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Andrew Robb's ASD Forum

Sandringham Yacht Club
31 October 2008

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Objective

This was an opportunity for Andrew to canvas the problems associated with autism from parents, and others involved in the care of autistic children.

Key speakers

Andrew Robb AO	MP
Val Spence	Autism Victoria
Patrice Duggan	Principle Larmenier School, Hampton
Josephine Barbaro	Olga Tennyson Research Centre
Kim O'Neill	Baptcare
Kerrie Lyons	MOIRA

Also present Maureen Robb (Andrew's wife), Bruce Bilson (Federal MP for Frankston), Samantha Russell (Andrew's Electorate Officer)

Summary

Some 60 people attended, mostly women (about 5 men including AR and BB). This was an excellent and very informative meeting, both from what was delivered in the speeches (approx 15 minutes long), and in the forum sessions after lunch. I think all appreciated the opportunity to talk to their MPs directly, as well as to be able to network with other interested parties.

Andrew Robb

He admitted not knowing much about autism until he had a long conversation with Lisa Thomas who is on the board of management for the Association for Children with a Disability (Suite 2 98 Morang Rd, Hawthorn 3122 tel 9818 2000). He said he was keen to learn more and to help where possible.

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Val Spence

1. Val mentioned the State Plan for Autism was being considered at the present time.
2. The Federal Autism Initiative was also touched on in the context of Autism Victoria (AV) having won the contract for Victoria.
3. She said the level of support required by families with autism was among the highest for all disabilities.
4. The prevalence of autism in Australia is 1:160 children whereas not long ago it was 4 or 5 per 10,000. The reasons for this substantial increase are unknown.
5. She insisted we need local research and Australia should not be reliant on USA or European research.
6. The wait for assessment at the Children's Hospital is ~1 year which is far too long when all the research literature indicates the need for early intensive intervention. Without assessment, there can be no services or early intervention in the public service, though individuals can seek help privately. (See Kim O'Neill's talk later). Indeed she said many parents use the internet to find the services and help they need eg for ABA type therapy. [One person indicated they had spent \$70k and was in debt, while another mentioned a figure of \$30k just in this year!]
7. A key problem in Victoria is that autism is not considered a disability (Department of Human Services Revised Disability Act 2006). The Act uses a functional qualification rather than a diagnostic approach. Apparently multiple sclerosis and cerebral palsy are included, but not autism. The Act completely ignores the fact that most, if not all cases of autism have co-morbid physiological problems which create enormous problems for parents/carers. She urged all parents to lobby the Government to get the Act changed so that autism is accepted as a disability, regardless of the severity.
8. The subject of early intervention therapy was also mentioned as many parents are lucky if they are able to secure 1-2 hrs/week for their child owing to a shortage of therapists, and the way the system is operated.
9. State schools used not to welcome autistic children but then the climate changed for the better, until more recently, when the support system appears to be

backsliding. The lack of teachers' aides is unfair on the teachers and the other pupils.

10. There is a scarcity of activities for autistic youth and adults. More respite support is required.

Patrice Duggan

1. Larmenier School is a new special school for Catholic (exclusively?) children with autism based in Bluff Rd Hampton. Most children attend 4 days/week and then have 1 day/week in normal main stream school.
2. Patrice claimed that autism is the new tsunami, and parents were her heroes.
3. Education in classes that involve student enquiry were not suitable for children with Aspergers who need quiet, predictable activities and set routines, rather than group/open activities. Larmenier has a maximum of 10 students in a group. Staff/student relationships are very important, and change/transition issues are a key issue for Aspies.
4. Autistic children generally love computers, and we should skill Aspies in IT which is where they feel most comfortable. Interests and hobbies need to be directed. Apparently NASA has a high % of Aspies.
5. She said funding for their resident psychologists is under review and may not be continued next year. She said it was not possible to expect the teachers to do the job of trained psychologists. Teacher levels and expertise need to be enhanced as some teachers have absolutely no idea of what autism or Aspergers are.

Josephine Barbaro

1. The Olga Tennyson Research Centre is a Joint Venture between Autism Victoria and Latrobe University set up with \$2million, 50/50 donation by Olga Tennyson and the University. It is also financially supported by Telstra and the Menzies Foundation.
2. Josephine said she would make her PPP available through Samantha.
3. New diagnoses in Australia in 2003 were 30,000 (Source ABS 2004).
4. A large percentage of parents identify their child is not normal in less than a year whereas until recently most diagnoses were not formally made till an average age of 3.
5. Key behaviours identifying autism include
 - Lack of pointing
 - Little or no eye contact
 - No response to name being called
 - Not sharing
 - No pretend play
 - Poor receptive language
6. She described the SACS (Social Attention and Communication Study) she is working on in conjunction with Dr Cheryl Dissayanake. The aim of the study is to identify early indicators of autism at 8, 12, 18, and 24 months. There will also be follow ups at 3-4 years of age. They are monitoring 22,618 children born between September 06 and June 07. 241 nurses were trained in signs of ASD in infancy. Findings so far indicate a loss of skills occurs in 1 in 5 ASD children between 18-

24 months and that something appears to happen around 15 months. If the suspect children are diagnosed in accordance with ADOS or ADI-R they are then referred to specialists. They were classified into 3 groups

- AD Autistic Disorder
 - ASD Autism Spectrum Disorder
 - DD/LD Development delay/Language delay
7. The difference between AD and ASD is as follows: Children were given a classification of AD if they clearly met criteria in all 3 areas of social impairments; communication impairments, and repetitive, stereotyped, or ritualistic behaviours. Those who were showing signs of autism, but did not meet criteria for Autistic Disorder, based on ADOS-G and ADI-R, were given a classification of ASD.
 8. So far there have been 121 referrals but not all these children went on to receive a diagnosis of ASD. The project is still ongoing and more referrals need to be assessed.
 9. Josephine mentioned the use of MCH (Maternal and Child Health) nurses. There was general agreement from the floor that this was a good means of helping early identification. She also said there was a lack of knowledge of early signs of ASD and education of primary health care workers was required. (Again there was agreement from the audience). Val Spence added that the literature suggests that there is a need for a multidisciplinary assessment rather than leaving it to a single psychologist or paediatrician.
 10. Josephine said there were no specific services for parents of newly diagnosed autistic children ie counselling, and that a happy family helps create a happy child. [Someone at the meeting mentioned that autism in a child gives rise to the highest rate of divorce in the whole range of childhood disabilities]. She said Cheryl Dissayanake holds workshops for paediatricians, educating them on the early signs.
 11. Elizabeth Barker, a speech therapist of 18 years, said there was a need to support not just the parents, but also the professionals working in the field.

Kim O'Neill

1. Kim's area includes the Western (Brimbank and Wyndham) and Northern Regions of Melbourne.
2. Bapcare was founded in 1945. It has an annual budget of ~\$70 million and handles 2000 individuals/day with a staff of 780. Bapcare's main focus is on Aged Care. However the organisation has become more involved as a disability provider for children and families brought about by assessment delays for autistic children. She said there were ~400 children in the west and ~100 children in the north.
3. Bapcare is doing its own research to find out the real extent of the problem.
4. She said there were 4 key issues
 - Stress on marital relations
 - Financial hardship
 - Grief and loss
 - Mental health, anxiety and depression

5. Baptcare can offer only short term “band-aid” support as Baptcare is not an early years provider. However, the organisation is putting \$0.5 million into providing its own services by supplying speech and early childhood specialists.
6. They offer afternoon and evening programs using the “Learn, Play and Thought” model. They also use the Hannan model because of its international recognition and it provides the best support for the child by the parents. “Support the parents, to support the child”.
7. Since July 07 they have introduced play groups and a Vietnamese speech therapist. They also have a play group for parents coming from the Horn of Africa. At present they are providing support for ~100 families but still have ~400 on the waiting list!!!(ie those waiting for assessment, as mentioned earlier).
8. Parents find navigating the support system very difficult, particularly when English is not the parent’s first language.
9. Kim said that despite continuous lobbying, there are still major problems in the system.
10. There is a 4 year wait list for obtaining services through the DEECD (Department of Early Education and Childhood Development).

Kerrie Lyons

1. MOIRA Child and Family Support Inc (www.moiraproject.org.au) mainly provides support to parents in the 10 Local Government Authorities (LGAs) in SE Melbourne. It also acts as an advocate for various organisations. She confirmed the rigidity of criteria for obtaining support is an ongoing problem. For instance MOIRA obtained money to run a club for high functioning autists from Glen Eira Council, but it lasted only 6 months.
2. There is a need for Government to provide information to parents through the internet so that things like Carer’s allowance, Centrelink, and local service providers can all be identified in a one stop shop. Val Spence said that this was what Autism Victoria did, which apparently was news to Kerrie!
3. Education is a problem, with a lack of understanding of autism in schools. Principles set the tone for a school. In South Australia teachers are required to do a couple of units on special education requirements for autistic and other childrens’ disabilities.
4. The overlap or lack of clarity between Federal and State funding for kindergarten and schools is a problem area.
5. Community outlets eg war gaming clubs for Aspies, or other social events are not available.
6. She was very impressed with the Baptcare model of support and I think this was the general feeling in the audience.
7. Waiting lists for obtaining support are >12 months and in general, advance up the list can only be obtained if the child’s behaviour is really bad.
8. One mother mentioned that the only way she was able to obtain recognition of the need for support was when her 11 year old tried to commit suicide!!!
9. Respite for parents is a big issue.
10. Support for families before and after school, particularly for working parents, is vital. She said Fahcsia (Families, Housing Community Services and Aboriginal Affairs – a Federal agency) had been able to fill in some of the gaps.

Groups Discussion of Key Issues

Each group was asked to nominate the 3 most important issues. Some groups provided more. There were 5 groups

Group 1

1. The Victorian Government to change the Disabilities Act for autism to be considered a disability, regardless of where the child is on the spectrum.
2. Family support as per the BaptCare model, regardless of age.
3. One stop shop post diagnosis

[Apparently 80-90% of calls to the Association for Children with Disability's Offices relate to autism in education. It is a major problem].

Group 2

1. Research and early detection
2. TAC type insurance schemes, so that money becomes available at the right stages of a child's life.
3. Professional pathfinder to help parents negotiate the system
4. Equality of access to services
5. More specialist schools

Group 3

1. Classify autism as a disability
2. Respite , recreational activities
3. Aides funding for both primary and secondary schooling

Group 4

1. Compulsory, practical, ongoing training for doctors, health professionals
2. One stop shop/case manager
3. Practical help from local councils eg dispensations for various services

Group 5

1. Education
2. 100 days kit for parents as per Autism Speaks organisation in the USA [See [Autism Speaks, Community, Family Services, 100 Day Kit](#)

The *Autism Speaks 100 Day Kit* is created specifically for newly diagnosed families, to make the best possible use of the *100 days* following the diagnosis www.autismspeaks.org/community/family_services/100_day_kit.php

3. Community and Family education (telling their own families)
4. Families to take the fear out of the word autism
5. Respite for parents (kinder, community centres, play groups)

In Conclusion

Andrew Robb thanked everybody for attending, and providing him with an excellent insight into the extent of the problems associated with autism. He expressed a desire to try to do something to help improve the services in the mental health area.

Lisa Thomas gave a vote of heartfelt thanks to Andrew, and his officer Samantha, for making the meeting possible.

My Own Conclusions

There are plenty of really pressing issues which need to be addressed. In particular,

- 1) Government policy needs to be changed, particularly at the state level with regard to the Disabilities Act, followed by
- 2) a substantial increase in funding for education at all levels:
 - a) Universities (doctor, psychologists, nurses, physiotherapists, teachers, researchers etc)
 - b) Schools (how to maximise the capabilities of autistic children)
 - c) Parental support (How to navigate the system, what therapies are available, who can provide them, what is best for their child etc)
 - d) Respite carers (ie those who provide respite for children)
 - e) Federal and state politicians
 - f) Local Government Authorities

In fact everyone needs to be made aware of the extent of the problem, and Australia as a whole needs to work closely with USA and Europe to find out

1. the reasons for this so-called “tsunami” of ASD children
2. the best ways of treating them to maximise their potential

DMC
2.11.08

Convenor’s message

Dear A4 member

I am sorry I have not written to you since October 2008. I have been busy. I gave higher priority to bringing services to families in my region ahead of the A4 Update.

Here in the ACT, as in all the other states, our Autism Advisor service is up and running. It may not seem like much but in the ACT we made a huge step up from zero staff. Autism Asperger ACT Inc is also trying to get local early intervention providers onto FaHCSIA panel so families in the ACT region have choice in accessing early intervention services with their HCWA funding.

The advisor service is going well. In most states, the Autism Advisor service has seen and registered as clients all the families who have contacted them. The challenges now are to reach out to the remaining families and to get the children into funded early intervention.

One effect of the Autism Advisor registration process is that children are now more likely to get a diagnosis of a condition in the DSM-IV. Since the Advisors cannot register clients with a diagnosis of Autism, ASD or HFA, they need to get these diagnoses clarified so the child/client can be registered. Hopefully, clinicians and professionals will use the official terms for official purposes in future.

So far, the pre-existing ASD-specific early childhood service providers in our region are not on FaHCSIA's panel of providers¹. A major provider is starting operations in the ACT so a long-term outcome may be that families will have more choice, but this initial period is difficult.

At this stage, I am not sure how the rest of the HCWA package is going (see http://www.fahcsia.gov.au/internet/facsinternet.nsf/disabilities/services-help_child_autism.htm). These include:

- Playgroups (see http://www.fahcsia.gov.au/internet/facsinternet.nsf/disabilities/services-asd_playgroup_program.htm)
- Workshops (see http://www.fahcsia.gov.au/internet/facsinternet.nsf/disabilities/services-asd_workshops.htm) and;
- A website (see http://www.fahcsia.gov.au/internet/facsinternet.nsf/disabilities/services-asd_website.htm).

Personally, I see little value in standalone playgroups: my experience is that play skills need to part of a comprehensive program and require much more attention than they get in these playgroups. The other claimed benefits of playgroups can be achieved more effectively in other ways. Typically a standalone playgroup is respite for carers ... I prefer the available resources achieve more skill development for the child.

We are waiting to see what the workshops are about.

Do we really need any more autism/ASD websites? Would it be better to consolidate some of the existing websites? Why couldn't FaHCSIA and DEEWR have one ASD website?

Updates on the DEEWR and DoHA elements of the HCWA packages are also due.

I would like now to see the federal Government move on to addressing more of the needs of school age children, school leavers and adults with ASD. Now is a good time to remind our representatives that much remains to be done.

In another part of the federal system, Centrelink asks our doctors to complete a Medical Report Carer Allowance when people want Carer Allowance. In relation of eligibility for Carer Allowance, the form ² says:

The following, (not including Pervasive Development Disorder) when diagnosed:

- i) by a psychiatrist, developmental paediatrician, or a psychologist experienced in the assessment of Pervasive Developmental Disorders; and
- ii) using the current Diagnostic and Statistical Manual of Mental Disorders (DSM)
 - Autistic disorder
 - Asperger's disorder

The following conditions diagnosed by a psychiatrist using the current DSM:

- Child Disintegrative Disorder
- Major depression of childhood
- Childhood Schizophrenia

¹ See http://www.fahcsia.gov.au/disability/autism_panel/default.htm

² <http://www.centrelink.gov.au/internet/internet.nsf/forms/sa333tdr.htm>

Fortunately GPs understand this gobbledegook ... I am not sure I understand it. As best I can tell, a child is eligible for Carer Allowance if he/she has a Pervasive Development Disorder (PDD), being Autistic or Asperger's Disorder, that is not included in PDDs. A child is also eligible if it has another PDD, specifically Child Disintegrative Disorder, that was excluded in the preceding paragraph ... if the child is diagnosed with Childhood Schizophrenia from the current DSM: but Childhood Schizophrenia does not appear in the current DSM, the DSM-IV-TR (in the distant past, autistic disorder was called childhood schizophrenia).

And Rett's disorder (which is listed as a PDD in the DSM-IV-TR) migrated to the Chromosomal or syndromic conditions on another page.

If a child has severe and pervasive impairment in the form of PDD-NOS a special case needs to be made in each instance.

Interestingly, a psychologist experienced in the assessment of Pervasive Developmental Disorders can diagnosed Autistic or Asperger's Disorder for eligibility for Carer's Allowance but not for the HCWA package.

Regards
Bob Buckley

3/2/2009

Early Intervention Service Provider Panel

The list of early intervention providers who provide FaHCSIA funded early intervention for children under 6 years (and a few slightly older children) is on the FaHCSIA website. See http://www.fahcsia.gov.au/disability/autism_panel/default.htm. It is updated frequently.



New research highlights the lack of specialist support for autism education practitioners

New research carried out for the Autism Education Trust (AET) by the University of Birmingham has highlighted the lack of specialist support for autism education

practitioners, including speech and language therapists and occupational therapists. Asked about their biggest challenges in delivering educational provision for children on the autism spectrum, professionals cited lack of knowledge and understanding among school staff, increased numbers of diagnosed children on the autism spectrum and lack of therapists as their main concerns. Around 1 in 100 children is now thought to be on the autism spectrum. Timely and appropriate educational support is essential to ensure positive outcomes and future opportunities for all.

The AET is England's only umbrella organisation for autism education. It has published online the most comprehensive review undertaken to date on the state of autism education in England. The research, carried out by the Autism Centre for Education and Research at the University of Birmingham, reviews current practice, issues and challenges facing professionals, parents and children and young people on the autism spectrum. It draws on existing evidence, as well as new surveys of parents and professionals, to provide detailed recommendations at each stage in a child's journey through the education system.

Bob Lowndes, Chair of the AET Steering Group, said:

"This research can be heralded as a new beginning for our autism education system in England. We are now very clear on the priorities for improvement, as well as the areas of good practice. Its publication comes at a time of exciting awareness of the need for better autism education services, and follows the recent publication of the Bercow Review of the SEN system and his subsequent debate in parliament.

"An important message running through the research is that better cross-agency co-operation and communication is urgently needed to ensure that each child is treated as an individual and an appropriate course of education is planned and implemented."

See <http://www.nas.org.uk/nas/jsp/polopoly.jsp?d=1499&a=17992>

Sue Napier MP

Shadow Minister for Education (Tasmania)

Tuesday October 28, 2008

Government ignores autistic kids

The State Opposition has today expressed alarm about the number of autistic children who the Department of Education are trying to manage through Distance Education, and the number of children who are supposedly enrolled in school but not receiving assistance.

Shadow Minister for Education, Sue Napier, today raised the matter in Parliament as a Matter of Public Importance.

"We are advised there may be some 33 new enrolments into Distance Education of children with autism in this State this year alone and possibly 50 or 60 children with autism inappropriately being educated by a Distance Education system that cannot assist them with their education," Mrs Napier said.

"We are being told by families of these children that they are left with no other option for education in this State because their children cannot cope in the mainstream schools system."

Mrs Napier said that the Premier's suggestion that children with autism can receive funding of \$16,000 was misleading, because it only applied to children suffering from very high levels of the condition and only a small percentage of children with autism would therefore be eligible for assistance.

"Even then, children with autism are not provided with adequate teaching aide hours and teachers and teacher aides are not provided with appropriate training and resources to support their learning, let alone develop a targeted Individual Education Program," Mrs Napier said.

"The Premier also fails to acknowledge that people who suffer from Asperger Syndrome are not eligible for special support. The irony is that these kids could particularly benefit with accessing the Talented and Gifted programs."

Mrs Napier said the Education Department's recently released Disability Action Plan 2008-2010 failed to pick up many of the key recommendations in the submission from the Tasmanian Childrens Commissioner, Paul Mason, including for example, the suggestion that a program for autistic children needs to be at least 20 hours per week over an extended period of at least two years with continuing support thereafter.

"As Professor Brian Caldwell has said, successful education systems in the world have broadened their definitions of special needs and provide one-to-one and small group special assistance for all children who are falling behind," Mrs Napier said.

"The Tasmanian Liberals believe that we need to seriously consider this new approach and children with autism would certainly fall into that category.

"We have even heard of one instance where the Department was going to co-enrol a 9 year old at Hobart College and Distance Education, which sounds more like a statistical exercise than using an evidenced based approach for the education of children with autism.

"The seriousness with which the Premier considers this issue is evidenced by the fact that he wasn't even in the House during the debate. Instead, we got a Departmental-like response from his Parliamentary Secretary, Lisa Singh.

"The reality is that the current attempts to respond to the needs of children with autism are not working. Indeed, through ignorance, State Government programs for children do nothing more than babysit them.

"The Premier would have had enough complaints coming through his door to guarantee that he is well aware of the issue."

For further information or comment please call Kristy Mays – 0407 503 910

autism/ASD in the media

Media Release



Family Support Association Inc.
PO BOX 235, ASHBURTON, VIC., 3147 P: 03 9885 8777 F: 03 9885 0508 E: afsa_aust@bigpond.com
14 December 2008

Autism now acknowledged as a disability

The Brumby Government has today announced its acknowledgment that autism is a neurological impairment under the Disability Act 2006 allowing access to disability services from the Department of Human Services, Disability Division.

“Today’s announcement is as significant as giving every Australian the right to vote. It’s a great Christmas present for many desperate families, Meredith Ward, President, Autistic family Support Association said.

Latest Australian prevalence figures indicate that 1 in every 160 people have an autism spectrum disorder. Autism Spectrum Disorders (ASD’s - Autism, Aspergers Syndrome, Pervasive Developmental Disorder – Not Otherwise Specified) cause lifelong disability. A diagnosis of any one of the above disorders can only be obtained if the person has significant impairment in each of the areas of Communication, Socialisation, Restricted or Repetitive interests/obsessions.

“It means the many families in crisis who have in the past been barred from accessing the services they needed to help them, are now eligible to apply for those services.

This is a significant first step prior to the release of the Autism State Plan. The Autism State Plan, which is whole of life and whole spectrum, could not have addressed the issues for the entire autism community without today’s acknowledgement.

“We encourage individuals with an ASD and their families/carers to contact their Disability Intake worker on 1800 783 783 she said.

Media Contact: Meredith Ward 0400 226 408

Latest Prevalence report: <http://autismaus.com.au/aca/research.html>.

Autism State Plan: <http://autismstateplan.dhs.vic.gov.au/>

Parents fear for disabled

Thursday November 6, 2008.
Matt Johnston

PARENTS have pleaded with the State Government for more housing for their disabled children so the young people are not forced into nursing homes.

Teens with disabilities are living in nursing homes because of the crisis. At least 17 people younger than 29 and more than 200 people younger than 50 are also languishing in Victorian aged care.

Parents and carers at a state parliamentary inquiry into the disability and mental health housing crisis said some of the limited accommodation available was filled by people who had incompatible needs, leading to physical and sexual assaults.

Others said they were afraid of what would happen when they were no longer able to look after their children.

Sophie Pateras said her son was lashing out at home because he had nowhere else to go.

"He's getting frustrated. I am just not coping. I have been on a waiting list for six years and I don't want to wait for another six years," the Werribee mother said.

"I don't want to get to the stage where I have to go to a nursing home. I would have to book two beds, one for me and one for him."

The Family and Community Development Committee's inquiry, into supported accommodation for those with a disability or mental illness, also heard of abuse in community residential units.

One parent warned incompatible patients were sometimes housed together.

"We hope we (parents) can have more say in having a new resident in the house that's more compatible," the mother said.

The Young People in Nursing Homes Alliance later told the *Herald Sun* more people continued to be pushed into nursing homes at an early age.

National director Dr Bronwyn Morkham said there had been a spike in people entering nursing homes in their 40s, and there were now about 1000 people younger than 60 living in nursing homes.

"This is usually due to informal care collapsing — families no longer able to provide the bulk of the support required for a range of reasons, including family break-down due to the stresses involved in delivering care," Ms Morkham said.

Public Advocate Colleen Pearce told the inquiry some people with disabilities had spent a year in respite care, which cost taxpayers about \$170,000, when they should be living in supported accommodation, which would save the state \$70,000.

Ms Pearce said the social benefits of more housing for people with disabilities and mental illness were huge, but so were the economic benefits from reducing the strain on hospitals.

More media

<http://news.smh.com.au/national/coroner-backs-aspergers-accommodation-20081203-6qkj.html>

<http://www.smh.com.au/news/entertainment/film/triumph-over-tragedy-steals-the-show-on-a-shining-night/2008/12/06/1228257386789.html>

<http://www.canberratimes.com.au/news/local/news/general/autism-program-funding-blocked/1380019.aspx>

<http://www.canberratimes.com.au/news/national/national/general/fischer-set-to-take-up-role-as-our-first-man-in-vatican/1379583.aspx>

<http://www.canberratimes.com.au/news/national/national/general/dead-child-had-habit-of-putting-objects-into-her-mouth/1368910.aspx>

<http://www.news.com.au/couriermail/story/0,,24643013-3102,00.html>

<http://www.news.com.au/dailytelegraph/story/0,,24663902-5001021,00.html>

Letters

Hi Bob

I recently picked up an article from an American autism support website, regarding some cinemas in the USA offering 'sensory-friendly' screenings of family movies such as 'Madagascar 2'.

These screenings will have sound volumes turned down and house lights kept up, and will also encourage families to bring in any special dietary foods that their children might need, such as casein-free.

On behalf of my grandson Jack, who has Asperger's, I wrote to the MD of Birch Carroll & Coyle here in Australia, asking if a similar approach could be adopted here and received a very courteous and compassionate response, with an undertaking to investigate as an enhancement to a program that they are currently running.

If you would be interested in having sight of this correspondence, I would be happy to send you a copy – only have hard copies, not e-mailable – so please provide me with a snail-mail address if interested.

Thank you for the latest newsletter and for your ongoing efforts on behalf of the ASD community.

Regards

Ron Burton

Dear Colleague/Parent,

I am writing to alert you to a new survey that asks parents about the educational priorities that they have for their children with intellectual and developmental disability.

I am hoping that you might be willing to inform the parents of your organization about this survey so that they can complete the survey if they want to.

To access the survey, please use this URL link:

https://www.surveymonkey.com/s.aspx?sm=PPz22c4lhFLHZIAnkWEbNg_3d_3d

The Victoria University of Wellington Human Ethics Committee (New Zealand) has approved this research project. The survey consists of a list of a number of skills (e.g., self-care, communication). For each item, parents will be asked to indicate their child's ability level and how much of a priority acquisition of this skill is to the parent (0 = not at all a priority, 4= major priority). They will also be asked to provide some basic demographic information about themselves and their child.

It would be great to have as many parents as possible respond to the survey as we believe the results will provide important new information that could be used to inform the content of educational programming for children with these types of disabilities.

A more detailed information letter is attached for your information. Parents will see this information letter when they start the survey.

We would appreciate it very much if you could inform interested parents about the survey. The survey is anonymous and can be completed in about 15 minutes by visiting the following website:

https://www.surveymonkey.com/s.aspx?sm=PPz22c4lhFLHZIAnkWEbNg_3d_3d

If parents wish to complete the survey it is important that they keep this email so that they can access the survey. As this link is not individualized (i.e., we do not have parents' email addresses), it is important for them to note that if they start the survey they will not be able to exit and return at a later date, otherwise all their responses will be lost. So they should complete the survey in one sitting.

Thank you

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