simon Baron-Cohen has a new theory about autism. His research shows that autism could be an exaggeration of the male brain, and it appears that testosterone is the governing factor.

Transcript: Simon Baron-Cohen: Well, we decided to test whether the sex differences we were seeing at a later point in life might actually be evident on the first day of life. So we asked mothers at the local maternity hospital, The Rosie, whether we could film their baby whilst the baby was looking either at a human face or at a mechanical mobile. And we just filmed the babies' eyes to see how long they remained interested in the face or the mechanical mobile.

What we found was that these newborn babies did show a sex difference, that little girls looked longer at the face and little boys looked longer at the mechanical mobile.

Now, the fact that this was on the first day of life means that whatever role social experience is playing it wouldn't have kicked in yet - not at 24 hours old. And so, at the very least, we can imagine that biology is contributing some effect.

Genes, Fear & the Brain

Broadcast Saturday 01/11/2003

http://www.abc.net.au/rn/science/ss/stories/s975523.htm

Summary: A small group of otherwise normal people who have damage to a part of the brain called the amygdala, lose the ability to recognize fear and perceive other people's intentions, and Professor David Skews believes that there is a genetic link connected to alterations on the X chromosome.

Transcript: David Skews: Recognition of fear is intriguing. It was recognised a few years ago that there's a small group of people who have damage to a particular part of the brain, which is known as the amygdala, lose the ability to recognise fear.

US Government Mapping Out a Strategy to Fight Autism

By JANE GROSS

Published: November 19, 2003

Propelled by the skyrocketing number of diagnoses of the perplexing brain disorder autism in children, federal officials have for the first time mapped out a long-term, interagency plan to deal with the problem.

The plan includes objectives like the development of teaching methods that will allow 90 percent of autistic children to speak; the identification of genetic and nongenetic causes of the condition; and adequate services for all afflicted children in the next 7 to 10 years.

The plan, which is to be unveiled at a major autism conference in Washington that begins today, signals the start of the push-pull process over financing. Such a plan was required by the Congressional appropriations committee that controls the budget for scientific and medical research and education programs of all kinds.

Few of the nearly 150,000 autistic children and young adults now getting special education services under federal law will benefit significantly, experts say, since the most effective treatment involves early, intensive behavior therapy, which is poorly understood and in limited supply.

Autism is a disorder with a wide range of symptoms sometimes so mild as to let a child function in a regular classroom with special services and at other times so severe that a child is mute and institutionalized.

The three-pronged plan sets goals for more coordinated biomedical research, earlier screening and diagnosis, and effective therapy. The plan demands, for the first time, collaboration between scientists, clinicians, educators and policy makers in an array of federal agencies.

"Millions of people need help," said Robert L. Beck, president of the Autism Society of America, the nation's oldest and largest autism advocacy group.

"And this is a new opportunity and a very exciting one."

The need is enormous. According to federal education officials, in 1992-93, fewer than 20,000 of the nation's nearly five million special-education students, ages 6 to 21, were considered autistic. Ten years later, nearly 120,000 of six million special-education students had autism. That does not count the 19,000 children 3 to 5 receiving autism services under federal law, or those younger whose numbers have not been tallied.

Nobody knows the cause of the surge, although epidemiologists suspect it is largely a result of refined diagnosis and public awareness. That does not change the dimensions of a problem that strains schools, medical services and families. Nor does it affect forecasts of growing caseloads for decades to come.

Dr. Fred R. Volkmar of the Child Study Center at Yale University, a leading autism researchers and a member of the committee that drafted the 10-year plan, measures the crisis in more anecdotal ways.

Twenty years ago, Dr. Volkmar said, when he told people he worked with autistic children, they often misheard him and thought he had said "artistic." They had never heard of the disorder, which typically affects the ability to communicate, form relationships with others and respond appropriately to the external world.

By contrast, Dr. Volkmar said, it is rare these days not to know someone with an autistic child. He now sees children as young as 12 months, gets referrals from day-care centers and has a two-year waiting list. Were screening techniques to improve so that diagnoses could be made in infants, he would be hard-pressed to find schools, trained behavioral therapists or other services for them.

The plan, which will be reviewed by the Interagency Autism Coordinating Council, established by the Child Health Act of 2000, is presented in broad brush strokes, with few details and no price tags. It was drafted by scientists to assess the state of autism research and identify the roadblocks that might be hindering progress in understanding the cause and the best treatment options.

The plan lays out a timeline, in increments of 1 to 3 years, 4 to 6 years and 7 to 10 years and then ranks goals according to the likelihood of achieving them. Realistic goals in each of the three stages include the development, evaluation and institution of effective treatments, in collaboration with the Department of Education.

More challenging goals, by contrast, include finding effective drugs for the symptoms of autism and identifying environmental factors that may contribute to the development of the disorder.

"The idea is to be challenging everyone in the field to be reaching for the best we can possibly do," said Dr. Steve Foote, the director of neuroscience at the National Institute of Mental Health, which was designated the lead agency by the Child Health Act. The legislation, passed in the Clinton administration, addresses dozens of childhood disabilities.

Some parents are likely to be frustrated by the plan's suggestion that it will take at least seven years to provide treatment for all who need it. Mr. Beck of the Autism Society of America hoped that long-term research and improved services were not mutually exclusive. "There are good practices out there," he said, "just not enough of them."

He added: "And there's no money on the services and treatment side. What do we do with the kids for the next 7 to 10 years? We have to do both. You cannot just throw away a generation of children."

Many researchers and clinicians in the field credit the advocacy community with galvanizing the government, following in the footsteps of AIDS advocates in the 1980's. There are several such organizations, all included at the conference, that have shifted emphasis from looking for a cure to also fighting for a more systematic study of treatments and more services for children.

There is wide agreement that intensive behavioral therapy, which can include breaking a simple task like hand washing into a dozen component parts, beginning at the earliest possible age, is highly effective for many children. What remains a mystery is which children benefit and why, which techniques work best and whether early improvement is sustained over time, said Dr. Catherine Lord, director of the Autism and Communications Disorder program at the University of Michigan and an author of the interagency plan.

Parents of autistic children are stymied by how difficult it is to find properly trained behavioral therapists. Like others on the scientific side, Dr. Volkmar said that was because the Department of Education, under President Bush, had been "a real stumbling block." Mr. Beck agreed and said he was "quite excited to see them at the table."

Education officials denied a lack of interest. Robert Pasternack, assistant secretary for special education, said Mr. Bush had been generous in his financing requests for educational services for the disabled. Mr. Pasternack acknowledged a "critical shortage of special education teachers" and said the government was eager to "help states recruit and train them."

Schafer Autism Report (November 19, 2003) Vol. 7 No. 232

Autism on the Rise-Agencies Convene to Attest to this Disturbing Trend

11/17/2003 12:27:00 PM

MONTREAL, QUEBEC, Nov 17, 2003 (CCNMatthews via COMTEX)

The number of children diagnosed with autism and pervasive developmental disorders (PDD) is escalating at an alarming rate. Quebec has yet to implement a system to monitor and tabulate this growing rate. However, a growing number of government organizations that are witnessing the increasing demand to service these children and their families will convene at a press conference to confirm the seismic rise that they are observing.

Various government and community organizations faced with this growing demand have accepted to address this problematic and will report on the growing prominence of individuals with autism amidst their organization.

L'Office des Personnes Handicapes du Quebec, the Regroupement des CLSC, Readaptation Centres, and the Canadian Autism Society are amongst the representatives of government agencies and community organizations that will be assembled at the press conference. Through their accounts, this panel of specialists will illustrate the growing rate of autism and PDDs in Quebec.

While the increase of autism and PDDs is being witnessed by government and community organizations, various questions remain unanswered. Why so many children are being increasingly affected? What is causing this dramatic growth? What needs to be done to avert the perpetuation of this epidemic?

Bio-medical research and treatments are long overdue to understand the causes of this disabling disorder in order to halt its pandemic proportions.

In response to this urging need, the 4th International Medical Conference on Autism - Autism 2003: Understand, Act, and Heal - will take place on November 21st and 22nd 2003 at Place Dupuis of the Hotel des Gouverneurs

NEWS RELEASE TRANSMITTED BY CCNMatthews

Students and Employees with Disabilities

Source: EnableNet

A new Resource has been developed titled "Choosing Your Path. Disclosure: It's A Personal Decision". This Resource has been developed for students and employees with disabilities and also for employers, educators and support services. The Resource provides information about:

The options and pathways a person with a disability has when deciding to disclose their disability, the benefits and disadvantages of disclosing as well as providing some key considerations to achieving effective disclosure.

The rights, roles and responsibilities of employers, educators and support services when a person discloses a disability in post secondary education and employment.

We have also developed a Postcard that has the design on one side and an outline of the Resource on the other. If you would like copies of this Postcard sent to you, please email me your name, address and the number of postcards you require.

Please have a look at the Resource, link your website to the Resource and pass the web address on to your networks. The web address is: www.uws.edu.au/rdlo/disclosure

This Project is an RDLO/DCO Initiative, written by Anna Mungovan and Fran Quigley, RDLOs for the Greater Western Sydney Region and Western Victoria Region.

Thiomersal and MMR vaccines in Australia

By Bob Buckley

Internationally, interest in thiomerosal, also known as thiomersal, in MMR vaccines has been revived by several recent publications Thimerosal is an organic compound containing ethylmercury.. This sparked several inquiries to A4 on the subject.

In Australia, parents can decide to vaccinate their children with MMR vaccine knowing their decision will not result in autism due to thiomersal in the MMR vaccine since there is no thiomersal in the MMR vaccines available here.

Many parents are wary of unbalanced information. When given the carefully constructed spin that "there is no credible evidence to support a link between autism (or other neurological disorders) and mercury poisoning from thiomerosal" they become suspicious when it is not immediately qualified with the balancing statement that "evidence showing mercury has not contributed to the increasing rate of autism diagnosis is inconclusive at best". Professionals who give partial or biased information diminish credibility; they may destroy trust and respect for the profession and these are very difficult to restore.

While it is not A4's role to engage in scientific discussion, some members felt it would be useful to collect some of the information available in and relevant to the Australian context.

The Therapeutic Goods Administration (www.tga.gov.au) said there is no thiomersal or equivalent in any of the MMR vaccines available in Australia; nor has there been for some time. The TGA telephone consultant said there is no thiomersal in any vaccine on the NHMRC vaccination schedule (see http://immunise.health.gov.au/handbook.htm).

You can check the contents of one of the MMR vaccines on the Australian Vaccination Network, Inc (AVN) website at (see http://www.avn.org.au/Vaccination%20Information/MMR_vaccine_mmr2.htm). AVN expresses a number of concerns relating to vaccination.

Some members noted there is some thiomersal or equivalent in some vaccines that can be given to children, for example H-B-Vax II for Hepatitis B. If you are concerned you should ask the doctor who is administering the vaccine or check the packaging yourself.

One health professional I spoke with in the ACT was very concerned about MMR vaccination.

He warned me there have been two case of chronic encephalitis in the ACT in the last decade. He was previously unaware and apparently surprised that CAMHS alone diagnosed 45 cases of autism in the ACT in 1997.

A4 is seeking written confirmation of the history of thiomersal in vaccines for children in Australia.

Awareness

Newsweek's My Turn: Reaching the 'Point of No Return' in Public

When 'J' has a fit, spectators assume poor parenting is to blame. They never suspect that he's autistic. Marie Lee says public outings with J, her autistic son, are embarrassing and frustrating

By Marie Lee

http://www.msnbc.com/news/985045.asp?0cl=cR&cp1=1

On a sweltering August day, I decide to spend the afternoon with J, my 3-year-old, riding the trolley that cruises around our city. J is autistic with limited speech, but his smile tells me he agrees with my idea. “SHOULD I FOLLOW you in the car?" my husband, Karl, asks worriedly.

"We'll be fine," I say confidently. J's waiting patiently at the trolley stop.

Karl's worries aren't unfounded. Because J can't communicate functionally, he gets frustrated easily. Add to that his hypersensitivity to stimuli, and we never know what will happen.

J boards the trolley: no problem. Reluctantly, Karl drives away.

Today's ride is free because it's so hot out, but that also means it's crowded. The clanging of the bell, which sounds so quaint on the outside, is much louder on the inside.

Almost as soon as the doors swing shut, J shouts, "No! No! No!" and jumps off my lap. "OK, let's get off, then," I say at the next stop. But J grabs onto a pole and resists with a howl. He's descending into the "point of no return," where his brain short-circuits into an unstoppable outburst.

By the next two stops, he's causing such a ruckus that I carry him off like a flailing bag of potatoes. We've had the misfortune to debark at Thayer Street, the bustling center of the neighbourhood around Brown University. We're in front of a restaurant that has metal sidewalk tables, and J is flinging himself to the filthy ground as I do my best to keep his head away from the sharp edges of the tables.

"Bring him over here!" A white-haired man sitting at one of the tables motions severely to me. Older folks often see a child who "just needs a good lickin'." I ignore him, but J's siren-like screams have now attracted a crowd. Some parents with toddlers in tow shake their heads; I can hear them speaking smugly among themselves: "Glad our kids know how to behave."

In the meantime I'm on my knees, trying to get J to stand upright. He pulls my hair, tears my favourite necklace from my neck. When he realizes I'm trying to get him on his feet, he twists like Houdini and kicks off both of his sandals. I put him in a modified jujitsu hold, scooping him up by his bottom. He wails even louder. A few people openly glare, hands on hips. One woman even has her cell phone out-is she debating whether to call 911 because she thinks I must be abusing this child?

A homeless man approaches. "Hey, you got some kinda problem here," he giggles, obviously finding our situation hilarious.

"Marie? Is there anything I can do?" I look up; sweat streaming, to see my friend Deborah, a Brown professor.

"Tell these people to stop staring at me," I say. Deborah turns, but the crowd, seeing that an elegantly dressed professor has stopped to address the bad mother, is dispersing. Deborah helps me get organized and gracefully disappears.

I offer J his water bottle, making him ask for it properly. This mental activity of finding the word "water" distracts him enough that I can buckle on his sandals, get up-my knees blackened and bleeding-and hustle him away. When we arrive home, Karl asks how the trolley ride was. I burst into tears.

This is life with an autistic child. J looks like a healthy, beautiful little boy, but his autism diagnosis at the age of 3 is not the most dramatic thing that's happened to him. At 18 months he was diagnosed with a spinal tumour, and he spent the better part of a year in a body cast and a wheelchair.

I think back almost wistfully to that wheelchair. Then, people went out of their way to help us. "Oh, the poor brave little boy with cancer!"

But no one looks at J in the midst of a tantrum and offers to help the brave little boy with autism.

My urge during J's fits is always to scream, "My son has a neurological disorder!" But I've decided whatever satisfaction I might get isn't worth what it could do to J: who knows how much he understands, and despite what doctors tell us about the incurability of autism, who knows if he'll always be this way? Those out there who are so certain we are bad parents should take heed of the alarming rate of autism: a Centers for Disease Control study found that as many as one in 150 children had it in one community. That translates to one in 68 families, according to the Autism Autoimmunity Project. The next time you are inclined to judge a parent, stop and think. There might be more to it than "bad parenting."

Lee lives in Providence, R.I.

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Book Review

The Curious Incident of the Dog in the Night-time

by Nick Haddon

Published by David Fickling Books

RRP $29.95

Book Review by Alice Minchin (aged 12)

Oxford based author, Mark Haddon, wrote this intriguing novel. Mr Haddon (author, illustrator, screen writer) has written fifteen children's books. The Curious Incident of the Dog in the Night-Time was first published this year.

The main setting of the story is a house in Swindon, not far from London, where fifteen year old Christopher lives with his father. Christopher narrates the story. Christopher has Aspergers syndrome, a form of high-functioning autism. He has a brilliant photographic memory, he can understand maths and science, but he can't understand other people, or other people's feelings.

Christopher's favourite (recurring) dream is about the whole world being infected by a strange virus. You catch the virus from looking people in the eyes and understanding what they say or how they feel. Then you die. Soon, only special people are left in the world: people who don't look at people's faces and don't understand how other people feel, people like Christopher.

Christopher likes dogs. Dogs don't have complex feelings, only happy, sad, and angry. Christopher is devastated when he finds his neighbour's dog has been 'murdered'. He decides to find out "who killed Wellington" and write a murder mystery novel. But being a detective isn't easy, it involves TALKING TO STRANGERS.

Christopher's mother is 'dead'. She has been 'dead' for the past four years. But then Christopher discovers a box full of letters. If his mother is dead, how come the letters keep coming?

The main theme is about understanding the world from the perspective of someone with Aspergers Syndrome. The irony is, the reader understands more than the narrator.

This sad and funny novel, which really gets inside the Aspergers mind set, is a deadly accurate piece of writing. As the sister of a nine year old boy with autism, there were many behaviours that I could recognise and relate to.

I recommend this book for ages twelve to adult, particularly those who are related to or know someone on the autism spectrum. Of course, it would be an engrossing and educational read for those who are unfamiliar with autism.

I'd give it 10/10 for its amazing accuracy.

Diary Dates

A4 invites you to a weekend of Autism Advocacy

Where: The Priory Beechworth (NE Victoria)

When: 6 & 7 March 2004

What: Saturday → a day of advocacy information and workshops, with topics including: 'How to best access your local representatives and members of parliament', 'Education Advocacy', 'Public Speaking', 'Media Skills', and 'An Agenda for National Autism Advocacy'.

Saturday night → a chance to relax and meet other ASD families over a drink and casual BBQ

Sunday morning → the inaugural General Meeting of Autism Aspergers Advocacy Australia – A4, your chance to have a say in the future of our national organisation.

Mark your diaries now, this is an event not to be missed! Check this space for more details and registration form in next A4 Update.

To be kindly hosted by Oaks Inc (PO Box 556 Beechworth 3747) Email: ourautistickids@bigpond.com

Final costs, programme and registration forms will be available shortly after our next committee meeting on Sunday 30 November.

Biennial Australian Autism Spectrum Disorder Conference

Autism Association ACT & Autism Council of Australia

Friday, 1 Oct - Sunday, 3 Oct, 2004
Rydges Lakeside Canberra

The conference will be preceded by a day of focused workshops, on 30 September, also at Rydges Lakeside.

Keynote Speakers are as follows:

Dr Jeanie McAfee
[author: Navigating the Social World; see Dr McAfee's internet site here.]

Dr Tony Attwood
[well known author, trainer, presenter and diagnostician; see Dr Attwood's internet site here.]

Expressions of interest are invited for the Biennial Australian Autism Spectrum Disorder Conference
If you would like to attend the workshops or the conference or both, please e-mail the conference team at Autism ACT and let us know. We will put you on the mail list.

CALL FOR PAPERS

Currently we are seeking:

Papers or presentations - session duration 45 minutes - 60 minutes including a Q/A period;

Poster presentations - space will be provided to display your presentation and time scheduled so you can meet people to discuss your presentation.

If you wish to offer a paper, a presentation or a poster presentation, please contact the conference team at Autism ACT and indicate your interest, and if available, a subject/title.

You are urged to book early. Contact Autism ACT

November Profile

Meredith Ward is the A4 Update State Correspondent for Victoria. She kindly agreed to be 'profiled' for this issue of the Update.

NAME?

Meredith …or just 'last minute Meredith' because I'm always pushing the deadlines.

BORN?

1964 Kyabram, Victoria

LIVES?

Melbourne

FAMILY?

Hubby Andrew, sons Grant 7 ½ (Autism with ID) and Adam (too clever, lots of mischief)

INVOLVEMENT WITH A4?

Founding steering committee member. State Correspondent A4 Update - Victoria

OTHER ORGANIZATIONS?

Autistic Family Support Association (Vic), State Council member of Autism Victoria

DREAMING OF?

Oh ….that day when we won't have to advocate for better everything for our kids!

LISTENING TO?

Anyone who will talk to me

READING?

Only the books that the boys bring home from school

RELAXING?

Not often enough – usually a strong latte or a wine with friends

EATING?

I love really good seafood….who can recommend a good restaurant?

LIKES?

Just about anything

IDEAL WEEKEND?

Seaside, anywhere with warm weather.

LAST HOLIDAY?

Just before the end of term 3 the family went to Surfers Paradise – our first family holiday with no cooking, cleaning and just relaxing – free kids club deal. The kids had their first plane trip. We hope to do it again.