A4 UPDATE
Autism Aspergers Advocacy Australia

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Issue 4

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Feature

An Audience with Autism

People with an Autistic Spectrum Disorder will be represented by hundreds of white chairs lined up on the lawns of Parliament House in Canberra on Thursday 30th September.

An Audience with Autism is being staged by Autism Aspergers Advocacy Australia (A4), to promote public awareness of this lifelong disability that thousands of Australians face everyday.

All members of the Autism community are welcome to walk to Parliament House with invited Parliamentarians, where a sea of white chairs will represent those that can't be there and their silent pleas for acceptance and understanding.

You too can be a part of this event even if you can't be in Canberra on the day. We need you and everyone else you know involved with ASD to go to the A4 website, print out your template, attach a photo of your loved one and send your template and $10 (cheques made out to Autism Aspergers Advocacy Australia) to PO BOX 524 Traralgon Victoria 3844 attn: Kelley Harris.

To date, we have over 300 chairs sponsored by members of the Autism Community. If you don't want to miss the opportunity to be involved in the first ever National Awareness Event for Autism, you need to send in your templates before 20th September so we can finalise the hiring of the chairs.

Now is the time to act. Let's show the government how many families are touched by Autism, how many "voters" are involved in our community.

For further information contact:

Kelley Harris, Event Coordinator - awarenessevent@a4.org.au

Convenor's message

Dear A4 member,

Our Audience with Autism (AwA) event will be happening soon. You can be part of it even if you cannot come to Canberra. Please read about it on our website (www.a4.org.au) and sign up if you possibly can. We need plenty of photos so this event makes as much of an impression on politicians and the press as possible. Be sure your photograph is there on the day.

We would like people to promote this event within their state and local support groups, friends, contacts and to others affected by ASD. If you can help promote the event in your area, please let the AwA committee (awarenessevent@a4.org.au) or me (convenor@a4.org.au) know and we'll send you some material that may help.

Please remind your friends about this and help them get their material together. And please send your materials soon so we don't have to do all the work in the last few days before it happens.

The Audience with Autism provides an opportunity for us to put our case to politicians. It seems extremely likely our event will happen before the next election so politicians will be listening to their communities. This is our chance to show that autism spectrum disorders including Asperger's syndrome are of significant concern for our community. And it is a chance for you to contact your local politicians and political candidates to inform them of issues affecting people with ASD, their families, carers, friends and associates.

In the previous Update, I mentioned that we met with an advisor to the Minister for Health and Ageing. As a result, we asked the government for a meeting with health professionals and bureaucrats to develop an agreed plan of action at the federal level in relation to ASD. The cost of such a meeting would be quite moderate and it could happen quite quickly. We have not received a response from the government.

With the help of Bernie Ripoll MP, I met recently with Julia Gillard MP who is the shadow minister for health and ageing. She said "an incoming Latham Labor Government would instruct the Department of Health and Ageing to convene a working group comprising representatives of your organisation, the Autism Council and relevant medical organisations".

The Bundaberg ASD Support Group's conference was a huge success. They had over 400 people attend the first day and over 300 the second day. Congratulations to the organizers and to the conference presenters on an extremely successful program.

Regards,
Bob Buckley
Convenor

An Interview with Professor Margot Prior

Professor Margot Prior is one of Australia's most experienced and respected autism researchers. It has been almost 35 years since she first met a child with autism, when she first took up post-graduate study in psychology. Her first career was as a professional oboe player.

A former Professor Director of the Psychology Department at the Royal Children's Hospital, and Professor of Psychology at La Trobe University, Margot is now Professor of Psychology at the University of Melbourne.

Has the profile of autistic children changed over 45 years?

When I first started research in the 1970's, we saw predominantly very low-functioning children. Now in Australia we have got a big burst of Asperger's diagnoses. We are also seeing them younger, of course. Back then we would diagnose children at 5, 6 or 7 and older, now we see them at 2 or 3 so that has changed the profile as well.

Our expectations of the children have changed, we know they can learn lots of things and that they are capable of far more than we knew in the past.

What motivated you to work with children with autism?

I picked on the topic of autism for an essay I wrote for my fourth year psychology course. It was very new then (1969) and no one knew much in Australia so I saw that there was an exciting challenge to discover more through research and practical experience in working with autistic children.

I visited one of the first centres for autistic children in a hall in Mentone, also another one in Canterbury. This must have been in the late 1960's, I think. I saw what a mysterious and challenging condition this was. I was highly motivated to find ways of helping children and families, and wanted to explain where this condition came from, how it should be diagnosed and treated etc.

I was always focused on children, including my own, and keen to help those with handicaps of any kind. My psychology career became focused on children's problems of many kinds, learning difficulties and behavioural problems especially, and I am still exploring this area as researcher, teacher and clinician.

What can parents and others learn from your autism research?

That this is a biologically based disorder in which children have enormous difficulty in processing information of all kinds (cognitive, emotional, symbolic etc) and understanding how to interpret the world. I see their behaviours as a reaction to this inability to understand what the world is about, and as an attempt to impose order on it.

What is your current research?

I am involved in a few large-scale studies. One of these is a longitudinal study of children's language development. There are 2000 children in the study and we expect to pick up early signs of language and communication difficulties.

Then there are three autism-related projects. One looks at the characteristics of parents, their social and communication attributes. Another is looking at hyperlexia. The third focuses on siblings' problems and what affects how well they cope especially socially; for example how do they explain their sibling's difficulties to their friends.

I do more research and writing than anything these days and I am glad that towards the end of my career I have time to focus on getting my research finished.

You have an interest in the role of fathers. Can fathers play a special role in the lives of their children with autism?

Indeed, they are especially important in supporting mothers who usually bear the biggest part of the burden, and also in socializing the child and teaching him/her new skills and providing new experiences.

Fathers are also important in giving time and attention to siblings who may not always get their fair share because of the demanding autistic sib.

What sort of research would you like to see happening in Australia over the next 5-10 years?

More careful evaluation of treatment methods, how well they work, who they are suited for and who they do not suit; more work on understanding communication problems; and finding ways of understanding what lies behind this deficit and ways of managing this.

Australia is very, very poor at treatment evaluation, not just in autism but in everything. There isn't an evaluation frame of mind and the government is very slow at picking this up. The government should fund a randomised controlled trial of ABA and comparisons with other interventions. The government doesn't fund ABA, so at the very least they should fund a trial.

Where do you think the priorities lie for parental lobbying?

We are in critical need of funding for expert teams to assess and diagnose children. There are such long waits for assessment and diagnosis – it's unconscionable and a terrible blot on Australia. There also needs to be much better education of professionals, especially doctors in picking up the early signs.

A second major need is in early interventions services. There are some families who still get no help or pitifully few hours. Many families aren't able to speak up for themselves and to get the help they need.

The parents of autistic children have always had to fight and even all these years later, they are still having to fight.

Do you believe that we will see real progress within the next ten years, both in uncovering the genetic and environmental causes of ASDs and in their treatment?

We have made lots of progress and I expect this to continue. It has come about from research and therefore although families are already very burdened, it is important that they support research for their own sakes as well as for future generations. This is a very important point especially in a country like Australia where there are relatively few families to contribute to research.

Activity is high in genetics and also in understanding the co-morbidities like hyperactivity, attention deficits, anxiety etc., which so often go with autistic behaviour. Treatment is improving steadily, but we might have to accept at least for the moment that we are still far away from a "cure".

What advice do you give parents when their children are diagnosed with an ASD?

Go for as much early intervention as you can with well-trained high quality teachers. Don't take any nonsense; these children can learn what is OK and not OK, and you have to work hard to socialize them as best you can. Get support for yourselves and your family so that there is always someone to turn to when times are especially tough. Learn from other families with similar children. Expect improvement and work for that, but don't expect a miracle, celebrate small gains. Give your child lots of loving even if he/she does not seem to want it (they do!). Don't take up with charlatans who will promise cures and take your money when there is no evidence that they can fulfil their promises.

Your top five books for parents to read?

I usually recommend Tony Attwood's books; Lorna Wing's books are terrific for parents as well as professionals.

Sally Ozonoff is an excellent writer, her most recent book is:

A Parent's Guide to Aspergers Syndrome and High-Functioning Autism: How to Meet the Challenges and Help Your Child Thrive (Guildford Press, 2002). Sally Ozonoff, Geraldine Dawson & James McPartland.

My recent book on Asperger's is full of top quality helpful information from all the best people in the field. **Learning and Behavior Problems in Aspergers Syndrome** edited by Margot Prior (Guildford Press 2003).

An article by Professor Margot Prior concerning ABA will be published in the September/October issue of the Journal of Paediatrics and Child Health, Vol 40, Number 9/10, September-October 2004.

http://www.racp.edu.au/public/jpch_about.htm

HREOC conciliation in education

Reminder: Conciliated settlements are usually made without admission of liability and may not provide firm precedents for the outcome in other cases.

2003

Inclusion in primary school

Parents complained on behalf of their daughter, aged 7, who has an intellectual disability and Autism Spectrum Disorder, that she was discriminated against when she commenced attendance in Grade 1 at the local primary school. They claimed the school failed to provide her with reasonable accommodation for her disability in the means it employed to prepare and present the curriculum to her, by limiting her attendance to two hours a day, and by applying the school discipline policy to her when she exhibited adverse behavioural manifestations of her disability. They claimed the class teacher showed little interest or skill in including her in the general class activities, that she was sent home "at the whim of" the teacher, and that the principal suggested she be moved to a special school. They also complained that they were discriminated against as associates of a person with a disability by being treated less favourably by the school than it treats other parents by being requested to attend frequent meetings, to come and supervise their daughter in the playground and to be no more than 5 minutes away at all times. They removed her from the school after six weeks.

The respondent education authority claimed that efforts were made to ascertain L's particular needs so that it could prepare an individual program for her to assist her to access educational services in a way which was appropriate to her needs to accommodate her disability. It advised that it made sure it included the parents in meetings to discuss the program it was preparing to accommodate her disabilities. She was approved for disability support funding to provide an integration aide and occupational therapy and speech therapy services. It advised that the class teacher had provided detailed planning and resources for the girl and that her teachers received additional support from the Guidance Officer and an educational psychologist. It advised that the girl was still in the settling-in stage in starting a new school and denied it had discriminated against her by failing to provide reasonable accommodation for her disabilities.

A conciliation conference was conducted. The matter settled following post-conference negotiations by the provision of a written apology, provision of a computer to assist the girl's learning in the classroom at her new school, specialized equipment and educational programs for prepared for her, an assurance that the department would provide her with reasonable accommodation for her disability throughout her primary school years, and a sum of $5,000 in financial compensation for the stress and anxiety that the parents claimed they had experienced.

Accommodating a student with Asperger's syndrome

A woman complained of discrimination in education on behalf of her 15 year old grandson who had Asperger's Syndrome. The grandson had recently moved to his grandparents' home and transferred to the local high school. The complainant alleged that her grandson had been suspended from school for conduct related to his disability such as answering back to teachers and refusing to comply with the dress code. He was required to attend a behaviour management program at a different location which allegedly did not include any academic work. The complainant claimed that if the teachers had informed themselves about the condition they would have been able to develop strategies to manage his behaviour, which in any case was not serious enough, in her view, to warrant suspension. The complainant arranged for a medical specialist to address the teachers but she alleges that only two were sufficiently interested to attend. The complainant was keen for her grandson to complete year 12 as he was academically gifted.

The complaint was conciliated on the basis that the student would enrol in year 10 in 2003 and that he would do a mix of academic and vocational subjects. A computer would be loaned to the student for use at his home until he leaves school. The educational authority agreed to provide funding for a mentor for the student (a recently retired teacher) and to provide the school with support on disciplinary issues. The respondent also provided a nominal amount ($350) to cover the complainant's legal costs.

2002

Bullying

A mother complained that her son who has autism had been bullied and harassed by staff and students at his High School. The respondent apologised to the complainant and agreed to conduct training for all staff at the school in relation to Autism. The parties set up a chain of people for the complainant to contact to resolve any ongoing concerns. The complainant was satisfied with this outcome to resolve her complaint.

Inclusion of child with intellectual disability

A woman whose son has an intellectual disability complained that his school had made statements indicating that her son should not be in mainstream classes, that her son took up too much of the teacher's time and that there is not enough aide time available to cater for his needs. She also claims that the school had failed to act against children who bullied or teased her son.

The school responded that there was basis for concern regarding the complainant's son's ability to cope in mainstream class and that it has a responsibility to ensure parents are presented with all options for the education of their children. It also claims that it has a responsibility to ensure that parents are provided with accurate and fair feedback about the progress of their children at school.

The complaint was resolved through conciliation. An agreement was signed without admission of liability that the respondent will explore professional development appropriate to communication with parents of children with disabilities, will continue to work with her son in a positive and constructive manner to meet his educational needs and communicate with the complainant in a clear and timely manner about incidents concerning her son's welfare and safety. The complainant agreed to follow the school's procedures of making an appointment when wishing to meet with staff, attend regular meetings every 4 weeks with an advocate present so she can be informed about her son's educational progress and commit to treating staff at the school with civility and courtesy.

Disciplinary procedures reviewed

A parent of an autistic child complained that the child was being discriminated against when his school used suspension as a means of disciplining the child for his behaviour. The complainant alleged suspension was inappropriate given the child's behaviours were a manifestation of his disability and that the child could not comprehend that suspension was a punishment designed to improve his behaviour. The complaint was settled when the school agreed to trial revised procedures based on an independent report and to consult with the parents on the implementation process.

2001

Responding to bullying

A mother complained that her son who has an autistic disorder had been discriminated against when he was suspended from school. She said her son was constantly bullied at school and reacted to bullying by being aggressive, and that the school had taken action only against her son and not the bullies. After a conciliation conference and further negotiations an agreement was reached for the boy to return to school with the support of an intervention plan, additional teacher aide time and individual education program, as well as for review of the school's suspension policy and strategies for dealing with bullying.

Accommodation for exams

A woman complained that her son had been discriminated against on the basis of dyslexia and Attention Deficit Disorder when her request for a reading/ writing assistant for an exam was refused. The complaint was settled when the education authority agreed to permit an assistant for the exam.

Education aide funding

The mother of a child with Downs Syndrome complained that her daughter had been discriminated against by a State educational authority providing education aide funding for only part of the school day. Her daughter has behavioural problems requiring supervision including running away. Following the Commission's inquiry into this matter, the education authority advised that it had increased the level of funding for support services for the child such that the mother would no longer need to fund part of the aide's time herself.

2000

Autistic child at special school

The complainants alleged that a special school attended by their son had failed to accommodate his disabilities, which include intellectual disability, autism and epilepsy, when he was expelled after serious behavioural problems. The complaint was resolved when the school undertook a series of initiatives including procedures to be set in place to ensure a greater level of consultation between teachers and parents, development of more specific individual education plans for each child to accommodate the different levels of disability among the students, more appropriate accommodation to be made for children with multiple disabilities such this child, and attendance for all teaching staff at a two-day staff training course in autism.

Refusal of admission

The parents of a boy with a psychiatric condition complained that he had been discriminated against when he was refused admission to a secondary college after the principal formed the view that he was unsuitable for mainstream schooling. After a conciliation conference the college apologised and agreed to pay $5,000 compensation.

School enrolment secured

A mother complained that after the family moved to a rural centre, she had been unsuccessfully seeking for two months to have her son, who has a number of disabilities including autism and an intellectual disability, enrolled in a local school. Within two days of the Commission contacting the student services team of the relevant education authority, an enrolment in a special education class within a local school had been secured on a trial basis, and the complaint was withdrawn when the trial was successful to the satisfaction of all parties.

1993

Participation in school camp

A secondary student with an intellectual disability was refused permission to attend some days of a school camp because there was no funding for an integration aide to assist him on those days. The complaint was resolved on the basis that the school would permit attendance for the whole period using the assistance of a volunteer, and would provide an integration aide for the whole period of the next year's camp (1993).

Reminder: these reports show the applicants winning. Some people report that they may win a small battle such as these, but in their war for their child they feel they lost overall. The school and the school community may not accept the ruling. They may act on the letter of the law rather than the spirit.

Letters to the Editor

Regarding the reply to the "Sounds of Silence" poem

I think I shall remain angry about my son's autism for the rest of my life and I hope one day he too will join me in feeling this anger, not only about the lack of services or even the lack of knowledge about autism, but about his personal loss as a child and man. I feel the "Sounds of Silence poem" only partly describes the loss and hurt my family suffers everyday but also the appalling lack of interest by Government & the community. It's as if my son does not exist. I commend the poem!!

My son is severely autistic and I would have liked to have shoved him, head-butting & scratching, screaming & kicking in front of Minister Refshauge at the NSW parliament house during autism awareness week. How on earth does the autism association expect to get funding for autism research or disability payments or anything when they present such high functioning autistic people to people with the power to grant the autism community money & recognition?

Unfortunately, this is a "victim" society and as long as we are seen to cope or succeed, we will get no-where fast. I am so jealous of high functioning autistic people. I would give anything for my son to say one word to me or kiss me or smile at me. I know high functioning people and their families have it bad too but don't deny my son or my family our grief at experiencing exactly what is stated in the poem. Have a heart, show the government and the community the success stories after they have supported the finding of success and hope for all of us, after they have pledged and followed through on providing evidence-based, accessible early interventions, decent pensions, high quality & beautiful group homes, screening tests for siblings, employment opportunities, avenues for gifted autistic people to communicate & exhibit their achievements to the community, standards of excellence for schools, pre-schools & long day care centres, affordable high quality "Shadows" for school kids, etc etc etc. Don't be offended by the truth that some of us live with everyday, be angry not with each other but with our Government. Keep agitating, don't be compliant. Be a thorn in the government's side until they take notice of our autistic community.

Thank you A4 for being there for me. You do a wonderful job, with such limited resources.

Sincerely Peed-off and staying angry,
Caroline Cristina NSW

The following is a letter from Rosemary Vinton that was written to the Life Matters Team from ABC Radio. Rosemary has given us permission to publish this re-edited version of her letter in the hope that someone will find it useful.

Dear 'Life Matters' Team,

Congratulations on your excellent and well balanced radio documentary on Radio National on the subject of Autism and Autism/ABA funding issues. I am the mother of a 4 year old boy who has Autism and found these programmes to be an honest and accurate account of how it really is to live with a child with an Autism Spectrum Disorder (ASD).

As mentioned 'AUTISM or ASD' is a LIFELONG DEVELOPMENTAL and/or INTELLECTUAL DISABILITY and according to latest statistics affects '1 in 100' children. However, ASD remains notoriously difficult to diagnose at a very early age. I feel the problem with ASD - unlike other developmental/intellectual disabilities such as Down's Syndrome and others is that there is no clear cut features or symptoms in the early months/years of life to alert parents or others to take action and commence intensive early therapy/intervention at the first possible signs.

The fact is that most children with an ASD appear to be beautiful and relatively healthy, happy babies/toddlers maybe with a few odd or puzzling behaviours/habits or exhibiting extreme tantrums or repetitive/ritualistic behaviours. Often delayed speech around the age of 2 years is the first sign that may alert parents/others/health professionals that there may be some form of developmental delay.

From my experience, I now consider Autism or ASD to be 'THE INVISIBLE DISABILITY' to all who ARE NOT living and caring for such children 24 hours/day - 7 days/week! It is often difficult to get family and health professionals to REALLY LISTEN to your concerns about your child's development/behaviour even when your 'gut instinct' is telling you that there is something not quite right with your child and the developmental gap between your child and others continues to widen.

The reality of living with a young child with ASD is that it is exhausting, frustrating, challenging, chaotic, confusing and frequently heartbreaking as you strive to do your best for your child whose behaviours are often unpredictable, challenging or just plain inexplicable.

However, there are also moments of joy which parents of 'normally developing children' often take for granted - a fleeting smile of recognition when your child masters a new skill, a second or more of eye contact with a bonus smile, a new word uttered (or what you think sounds like a new word!) - these are precious moments when your heart soars and your spirits are lifted. Then you know all the hard times and heartbreak are worth going through just to get to that moment.

Life with our beautiful boy has been an absolute 'roller-coaster' for my husband and I, both physically and emotionally and our marriage and relationships with family have been strained to 'breaking point' on many occasions.

To add to the traumas of living with a child with ASD, we too like many other families have suffered financially by trying to give our son the best possible chance to reach his 'full potential'.

Since our son's diagnosis (finally) of Autism at age 3 (which is considered a fairly 'early age' for such a potentially devastating/life changing diagnosis for families) he has attended an excellent Early Intervention Program at a local Special Developmental School. However, the school program is only for 3 days/week (we are lucky to be able to access 3 days/week as some Early Intervention Providers can only offer much less than this!). However, we have realised that whatever government agencies can provide in terms of Educational Support/Specialist Intervention is inadequate so we have taken matters into our own hands to 'fill the gaps' in the provision of specialist treatment.

As a result we have set up our own 'in home' ABA program in which we employ Special Education Psychologists/therapists to work at home with our boy in order to supplement/compliment his time spent at his Early Intervention/Education Program. This form of 'private' therapy costs us more than the average monthly mortgage repayment per month, however the benefits and gains our child has made with this additional therapy far outweighs the financial sacrifice (some countries such as the U.K. and U.S. have ABA type therapy as part of their government funded Early Intervention Programs). We believe that the more input our child receives NOW in terms of specialist education - hopefully the less he will require in terms of disability support in his adult life and therefore become less dependent on the welfare system (why does our government not understand this?). All we want for our child is that he be given the best possible chance to become a happy, well adjusted, independent adult able to contribute to society in some meaningful way! (Isn't that what most parents hope for their children's future?) Unfortunately, not all parents of children with ASD are able to provide the level of support our child receives and we consider ourselves fortunate to be able to provide this additional therapy for our boy. Moreover, most parents of children with ASD find themselves thrust headlong into the role of not only 'stressed out' parents but also Speech Pathologist, Physiotherapist, Special Education Teacher, Child Psychologist and Occupational Therapist not to mention the most important role of Advocate for their child with 'special needs'. As a result, sadly other siblings/family members often have to take a 'back seat' on the priority list, not to mention the personal/emotional and financial strains already placed on families!

Finally, it is totally unfair that parents who do not have the financial means to undertake ABA therapy for their child with Autism are unable to access this type of effective intervention as part of their child's basic right to 'equal access' to services. Australia has always taken pride in its 'egalitarian society' and 'fair access to health/education services to all'...why is this not happening. Although ABA therapy may not suit every child/family's needs our wish is to see government(s) respond to the need for more integrated services and support for families and children with ASD. We strongly believe (as parents of a young child with ASD) that the BENEFITS OF MORE EFFECTIVE EARLY INTERVENTION SERVICES FOR ALL CHILDREN WITH ASD will be seen in terms of more positive outcomes for families, children and government in the LONG TERM!

Rosemary Vinton
(Seaford Vic.)

From the Senate

On August 5, the government answered Questions on Notice No. 2942 and No. 3028.

Senator Ian Campbell tells us that in 2002, at least 7.5% of people receiving disability services had ASD. Much of the data presented was for a “snapshot day” in 2002. This data is a challenge to interpret and on its own tells us very little. We remain interested to see what the new data collection process shows.

Senator Paterson said carers for 11,694 children with autism and 2522 with Aspergers syndrome aged under 16 years receive carers allowance.

Senator Paterson did not give any figures for PDD-NOS or other conditions on the autism spectrum.

Clearly, FaCS is aware of 14,216 children with autism or Asperger’s. There are a small number who have a diagnosis but who had their applications rejected.

ABS data says there are around 4 million children aged under 16 years. This shows there are at least 35 children per 10,000 under the age of 16 years who have a diagnosis of autism or Asperger’s syndrome in Australia. There are many more children aged under 16 years who have autism or Asperger’s syndrome but who do not (yet) have a diagnosis. Previously, FaCS claimed ASD affects just 10 children in every 10,000. This data shows autism and Asperger's are at least 3½ times more common than FaCS has recognised.

Senator Paterson says there are 5125 new claims in relation to autism and 1944 claims relating to Asperger's syndrome in the period 2000 to 2003. This gives 7069 new claims compared to the birth rate of around 1 million children over a four-year period. The number of applications for carers allowance relating to autism and Asperger's (just part of ASD) is around 71 per 10,000 or 0.71% of children. This is more evidence that ASD now affects more than 70 children per 10,000 and that the numbers now affected by ASD are around 1% of the population.

Senator Paterson said 1841 applications were successful out of a total of 1944 applications for carers allowance relating to Asperger's syndrome. In other words, 94.7% of applications for carers allowance relating to Asperger's syndrome were successful in the period 2000 to 2003.

The government's data shows that most applications for carers allowance relating to Asperger's are justified. There is a reasonable basis for adding Asperger's syndrome to the list of disabilities that automatically qualify for carers allowance.

Secondly, Hansard records the following speech on 9 August 2004.

> Senator HUTCHINS (New South Wales) (9.55 p.m.) —I want to speak briefly this evening about the development of strategies to treat autism. As we know, autism is a serious disorder which affects one in 100 Australians. Sixty-five in 10,000 children are born with autism. Families with autistic children face pressures and difficulties which can only be imagined by most of us in the community.
>
> As a result of extreme or diminished sensory perception, many people with autism experience a sense of frustration and anxiety that can be brought on by merely attempting to lead a normal life. I could not imagine anything worse than bringing up a child who cannot enjoy his or her life in the way that most children do, simply because of a disorder which was unforeseen and unavoidable. In my opinion, governments across Australia should do all they can to improve the quality of life of those children with autism and that of their parents.
>
> I was recently approached by a couple whose family has been seriously affected by autism. However, through the use of a technique known as `applied behaviour analysis' they have seen a gradual but perceptible improvement in the effect of the disorder on their family. Because of the greater ability of children to modify their behaviour, this technique is most effective when applied as soon as possible to young children following their diagnosis, which normally occurs at two or three years of age. In some cases applied behavioural analysis has been so successful that some children who were again tested for autism came back with a negative diagnosis.
>
> Applied behavioural analysis has been used for a number of decades, but it was only accepted in the mainstream body of knowledge in this area quite recently. Most organisations in Australia which represent those with autism and their families have expressed support for this method of treatment, and it is time that the Australian, state and territory governments took notice of the treatment with the aim of increasing its implementation.
>
> The unfortunate matter is that this type of treatment is exceptionally expensive. Only in Western Australia is funding provided for applied behavioural analysis. Western Australian families can access funding through the early intervention program provided by the Disability Services Commission. The rates vary according to the age of the child because of the dependence of the method on the age of the child, and funding is provided with the objective of readying the child for entry into year 1 at school. I have been told by the Disability Services Commission—but I have not been able to confirm it—that the amount available can be up to $5,000 for each year that the child receives the funding.
>
> Let me say that I am not making a political statement here, nor am I attempting to score any political points. This is an important issue, and I would like to see applied behavioural analysis tested by more governments in an attempt to alleviate the problems faced by families which deal with the difficulties of autism on a daily basis. I understand that the cost associated with applied behavioural analysis may be an impediment to the provision of funding, but it is a method of treatment which has been proven to be effective and which can have a significant effect on the quality of life of the individual and their family. I look forward to doing further work on this matter and speaking to the relevant stakeholders in an attempt to improve the services available to autistic children. I further look forward to personally approaching the minister, Senator Patterson, on this issue to see what assistance the federal government can provide to help these families.

If you agree with the Senator's words, please write or email him and thank him for his speech … especially if you live in NSW.

Workshops/Course/Training Information

A study being conducted at the University of Western Australia is examining friendship and loneliness in individuals with *Asperger's syndrome*. It is well-established that there is an increased rate of depression in individuals with high functioning autism, and a similar picture is starting to emerge in research that has examined individuals with Asperger's syndrome.

One factor that is related to depression in typically developing children is the development of peer relationships. That is, the greater the quality of peer relationships, the lower the likelihood of one showing depressive symptoms. Once again, a similar relationship is starting to emerge in those with high functioning autism. The current study is seeking to explore whether such a relationship exists for high-school aged children with Asperger's syndrome. The information obtained from this study will be crucial for the knowledge base of those with Asperger's syndrome as well as subsequent interventions.

We are seeking high-school aged children who have a diagnosis of Asperger's syndrome. Participants' will be sent a series of questionnaires (each will take 5-10 minutes to complete) and they will be asked to return them to the University of Western Australia in a reply-paid envelope (this will be provided). All of the questionnaires have been designed to be interesting and fun for your child, with confidentiality being maintained at all times.

If you would like your child to participate or you have *any* questions regarding this project please contact Andrew Whitehouse at the University of Western Australia on (08) 6488 1425 or email him on whitea08@tartarus.uwa.edu.au (that's a 'zero' after the 'a'), and a package will be sent to you.

Autism Behavioural Intervention Tasmania Inc
Supporting Families Teaching Applied Behavioural Analysis

Autism Behavioural Intervention Tasmania has a very exciting project on the drawing board. It is exciting because it involves members' children directly, even those members who live further away. In late August ABIT ran a Christmas Card Workshop where families gathered together and with the assistance of a local art teacher put their ideas and pleasures about Christmas on paper. This project is such a positive statement about our children's abilities and will do a great deal to raise awareness in Tasmania and abroad.

Rosemary Rush
President ABIT

Upcoming Workshops for Parents & Carers in 2004

The University of Sydney, Centre for Behavioural Sciences offers workshops on Intellectual Disability and Autism, both for organisations and individual participants. The upcoming workshops are for parents and carers and will be held at The University of Sydney. To register for these one day workshops please contact Katherine Schmidhofer on (02) 9351-2776.

Fundamentals of Structured Teaching, 18th October 2004 9.30am-4.30pm

Topics include: Characteristics of Autism, What is Structured Teaching? Informal Assessment, Understanding the individual child to incorporate strengths and interests, Physical Structure, Transitions, Individual Work Systems, Daily Schedules, Visually Structured Tasks, Home Programming.

Applied Behaviour Analysis (ABA), 1st November 2004 9.30am-4.30pm

Topics include: Autism Spectrum Disorders, Characteristics of Autism, What is ABA? Operant Conditioning, The ABC model, Why use ABA? Instructional Techniques in Applied Behaviour Analysis, Teaching skills, The Behavioural Support Plan, Techniques for Reducing Behaviours, Setting up an ABA program, ABA providers.

CARERS: all WORK NO PAY

Special Federal Election Campaign Alert…

Carers Australia, in conjunction with the state and territory Carers Associations has prepared a campaign document outlining the priority issues that carers across Australia expect our Federal Government, through its elected representatives, to address urgently in practical and meaningful ways to support carers in their everyday lives.

Click here for Carers Australia's election campaign brochure. (pdf document)

Click here for Carers Australia President, Louise Gilmore's letter to carers. (pdf document)

Click here for Carers Australia Media Release - All Work, No Pay. (pdf document)

Carers Victoria is on the campaign trail. We are:

- Meeting with politicians and candidates
- Encouraging carers to:
  - ring, write to or meet with politicians and candidates in their electorate
  - write to the press and ring talk back radio
  - get their carer support group to organize a meeting with politicians/candidates
- Attending relevant forums and meetings to promote the "carers platform" and to distribute badges "Carers: all work and no pay."

Sibling Research Project information sheets

University of Melbourne **'Siblings of Children with Autism' –** contact Professor Margot Prior (03) 8344 4906 / m.prior@psch.unimelb.edu.au

Swinburne University **'Resilience & Vulnerability in Children with a Chronically ill or Disabled Sibling' –** contact Meredith Rayner 0425 719957 / sibling.research@optusnet.com.au

Flinders University, South Australia

January 27th and 28th 2005

DisAbility and Rehabilitation Professionals' Association 2 nd State Conference - Embracing Diverse Abilities PDF 44 KB

Coming Up In Adelaide

PECS and related workshops in October and November

Using Verbal Behavior to understand PECS… PDF 116 KB
October 5, Andy Bondy
Using the Pyramid approach to education PDF 116 KB
October 6-8, Andy Bondy and Amanda Reed
Introduction to PECS PDF 84 KB, Nov 20 & 21, Amanda Reed
ASSID National Conference, 9-12 November, Adelaide, South Australia
(http://www.plevin.com.au/assid2004/welcome.htm)

From The Age in Melbourne (http://theage.com.au/articles/2004/08/26/1093518002656.html)

Anti-tantrum scheme for families

By Misha Schubert
August 27, 2004

Parents of intellectually disabled children prone to temper tantrums and violent rages will have greater access to a program aimed at improving their children's behaviour.

Under the program, parents of children with conditions ranging from autism to a mild learning disability are being taught how to handle self-harm, wild rages, and obsessive rituals that distract children from learning.

The scheme offers parents training manuals, group support sessions and telephone counselling services.

Since its inception in 1998, hundreds of Victorian families have been helped by the Signposts for Building Better Behaviour program, developed by Professor Alan Hudson, head of health sciences at RMIT.

The program will become available to 3000 more families thanks to a $4 million federal funding boost to be announced in Melbourne today.

Federal Family and Community Services Minister Kay Patterson said the money would fund telephone and web counselling, training for 300 support group facilitators, and a co-ordinator for the program.

"The Signposts program provides help... before challenging behaviours escalate to the point where intensive behavioural intervention is required," she said. Victorian Community Services Minister Sherryl Garbutt said the program, which was allocated $1.43 million in the May state budget, was helping to create happier home lives for many families.

"Parents in the pilot programs talked about their child being excluded from games at school and not being invited to birthday parties because of their behaviour," Ms Garbutt said.

"But as a result of being in the program, many parents felt less stress, became more effective at managing behaviour and said their child's behaviour improved."

Queensland acknowledges ASD numbers

In Queensland, the Minister corrected his statement made in Autism Awareness week. He told his parliament that 10% of Queenslanders who have a disability have some form of autism. This could well be true.

This shows autism/ASD, including Asperger's syndrome, is a major disability in terms of numbers. It is surprising that existing policy and service provision at state and federal level do not reflect the importance of this group.

Expired email addresses

Quite a few email addresses have expired. If you change your email address please let us know otherwise we simply lose contact with you.

If you know anyone who might be an A4 member and whose email address has changed, please remind them to tell A4 about their new email address. We generally stop sending Updates when the email address is reported as invalid.

Some of our members have email "in boxes" that are full. This means the Updates don't get through.

A4 Membership

Membership continues to grow. We welcome 44 new members since the last A4 Update was sent out. A4 Membership in September 2004 is shown by state in the following table.

ACT	NSW	NT	QLD	SA	TAS	VIC	WA	Unknown	UK	Total
40	188	7	156	32	28	195	41	56	1	**744**

Politicians are interested in the number of members in A4. The more members we have, the more they listen to us. So please encourage others to join A4. Please help them if they are not sure how to go about joining.

A4 Contacts

Update team (newsletter)
edit@a4.org.au

Treasurer (donations)
treasurer@a4.org.au

Awareness Event
Awarenessevent@a4.org.au

A4 Convenor, Bob Buckley
convenor@a4.org.au

Profile

Our September Profile is on Anita Harvey. Anita is involved in a number of Autism related groups including the AwA committee, Chief Editor of the A4 Update, member of the AFSA (Autistic Family Support Association) Organisational sub-committee, member of the Committee of Management at Irabina Childhood Autism Services (Vic), member of IPAG (Irabina Parents Action Group) and is about to become President of her sons kinder.

NAME: Anita Harvey

BORN: 13th April, 1970

LIVES: Melbourne

FAMILY: Husband Nick, Jack 5, Alex 2 & Mara 4 (St Bernard dog)

LIKES LISTENING: to people who can teach me something and all types of music

LIKES READING: anything light

LIKES RELAXING: what's that? On the couch

LIKES EATING: anything yummy!

LIKES: patchwork, talking on the phone and people who do what they say they'll do

DISLIKES: people that complain, but don't do anything to help themselves and spiders

IDEAL WEEKEND: sewing, massage, spa, chocolate

LAST HOLIDAY: patchwork weekend at Rawson (Vic) at the end of July

NEXT HOLIDAY: Biennial Autism Conference in Canberra