

Autism - Stop the Robbery

Priorities for the 2010 Victorian State Election

Autistic Family Support Association Inc. (A0007531T)

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Contact: Meredith Ward – President - 0400 226 408

September 2010.





2nd September 2010
The Honourable John Brumby
Premier,
1 Treasury Place
East Melbourne Vic 3002.

Dear Premier Brumby,
Re: 2010 Victorian State Election Priorities to Stop the Robbery

The Autistic Family Support Association Inc. (AFSA) represents individuals with an ASD, their parents/carers and families. We hold Government accountable to the Autism State Plan vision and its priority areas of action.

AFSA is an incorporated, self-funded, statewide, voluntary, parent based support group. Our membership is free to the community thanks to small non-recurrent amounts received from State and Federal Government grants. We don't receive any recurrent funding.

Through systemic advocacy our aim is to improve the outcomes and quality of life for individuals with an Autism Spectrum Disorder (ASD) and their families and carers.

AFSA, acts upon information from individuals with an ASD, parents/carers and others about issues facing them often conducting surveys around the state and then presenting the facts to ensure change for the better.

ASD's are lifelong complex pervasive developmental disorders. The cause is unknown, there is no cure, but interventions are beneficial in reducing the impact of autism upon the individual. We do not consider that autism is a disability any worse than any other disability, but it is different, is not well understood and is an emerging problem for a number of reasons.

Immediate action is required by Government given that Research findings are that ASD's have a genetic basis and anecdotally it seems that each generation is more affected than the previous.

Action Required:-

Fund AFSA as a PEAK advocacy body to continue to build capacity of parent support groups and families.

Autism State Plan Introduction pg 9

We know that people with ASDs have varied and complex needs and many require support across their life course, from formal and informal services and from their families and communities. The impact on families caring for a person with an ASD is significant and it is not uncommon for families to have more than one member with an ASD.

ASDs are poorly understood conditions in the community, including in culturally and linguistically diverse and Indigenous communities. There is a good deal of misinformation. Improving community understanding and awareness of ASDs and the impact of these conditions will have benefits for people with an ASD and their families as well as for the broader community.

The development of the Plan acknowledges that present services were planned for lower ASD prevalence and are now under significant pressure. Future service planning requires a better understanding of service demand trends and the service needs of people with an ASD and their families over the life course.

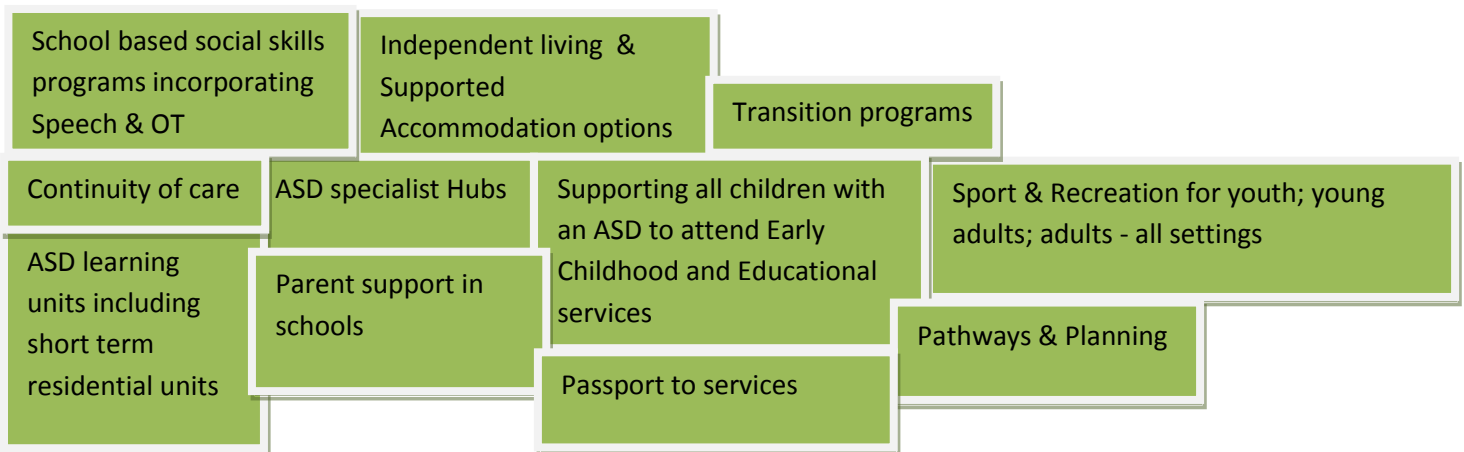
As with the development of the Autism State Plan, AFSA remain committed to its implementation and we concur with the Autism State Plan (ASP) vision **“All people with an ASD and their families are supported to fulfil their maximum potential, enjoy life and contribute to their community”** and support its six priority areas being:--

A vision for support. Pg 21 of the ASP

The Plan’s aims

This Plan aims for a service system of support across the lifespan to improve the ‘quality of life’ of people with an ASD, their families and carers. Support will be provided by government funded services, private providers, families and carers and the wider community working together. Support services will be delivered in a timely manner, recognising the diversity and distinctiveness of people with an ASD and their families, inclusive of their cultural and linguistic preferences whether the person lives in supported accommodation, at home with family or independently.

1. Make it easier to get support
2. Strengthen the ASD expertise of the workforce
3. Extend and link key services and support, especially during times of transition
4. Enhance and provide appropriate educational opportunities
5. Facilitate successful participation in the community
6. Develop a robust evidence base about ASD



Priority areas 1, 2, 3 are also integral to achieving priority 4 & 5. Notwithstanding this, it is evident that the needs of families of people with an ASD are not being adequately met due to a lack of sufficient investment.

In the past governments have adopted a piecemeal approach to problem solving and perpetuated a ‘departmental’ approach to funding the autism community’s whole of life issues. A forward commitment would support the philosophy of the ASP as it aimed to... *‘build new and better approaches across government for meeting the growing and complex needs of people with autism and Autism Spectrum Disorders’*

Action Required:-
A significant financial commitment in the forward estimates to fund the Autism State Plan for the life of the plan.

Improving each student's educational outcome remains the single most significant issue confronting the autism community, and government. The consultation process identified students with an ASD in all educational settings (Government, Non-Government, Catholic, Independent, Mainstream, and Special) are being progressively disadvantaged as they move through the developmental and educational stages. Research by Tonge et al evidences the compounding impact seen in such very poor outcomes for the individual and their families.

New and Better approach across Government:-

- Establish ASD specialist hubs in each region servicing DEECD-OfC; DEECD-OGSE; DHS-Disability Services; Mental Health; DPCD-Sport & Rec. Hubs provide expertise, support, PD to other service sectors .
- Review the potential for Children's Hubs to be expanded to incorporate ASD Hubs.
- Review the potential of Local Learning & Employment Networks & Regional Youth Commitments to achieve better outcomes for early school leavers with an ASD.
- Strengthen Dept of Planning & Community Development AAA program.
- Utilise expertise from a range of sectors to introduce small group intervention/social skills programs provided to all students and adults diagnosed with an ASD.
- Streamline and reduce gate keeping to services & supports.

We commend the move to a range of educational models including the new ASD learning units, and Satellites. They are an exciting contribution to the current educational landscape. But with **hundreds of displaced students** urgent action is required to reduce the damage caused by unmet educational need. We recognise the work done around flexible learning options (refer http://www.eduweb.vic.gov.au/edulibrary/public/stuman/wellbeing/Re-engaging_Our_Kids_KPMG_Apr2010.pdf)

However, implementation is urgent and adequate investment critical.

Recently we conducted a survey to inform us about what should be funded next under the Autism State Plan. We received 265 responses.

Question 7 asked 'The Plan acknowledges that for many reasons it is difficult to obtain support. In your opinion which area or areas do you think are most important to get support and should be funded by

government next?

An average of **81.5 % of the school aged cohort said it was most important to fund support at School next.**

48.9% did not have access to the Program for Students with a Disability (PSD).

66.1% did not have access to a Life Skills program.

58.0% did not have access to a transition support program.

84.4% of respondents reported that their educational needs were not being met, or being met only sometimes.

When asked if their child's educational needs were not being met Which of the options offered should be funded next?

82.2% chose ASD training for teachers/aides and non teaching staff;

76.2% Social skills programs;

65.4% Specialist Interventions at school; 63.5% Access to PSD;

57.2% Flexible Curriculum; 56.3% Individual Education Plan

Action Required:-

- \$10m pa. recurrent to enable ASD expert consultants for ASD Hubs in each region of Victoria. Includes replication of Fed Govt. Positive Partnership Initiative.
- \$6m over 4 years to establish 6 additional ASD Learning units and 20 incentive programs for schools to include/support students with an ASD who do not meet the PSD criteria for funding.
- \$2m over 4 years to establish short term residential educational/respite units.
- Commitment to a 'Grandfather clause' that no student will be disadvantaged with the introduction of the new Abilities index (refer student wellbeing branch)

Supported accommodation and independent living ranks highly as a priority in our survey. **84.65% in the 18-39 age cohort and 93.8% of the 40+ cohort chose it as the area which should be funded by government next.** All results are available at www.afsaconnect.org.au

Despite additional investment by government, people with disabilities wait for their accommodation and support needs to be met. (refer table below source http://www.dhs.vic.gov.au/disability/supports_for_people/information_planning_and_advocacy/how-we-provide-services-to-people)

The number of people recorded on the Disability Support Register as at 30 June 2009 is shown in the following table.

DSR Category	All Requests
Disability Services Supported Accommodation options	1,292
Support to live in the community	1,095
Daytime activities	188
Total	2,575

This table represents current need only. It does not reflect future need.

Respite emerged in our survey as an urgent need across all age cohorts.

People with an ASD and their families are amongst the most disadvantaged due to social, emotional, employment and financial isolation. People with an ASD of all ages find it difficult to access daily mainstream or specialist services hence the increased burden of stress upon families, and therefore the need for increased respite. Specialist knowledge and the need for training across all sectors were highlighted during the consultation of the Autism State Plan.

Action Required:-

- LGA/State/Federal shared agreement to build 1 CRU and 1 respite house in every LGA.
- \$8m for 100 additional Individual support packages

New and better approaches across Government

- Extend ECIS services to provide transition to school program for children up to 8 years of age.
- Fund only high quality, best practice models.
- Replicate the HCWA (Fed Govt) Panel to endorse ECIS providers who use best practice models of intervention based on recommendations by Prior & Roberts report.
- Revert to utilising ECIS ASD specialist providers to conduct 'Gold Standard' diagnostic services for children.
- Provide a 'Passport' to apply for services upon diagnosis.
- Better collaboration between Federal/State/Local government initiatives.

People with an ASD of all ages need to be taught social and life skills to enable them to be included in the local community. Early childhood, school, or non school settings like ACFE providers, and the disability programs all provide opportunities for continual capacity building and support.

Action required:-

- \$0.5m pa. recurrent to build capacity of parents/carers through Parent mentoring/support program for all age groups.
- \$5m pa. Social skills/Life Skills/Interventions programs all ages all sectors. Includes transition programs
- \$20m over 10 years to increase the intervention services by specialists to children with high and complex needs such as ASD in early childhood and educational settings .
- \$1m p.a recurrent for diagnostic services allowing access to new Federal Govt HCWA initiatives.

The report *The State of Victoria's Children says' Australian research shows that a considerable proportion (around 63 per cent) of children with a disability experience difficulties at school. In Victoria, around 20 per cent of people aged over 15 years with a disability have not attended school or have only progressed to Year 8, compared to 5 per cent of the general population, and only 55 per cent of people with a disability are employed, while over 81 per cent of the total Victorian population is in paid work'*. <http://www.education.vic.gov.au/about/directions/children/annualreports.htm>

AFSA understands that there are many competing interest, however we know too the suffering of those within our community, the poor outcomes for individuals and families, and provide this submission for your consideration in order to address the most urgent needs.

Attached are the comments respondents to our survey made when asked the question 'What else would you like Premier Brumby and Minister Neville to know about what should be funded next'. We hope you can take some time to look through them.

We thank you for the opportunities to discuss the issues confronting our community and welcome any further opportunities to discuss this submission with you.

Yours sincerely



Meredith Ward
President
0400 226 408

1.	Lectures/talks by professionals should be subsidised for parents carers and the community to be better informed in all areas of ASD.	Mon, Apr 19, 2010 6:03 PM
2.	Give families help when they can no longer help. Create a DHS which can do their job and not make it more heart breaking for families.	Mon, Apr 19, 2010 5:53 PM
3.	I am limited in the type of work and hours of work hence i am financially disadvantaged, single parent with 2 kids on the spectrum. School holiday periods especially the long summer break is difficult to manage except for a supportive employer (as present). I have very little superannuation and mostl likely will be on an aged pension once i reach that age. Making ends meet is very difficult at times. I have no idea what /who will support my son's when i die.	Sun, Apr 18, 2010 5:44 PM
4.	Mainly the crisis parents are in trying to raise a child with ASD. When my child was diagnosed I was told it would be months before I could get into Irabina and when we did my son would only be eligible for 1-2 hours of intervention a week. I withdrew my superannuation to pay for speech pathologists etc. NOTHING at that time was claimable on Medicare. I had to jump through hoops to keep him at Kindergarten for many parents wanted him out. I have not been able to work for years as I am his full time carer. He has been to four schools by the age of seven due to the system. I have been cut off from society I have been isolated I have given up everything else I wanted to do in my life, I also have another child to raise and it is 2010. Families I know got more support in the '70's.	Sun, Apr 18, 2010 5:17 PM
5.	More funding support to students in a secondary setting for teacher PD's and integration staff for ASD students.	Sun, Apr 18, 2010 10:34 AM
6.	Flexibly educational options for ASD kids/teens. Allow them to focus on their strengths - the current education systems focuses on their weaknesses - routine, organisation, homework etc..	Sun, Apr 18, 2010 10:20 AM
7.	More aids neede in kinder and schools so children can have more hours.	Sun, Apr 18, 2010 10:05 AM
8.	People with ASD and their families need help and support by quality service providers. The research says that an early diagnosis means the ASD person will benefit more from programs to help them learn social skills etc., which in turn will equate to better use of moneys allocated to such training programs. ASD is a very broad, complex condition and I think it is vital that the people who diagnose through to teachers and even families need to be able to access the very best training/support to bring out the best in the ASD person they are dealing with, to give them the opportunity to have a quality of life that is the best we can help them to achieve.	Thu, Apr 15, 2010 9:45 AM
9.	ASD disorders are now recognised as a disability. My ASD child has also been diagnosed with dysgraphia and adhd. Yet an arduous process will be required to obtain any special accommodations for his VCE, possibly similar to someone trying if they have had an illness around exam time. I am advised that neither his dysgraphia or pyschologist's reports over the years will be considered for special accommodations. This seems unfair in the least but is probably discriminatory. If a person is unable to write, how are they to effectively communicate their knowledge in a VCE exam? Also, when will they be required to handwrite reports, etc when they have finished school? Some areas of the VCE need to be modernised and reassessed so they are not discriminatory for those with an ASD.	Wed, Apr 14, 2010 4:09 PM
10.	I believe there is quite a lot in place now for younger kids (primary). The shortages are support for parental respite and training, and supports for adults; including work, independent living and social skills training and support.	Tue, Apr 13, 2010 11:48 AM
11.	I feel the government is obliged to provide greater education and training for staff in supported accomodation in order for people with ASD to reach their full potential. Despite applying for early intervention and being waitlisted, support never eventuated. Lack of early intervention, education and specialist care has resulted in ongoing unmanageable behavioural issues that have negative family impacts.	Sat, Apr 10, 2010 9:56 PM
12.	Autism is a complex issue, and there is no one answer to allow a person suffering from Autism to reach their full potential.	Sat, Apr 10, 2010 9:43 PM

One of our main issues has been staff training and support of our brother suffering from ASD. Inadequate training and financial support has been one of the primary issues.

The existence of waiting lists further exacerbate the suffering of families and ASD sufferers.

It is vital for the Government to facilitate appropriate support for ASD families and sufferers. Unfortunately to date the Government support has failed to live up to its promises.

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13. After having been eligible for the Autism Package funding last year we now find we are not eligible under the current criteria for any funding now that our child has started school. It seems all support has stopped since we entered the school system. My child will now not receive the education that other children will and that I feel she is entitled to because we have no support at the government primary school due to the toughening of the eligibility criteria. Sat, Apr 10, 2010 4:16 PM
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14. In my opinion, having just gotten my son through Early Intervention - I would say that is King! Early intervention is the most important time in these children's lives. My son does not have to go to a special school because of Early intervention. He has a chance at a 'normal' life!
My biggest (and most immediate) issue now revolves around the fact that funding has ceased. My Son's needs have not ceased, but all he gets is \$50 per week and limited aide time at school and \$800 per year of speech at school. More funding is needed for primary (and secondary) aged children. Sat, Apr 10, 2010 10:35 AM
Having said that, even if there was funding, there is a shortage of Occupational, speech therapists who are actually trained in ASD. Even a good psyc is hard to get hold of. So more time needs to be spent in getting these professionals trained and perhaps incentives to intice them into suburbs away from the city (we live 40km from Melb).
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15. We as a family struggle on a daily basis. Life totally revolves around autism. We never know when we wake in the morning if we are going to be able to function in any way slightly normal. Our child is constantly overwhelmed by the world and at 12 years old has become an even bigger strain. Any help and support would make an enormous difference, life is so difficult for him!
Access to any type of help costs us a lot of money, surely assistance from the government would save us all in the long term, and make life easier for our child Sat, Apr 10, 2010 12:09 AM
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16. I would just like to repeat previous comments. If the government is really serious about making change, put mental health as a priority. Be brave. As I said, it's not a major vote winner, but sanity and mental health are basic human needs, and we are in the middle of a mental health epidemic. If something drastic isn't done now, crime, suicide, depression and family dysfunction is going to dramatically increase. So ask yourselves whether having a future generation unable to manage itself is something you can live with.
Some of the 2010 priorities are counter productive, such as increasing police numbers and the other crime focuses. If you tackled the reasons behind crime, which a significant contributor is mental health, you wouldn't have so many reactive priorities, and you would save a lot of money and a lot of heartache. Fri, Apr 9, 2010 9:30 AM
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17. Funding for more aides in the Secondary system to help as teachers do not seem to be able to cater for varying learning styles Thu, Apr 8, 2010 8:03 PM
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18. Support the whole family. The siblings are always left out of this equation. Education is very poor for kids with ASD in the West. Dhs should be employing those parents that know and advocate for change. Instead of funding services that have limited if any contact with the actual families.
The parents/carers are the key to the child's success. They are not being supported enough. Thu, Apr 8, 2010 6:33 AM
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19. Paramount is access for families to a "one stop shop" where child/children and entire family can be assessed for their individual needs. We struggle as a family most with sibling rivalry, lack of respite services, support with home services - eg: home help and financially to offer our child the range of services available. Time is against us to navigate the system and I have found many services too bogged down to return calls, I have been lost on waiting lists and couldn't even get start up service from special children's services. Information should be given to GP's and health care centre nurses to begin the navigation on this journey but ideally each family would have a case worker to find out what they need and what they can get. Wed, Apr 7, 2010 2:55 PM
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20. A LOT OF KIDS WITH AUTISM HAVE A LOT OF TROUBLE WRITING....THEY HAVE THE INFORMATION IN THEIR HEADS BUT THEIR MOTOR SKILLS ARE POOR....I WOULD LIKE TO SEE A PROGRAM IN THE SCHOOLS WHERE THEY LEARN THE BASIC WRITING ETC BUT WHEN IT COMES TO DOING A LOT OF WRITING, I WOULD LIKE TO SEE KIDS LIKE MY SON ,PUT ONTO A COMPUTER TO FINISH TASKS. A COMPUTER PROGRAM FOR KIDS WITH AUTISM FOR WHEN IT COMES TO HOMEWORK WHICH IS ALWAYS A CHORE FOR THEM. Wed, Apr 7, 2010 11:41 AM
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SPORTING PROGRAMS...LIKE TENNIS

MORE SUPPORT WHEN THE KIDS ARE NO LONGER UNDER THE EARLY INTERVENTION.....
NEED PRIMARY SCHOOL SUPPORT.

HELP WITH EDUCATION COSTS WHEN GOVERNMENT SCHOOLS ARE JUST TOO BIG.

21.	what should be funded is the accessibility for anyone whether adult or student to medicare funded diagnosis of autism, the costs of trying to get an adult diagnosed is huge, also the grossly insufficient amount of funding available for those with autism to have an aid fulltime at school, its needed for every autistic child	Tue, Apr 6, 2010 10:57 PM
22.	Educating school teachers/staff/aides about ASD (that is ongoing, not one-off thing.)	Tue, Apr 6, 2010 12:29 PM
23.	Funding and community education is a disgrace. It is time teachers are taught that a child does not have to be in a wheelchair to have a disability.	Tue, Apr 6, 2010 10:58 AM

24.	<p>The number of services and schools available to the children with ASD in the Western District of Melbourne is vastly inadequate.</p> <p>We need more high primary or secondary programs for children that are too high functioning for special schools but require support in mainstream/independant schools.</p> <p>We have funded many of our children's programs personally, so that we wouldn't place undue stress on the existing early intervention programs (which we were entitled to but in view of the long wait time, we decided to fund ourselves). This in turn places a false impression of the true waiting list (ie there are many parents like us that drop off the list, frustrated by the lack of support).</p> <p>Our child is struggling in mainstream but there is no real alternative. Children with high functioning autism require a lot of psychological support as they transcend through the middle to higher grades of primary school and into early secondary. This support is simply not present or not funded by the present government and it is left to the long-suffering parents to ensure their child's needs are being met (regardless of the financial and personal toll on the family).</p>	Tue, Apr 6, 2010 9:28 AM
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25.	training for support staff in all areas across the life of the person with ASDI	Mon, Apr 5, 2010 9:49 PM
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26.	Like I have said before we need a step by step list of who, how, why, where, when... etc. Families need a step by step guide of where to start with getting help. If everyone was walking the same path it would make life a lot easier, at all levels and stages on the ASD.	Mon, Apr 5, 2010 9:05 PM
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27.	To be the parent of a child with ASD is isolating. Our kids experience such a sensory overload it is difficult to enjoy the simple things such as attending a family birthday or engagement party. Outsiders see them when they are having a meltdown and think they're naughty! I'd dearly love to see more public awareness & inclusion rather than sneers & condemnation. Create an ASD simulator similar to the intoxicating goggles? Take it to schools, the community etc & have everyone wear them so as they too can experience what it's like to live with every sound, sense etc all jumbled in your head at the one time.	Mon, Apr 5, 2010 8:27 PM
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28.	<p>The transition to Primary School has been the most difficult process to date. Staff should be better educated about the needs of children with ASD's. There needs to be better services provided by schools in the fields of speech therapy, psychology and occupational therapy.</p> <p>There are so many funding programs available but they are so difficult to navigate and access. GP's are not willing to assist with Mental Health Care Plans or Enhanced Primary Care Plans (I have been to 5 appointments and no-one has been willing to complete the forms). All funding programs need to be rolled into one and offered to families as per the FAHCSIA funding program. It would be more appropriate to allocate the funding over a number of years instead of only two. To start intervention and then stop it suddenly due to no more funding, can be very detrimental to our children.</p>	Mon, Apr 5, 2010 6:59 PM
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29.	afaiere tax rebate on medical expenses. Treatment plans etc. we have private health Insurance, we pay a medicare levy. Even after taking of the first \$1500 we were still \$7500 out of pocket in medical epenses.	Mon, Apr 5, 2010
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	Paediatrician(Even on a child's health care card and being @ the RCH they dont bulk bill), Speech therapist, Psychologist, Dr, medication, etc.	4:15 PM
30.	<p>All people with A.S.D. need some kind of help none of them are able to function at their best without it. A.S.D. is quite often not diagnosed until a child is in primary school and then they miss out on the early intervention packages that are available. My Son has not made the transition from home to kinder to primary school to secondary school well. Each time it has become more difficult than the last. He is currently still in shock from leaving behind his primary school years and he will tell you himself that he cant cope with the changes that are expected of him in his new school. The school currently only gives him four sessions a week with an aid as he does not receive any funding and that is about the only time that he ever does any work in class. The rest of the time he is disruptive and unable to focus on the classroom tasks which means that not only is not receiving any education but neither are the other 25 children in his class! My son was diagnosed late he did not receive early intervention he has only had one year of various therapies that we fund personally and he does not receive any help from the government beyond a carers allowance. We need help now or otherwise our son will become totally dependant on the government by the time he becomes an adult as he is and will continue to be unstable and uneducated neither of which is employable.</p>	Mon, Apr 5, 2010 3:52 PM
31.	<p>More financial assistance for families - yes we get a carer's payment and a HCC. The HCC isn't worth the paper it is written on - we see a Psychologist with our son weekly and GP regularly - none of the support services we use accept a HCC.</p> <p>My son is very destructive - it costs us so much money to replace the things he wrecks or tips down the sink.</p> <p>Even respite care costs a fortune.</p> <p>More support in schools - more aides (not just based on intelligence)</p>	Mon, Apr 5, 2010 2:12 PM
32.	<p>The Education teaching staff over all areas, be more educated about the needs of young children/adults with ASP;</p> <p>Attend more workshops to educate them of the needs/problems of these special people.</p> <p>In the health section of education for students,have them more aware of a understanding of ASP.</p> <p>NEED MUCH MORE HELP!!!! in Primary and when they reach High School.</p> <p>A lot more help with pathways when did leave school (my son nearly got to the end of year 12 and they just quit because it all became too much... due to anxiety, social anxiety, stress, and there was a lot of teasing from his fellow students, and in some cases not much understanding where teachers were concerned..</p> <p>I would sincerely like much more understanding of these very special people, and have them more acceptable in our society.</p>	Mon, Apr 5, 2010 2:01 PM
33.	Support for siblings, for example educational services.	Mon, Apr 5, 2010 12:49 PM
34.	Funding to continue the capacity building which has been started through the 'Positive Partnerships' initiative. This attempts to establish a long-term self-sustainable model of collaboration for parents and teachers of children with ASDs; parent to parent, teacher to teacher, school to school and parent to school.	Mon, Apr 5, 2010 12:48 PM
35.	Many families and professionals wish for their ASD clients to participate in social skills programs. This is one of the key areas in which people with ASD experience difficulties. However, because of the limited research in the area of social skills programs, they haven't been included in the Best Practice Guidelines. Social skills programs are greatly needed to assist people with ASD in their everyday wellbeing.	Mon, Apr 5, 2010 11:48 AM
36.	<p>Focus on the adolescent age bracket, More AFFORDABLE access to therapy programing such as art therapy, speech, OT. Educating school professionals, Funding for independant parent groups (such as Casey Aspergers Support Service) so they continue to provide opportunities and support for community members. More face to face consultation forums with community groups such as Casey Aspergers Support Service Acknowledge the potential these children have, and harness the prospective capabilities, invention and knowhow that the future holds for these children</p>	Mon, Apr 5, 2010 10:54 AM
37.	Children with Autism look reasonably "Normal" and even at birth appear to be the "perfect" baby but as time	Sun, Apr

	<p>goes on their uniqueness is more and more displayed. This uniqueness is individual to each child/person with Autism. Unless you live with this everyday there is no way that you can fully understand the needs of these beautiful people.</p> <p>When considering what is to be funded next you need to get a better understanding of these individuals and people who care for them (their families).</p> <p>Gaining access to intervention between 0 and 6yrs was vital and life changing for us all. However waiting lists are getting longer now for others. Now as my child enters school i again am having to "lobby" for my child to gain the necessary help in the class room. Transition to help him move from kinder to school was not well planned to meet his needs. Application for an Aide was a case of meeting the criteria. What!! My child has Autism is that not a criteria on its own. And the teacher had no experience or training for a child with Autism. I now have more stress and concerns added to my already stressed life.</p> <p>Then you find out your other son has Autism too. But he is not eligible for any funding because he is 8yrs. So no intervention and no government funding offered to provide needed therapy. (Unfortunately he slipped through the cracks until i began to learn more about this disability and could see the similarities. So you go through the process again because you need a formal diagnosis for any one to believe you.)</p> <p>But no funding to help with social skills groups, ot or social activites like camps or holiday programs. So you do the best you can but he really needs more. Not to mention no additional support at school because again he needs to meet the criteria. What! Another wall.</p> <p>No support packages because we don't fit the criteria, no funding because he is too old, no educational help because it means more paper work for the teachers, psychologists and others and it may not be successful. Where do we go now?? Can you answer this??</p> <p>*You need to move on to funding for school aged children especially aides for children with autism along the whole spectrum. Holiday programs, social skills therapies, ot therapy, speech therapy. Family financial support to help pay for programs/activities/camps/respice and even sibling support camps/activities. These children don't just turn 6yrs old and are fixed. Thats step one (Early intervention) now lets move on to step two and keep them moving forward so they can reach their full potential. Trust me they are worth it and have lots to give.</p>	4, 2010 8:33 PM
38.	<p>I would like to say that living with a child with Autism is a full time job in itself and is very draining. I do not believe there is enough support for the parents and sibilings of a child with ASD. I do not believe that there is enough support for a child with ASD. Should you happen upon some support, the waiting lists are high, or you are not intitled to it as you do not fit the critrea.</p> <p>Better respice options for a family like ours would be life changing, as it is very difficult for my husband and I to spend quality time with our other children, when Jordan requires our attention 100% of the time.</p>	Sun, Apr 4, 2010 7:12 PM
39.	<p>More schools in all areas that cover primary and secondary schooling in the one school, to limit the stress of change. My son has to travel nearly 4 hrs a day (2 hrs each way) so that he can attend secondary school, when he was in primary school he had to travel an hr each way, we need combined primary and secondary schools in more areas so that all kids can get to school in a reasonable time.</p>	Sun, Apr 4, 2010 6:42 PM
40.	<p>I have no funding for my son his pragmatics are very low I want you to tell me how he is supposed to get through grade 4 5 and six let alone high school as the lack of knowledge of haw to teach these kids are scarce I have had to cut my days of work to 3 days and am looking at giving up work full time as my son cant cope with tghe day to say lifestyle of after school care and long hours of school but hey according to you he isnt severe enough for funding but hes severe enough for me to have to give up my job and the teachers and principle to call me a he is sleepy from his anxieties of not understanding or coping with the confussion of learning good on you I say pur ignorance you have no Idea what its like to raise a child with as I think its about time you either learnt step up to the plate or step down our kids need help now and for always these kids are for always it doesnt have a cure I also think you have no right to judge how much or how little these kids need funding the families are the ones that suffer</p>	Sun, Apr 4, 2010 5:39 PM
41.	<p>early intervention is the most important thing that can be done for any child with any disability. Schools like Essex Heights Primary School, are most important for children with High Functioning Autism because they provide an environment where the child can develop in a supportive community. I believe that no amount of funding can replace the playground environment that my grandson was able to have at EHPS; this, together with the support services provided by the staff at the school has helped my grandson immensely in his development.</p> <p>I believe that there is a need to fund special schools for children with severe disabilities, but a lot of children that can be integrated in the general education system will benefit greatly from a school with a sufficiently large population of children with varying disabilities, this has the double benefit of rendering individual children "invisible" in the playground and exposing all the children to individuals with "different" behavior.</p>	Sun, Apr 4, 2010 12:51 PM
42.	<p>I would like them to know that the basics for autism support is to go back to basics - Respect, Love, Acceptance and Protection. and to recognise that it is a different way of perceiving and being in the world not lesser than...understanding, compassion...services and therapy are important but not if they only focus on 'fixing' and 'normalising' and hence stigmatising</p> <p>thanks</p>	Sun, Apr 4, 2010 11:01 AM

43.	All children with ASD should have equal support despite their financial circumstances. Funding should be allocated to each family equally once a diagnosis has been made.	Sun, Apr 4, 2010 6:12 AM
44.	Something needs to change for children in school who have a normal IQ and ASD. There is no support, the child is left to make the best of an almost impossible situation. Yes they might be able to read and write but they are not learning any of the other skills a person needs to survive once out of the school environment. A normal IQ doesn't help you manage in a noisy, bright classroom where people touch you, how do you learn and hold it together when you are struggling not to throw yourself on the floor and scream? My child has a normal IQ and doesn't qualify for any support at all. She refuses to go into school every day because she is scared, its too hard to cope and she is bullied. Her normal IQ doesn't make her less autistic, in fact sometimes it makes it more difficult for her. Something somehow needs to be done to help ASD children in schools who have a normal IQ.	Sun, Apr 4, 2010 12:02 AM
45.	There is certainly not enough funding for aides in schools..	Sun, Apr 4, 2010 12:01 AM
46.	Please give parents more early intervention options. Longer sessions ans where parents and siblings do not have to attend. Please help teachers teach in an ASD friendly manner - all students would benefit to a different learning style in some or all subjects. Please help with bullying at school - create safe places for ASD kids to go to during recesses. Please help the carers - do not let us burn out!!! school holiday programs, support groups for parents and teens are vital.	Sat, Apr 3, 2010 10:13 PM
47.	A person with ASD is human, and needs to be treated as such.	Sat, Apr 3, 2010 7:26 PM
48.	Special schools for children with high functioning autism are vital, since these children are in my opinion 'slipping through the cracks', due to lack of adequate attention. social networks and educational support.	Sat, Apr 3, 2010 5:59 PM
49.	The primary school education system, there are so many unhappy ASD children in public schools due to the lack of support, maybe we need some schools for ASD children where they are not bullied and ridiculed on a daily basis.	Sat, Apr 3, 2010 1:07 PM
50.	It is vitally important we address the needs of our children with ASD to ensure where possible they are helped to assimilate into normal schools, supported to ensure they have individual learning programs by teachers who know how to teach these special children. If we can get them through high school with the skills they need to secure gainful employment, we will increase their quality of life and reduce lifetime govt funding. How wonderful it would be if we could make them happy and understood - imagine the reduced load on psychologists. The current mental health and Aspergers support funding is great but only scratches the surface of what is needed. We need more.	
51.	Each child with ASD is unique and should have every chance of succeeding in life it is so hard for both parents and siblings and ASD kids to live without the support groups for us. So please make a change to the funding for aids in the classrooms as it will make a lot of difference to our children.	Sat, Apr 3, 2010 11:30 AM
52.	Get off your butt and stop putting limits on this. It's not like the kids outgrow Autism. There needs to be ongoing support for people on the spectrum and their parents and siblings, no matter how old the person on the spectrum is. We need a better Educational System for them including Secondary and Tertiary settings. We need Independent Supported Accomodation for older teens and adults. Parents can't look after those	Sat, Apr 3, 2010 11:23 AM

on the Spectrum for ever.

We also need to be able to have Assistant Dogs for those who want to use that service. In other countries such as America this is recognised and things are in place for people to train their own Assistance Dogs. We need that in Australia, especially Victoria. Queensland, NSW and Tas has legislation set up, we need it in Victoria

Early Diagnosis and Early intervention are the key factors in diagnosing and treating ASD. These 2 factors are the most relevant in any child's future well being. Funding is required to assist parents with the financial burden to provide the best possible services for their child and therefore providing them with the skill sets to cope with life.

Sydney is the leading state in Autism awareness and providing a number of services for specialised and intense early intervention. With proven results, this is the way for our future in every state. We should be able to provide the same level of intense therapy for every child with ASD. Whether it is through one major hospital or we start to provide necessary services in schools.

53. My sons' school provides Speech Therapy but the school advised he was not eligible so we have continued to pay privately along with many other necessary services. He has been diagnosed with ASD and has an Aide - I simply cannot understand why the school cannot prioritise this service to children in my son's situation. We have privately paid for several years for Occupation Therapy, Psychology, Speech Therapy and a number of sporting activities to try and get the best early intervention possible. We also paid for his diagnosis and Paediatrician's etc at a huge cost. We are one of few lucky families, we only have 1 child to support financially and both parents work to cover these expenses.

Sat, Apr 3,
2010
11:23 AM

Please consider my thoughts, there is a lot to consider when you are raising an ASD child. It is mentally and physically exhausting. It shouldn't also be financially burdening just to provide your child with the same life skills as any other child. It usually coincides with a number of immunity and health issues and also food intolerances. Also, there are further medical expenses that are not considered. I have often had to purchase prescriptions for my son that have not been on the Health card authority. If my son is too sick for a therapy appointment it is often a relief that we will save some expense that week.

We also pay for private health cover but it really isn't worth it as most of the required extras are either not covered or only return a very small percentage. I keep paying for peace of mind. This is at great expense to our quality of living but my son is everything to us and I will continue to put him ahead of obstacles. I am determined to give him the future we all want for our children. A future of hope, independence, love + family, good health, life skills and normality.

Thank you for taking the time to read my comments.

54. Funding for those children over the ages of 8.....who are already diagnosed.

Sat, Apr 3,
2010
11:02 AM

55. Politicians need to realize that ASD does not disappear when children turn 16, funding and programs are needed across all ages. More family support is also needed. Aides and teachers need more training in ASDs, so they understand the difference between "naughty" and a melt-down and can act appropriately.

Sat, Apr 3,
2010
10:52 AM

56. All ASD children should have access to funding on some level to assist with their everyday living. Just because a child has an academic capability does not mean that he does not need funding at primary/secondary school. Social issues can severely impact upon a child's life which therefore affects their learning and everyday life.

Sat, Apr 3,
2010 9:25
AM

57. 1. Support for those families who are Homeschooling their children with ASD not due to choice but due to compulsion caused by the lack of knowledge by the school professionals leading to severe health issues for these kids.
2. Simplify funding criteria in schools (primary/secondary/tertiary) leading increase access to Aide hours.
3. Broader access to support services without meaningless clauses and barriers.
4. Regular ASD education program for school professionals and the school community as a whole to be able to embrace ASD more positively rather than look at it as a stigma.
5. Unconditional easy access to ASD professionals for parents and professionals.

Sat, Apr 3,
2010 9:12
AM

58. I want Premier Brumby and Minister Neville to know that Autism just does not go away after the age of 7. My son was diagnosed with Asperger Syndrome (AS) at the age of 6 well before the early intervention funding became available. Many children with AS are not diagnosed until after the age of 6 when they are immersed into Kinder or School - very social situations. Because AS kids have average to above average intelligence their diagnosis often goes undetected until a teacher or parent realises that something is 'not

Fri, Apr 2,
2010 9:24
PM

quite right' about a child.

I have seen what a difference the early intervention funding has made to children on the Autism Spectrum and it was a wonderful initiative.

It is now time to focus on the next group of kids. The kids who are aged 6 and up. Many of them have not had early intervention support and are well behind with many social and life skills.

Funding packages could be allocated to schools to support these kids. To provide speech therapy, Occupational Therapy and Psychology - one on one and group work.

Extensive ASD training must be allocated to all areas of the education departments from Principals down to support staff.

Disability support packages in the schools need to be improved and more easily accessed.

Financial assistance to families who are often on one wage as the caring of a child with AS is often stressful.

The list could go on and on but these are the main areas I see need to be addressed in the next election!!!!!!

59.	There is a desperate need for social and life skills groups for teenagers. These need to be affordable;	Fri, Apr 2, 2010 3:16 PM
60.	<p>As a mother of a child on the spectrum who also has other health issues as well, the program for children with a disability needs to be fixed fast. My child fits three categories but each one cancels out the others. This is a farce.</p> <p>Respite is another area that is needed but is not funded enough. We are unable to access any respite due to limited funds at the local council.</p> <p>Also due to my child's medical needs, we regularly (at least once per week) travel to the Royal Children's Hospital. However because we live 96km's away from the hospital and not 100km we do not have access to any travelling allowance or parking fee reimbursement. There is a cumulative amount but you have to travel 500 km each week for 5 weeks to receive this and we only travel on average 192k's per week, however we also have other specialists (my child sees 13 different specialists and therapists) that are closer to us. This needs to be changed as we spend an extraordinary amount of time and money just going to appointments and paying for car parking. The cumulative amount should be an amount (say 500km) per month to receive funding.</p>	Fri, Apr 2, 2010 1:15 PM
61.	While funding is one of the number one issues for us, the consistent 'loop holes' that have to be jumped through in order to access services is wrong. What compounds this difficulty is the fact that there is simply too much paperwork and seemingly insurmountable eligibility requirements, making it virtually impossible for those who genuinely need the assistance to actually obtain it. If helping 'special needs' children is a genuine priority, this must be changed!	Fri, Apr 2, 2010 11:56 AM
62.	Funding for adults who, either because the diagnostic criteria was unavailable or they simply fell through the cracks, are forgotten by the system. I saw mental health professionals fairly consistently between the ages of 14 and 26, and then continuously from 26 to 34 yet they never worked out I was an Asperger (when I got my diagnosis I was told by the psychologist that I "OBVIOUSLY" had AS). When I found out about AS I had to bypass my psychiatrist (when asked, he incorrectly stated "you're not indifferent so you can't have AS") and get a diagnosis elsewhere. Why must I continue to pay the price for 20 years of clinicians' oversight and ineptitude?	Thu, Apr 1, 2010 12:29 PM
63.	<p>Get serious about helping kids in their formative years at school where the money will be well spent to set them up for life. Educate principals and all teaching staff about ASD and the importance of using flexibility of teaching styles to allow all students proper access to education.</p> <p>Stop moving the eligibility criteria so that fewer and fewer kids are eligible from one year to the next.</p> <p>I am on a committee of a support network and the difference between the life journey of individuals who never got any support and those who are now being earlier diagnosed and assisted with intervention support and better knowledge is very obvious. The lows and disadvantage are much more pronounced in those people who never got that support, for them and their families.</p>	Thu, Apr 1, 2010 9:38 AM
64.	I would like Premier Brumby and Minister Neville to know that supporting children with ASD is not difficult. Other countries have managed to do it and there is no reason that Australia cannot. It is a myth that the problem of children with ASD in mainstream schools are the children themselves--the problem is a poorly executed program supporting them. This idea that ASD is new, challenging, different is silly. Children have had disabilities for a long time and good and bad programs have supported them for a long time. There is a wealth of information in the world about what works and what does not. The issue is not what Premier Brumby and Minister Neville will do about ASD as much as what they will do about failed public	Thu, Apr 1, 2010 8:55 AM

administration of programs for children with disabilities in their administration. Victoria has examples of well run government programs. The same critical success factors for those programs apply in this domain. Successful public programs do the following: 1. Listen and incorporate the views of stakeholders into public programs and 2. Monitor and evaluate all public programs. This is not being done for children with ASD.

65.	Case managers need to be funded. I spend about 3 hours most weeks briefing agencies about services that I require for my two sons and providing background information. Sadly, once I establish eligibility it is usually only for one of my sons because of their 5 year age gap. So then I go searching for other services that have different eligibility criteria to meet the needs of the other son. I should only have to provide this information once and then it should be the role of a case manager to source agencies/services and to provide this information, with my consent, to these agencies. This is such a tiring impost on parents who are already struggling to survive each day. It is even necessary to repeat the briefing as one moves through different sections of the same agency or when a staffmember leaves an agency. This is such a colossal waste of time and energy, neither of which is in abundant supply for a parent of a child with ASD.	Wed, Mar 31, 2010 8:57 PM
66.	we need to be able to use our fahcsia money for teachers aides who are on the ground doing the hard yards and getting paid 1/10 of what the psycs get. We would get 10 x as many intervention hours if we could use our funding for an aide in the school	Wed, Mar 31, 2010 4:48 PM
67.	Give families access to a case worker for all ages (not just those with children diagnosed young enough to be accepted into early intervention). There is a feeling of despondency when a parent realises that their child has missed out on services because they are too old.	Wed, Mar 31, 2010 2:48 PM
68.	We are dealing with a very mild ASD and managing perfectly as it, so my concerns are somewhat minimal. I do think Aides in school particulary in the early primary school area are important.	Wed, Mar 31, 2010 2:44 PM
69.	My priority is for my son who is in Year 11, who has struggled through school NOT because of his academic ability as he has an above average IQ but that the system has failed to teach him in a way that he can reach his potential. I am studying Special Education because I want to help other kids like him at an earlier age. Teachers jsut do not 'get' these kids and they need to, to be able to help them succeed. All teachers with ASD students should be funded to complete a ASD course. Any school with ASD children should have their teachers complete an ASD course. I despair that the education system has failed my child - I hope and pray the employment system doesn't otherwise my child will end up being on support for the rest of their lives and that is not what I want or I'm sure what the govt wants for any of these kids!	Wed, Mar 31, 2010 2:09 PM
70.	They have done a great job with programme for under 6 year olds - now time to tackle next age level of primary school when many kids are diagnosed with higher functioning autism & how to help them.	Wed, Mar 31, 2010 12:46 PM
71.	Access to appropriate amounts of early intervention as it's proven that it makes a huge difference. The child does not benefit from a drip feed / on & off approach to early intervention due to lack of funding. instead they require continuity of services at an early age so that they are hopefully less reliant on as many costly services as time progresses.	Wed, Mar 31, 2010 12:41 PM
72.	Funding should be streamlined and handled through ONE source (eg Medicare). All children should get equal funding regardless of the school they attend. Funding criteria should be more relevant to children with Aspergers/Autism. It should be recognised that these children can often have multiple areas of deficit and don't fall neatly into one category.	Wed, Mar 31, 2010 12:23 PM
73.	More staff who know about how to deal with ASD in the schools.	Wed, Mar 31, 2010 11:33 AM
74.	If we don't get it right through primary and secondary school, there will be little hope after that.	Wed, Mar 31, 2010 11:23 AM
75.	Number 1 priority for me - consider those children that are falling through the net as a result of not meeting certain criteria (could be because of age, parental income, level of severity, lack of services, in the independent school stream not government etc). My child has missed out on new funding as he is older (over 8) but is not getting any assistance (unless funded privately) although all medical experts agree that he requires some intervention.	Wed, Mar 31, 2010 11:13 AM

I have been unable to access services as most specialists that are 'autism aware' have either closed their books or are unable to see my child on an ongoing basis. I am left to use other 'specialists' that are of little assistance and waste my money. I spend a lot of time trying to educate the 'specialists' on what my son needs. The areas of intervention that my child needs are not in the medical field - they relate to social skills, after-school care and vacation care. Currently there is no option but to place my child in the mainstream setting or privately fund the alternatives.

76.	Please take the burden off the secondary schools who are trying to do their best. Much more specialist support for the teachers and parents is needed to give these children the best possible outcomes for their adult life.	Wed, Mar 31, 2010 10:58 AM
77.	Bring your state schools up to speed! You need to make sure that ALL teachers are taking ongoing education about the needs of children with ASDs. So many children are just falling through the cracks and desperately need help. We are good parents and actively engaged in gaining access to services that our son needs (drama classes, social skills classes, speech pathology, psychologist, paediatrician) and we are funding almost all of this from our own pockets. However all of this is constantly undone when my son is at school because he is thrown in to deal with other kids in the school yard every day with no respite. He is bullied and despite many, many visits to the school and the principal this has STILL not been addressed. He is on medication for his anxiety and STILL the teacher is unable to read the signs of his escalating anxiety or oncoming panic attacks. His teacher does not understand his need for personal space and constantly forces him to sit in a large group with the other kids; he is frequently overwhelmed in the class room because he requires short, simple instructions. However because he is extremely bright and can 'do' his work his teacher and the school are not interested in anything we or his psychologist suggest to help him. If you don't provide better education for the teachers and MAKE them acknowledge and support these kids nothing is going to improve!	Wed, Mar 31, 2010 10:21 AM
78.	Personally I have very limited knowledge about what services & support is available to me and my family. We know what we need but I guess we are not sure where or how to get it.	Wed, Mar 31, 2010 9:46 AM
79.	Funding for employment through organisations like Alpha Autism is crucial. Funding training for employers who link to this program so that they are aware of the issues. Social skills funding for people with Autism. Funding for family support as ASD disorders cause huge stress on families and marriages, siblings etc. The disorders often occur more than once in families which complicate the family dynamics. Studies on this and support are very important.	Wed, Mar 31, 2010 9:32 AM
80.	Employment for ASD people. Many are left to waste their lives on Disability Pensions with no active support to get a job, live independently and live fulfilled lives	Wed, Mar 31, 2010 9:06 AM
81.	Simplifying a complicated system would be the number one priority. After a diagnosis, it is very difficult to collate the information and understand what support services and assistance is available.	Tue, Mar 30, 2010 8:59 PM
82.	Education is very important, not only for people involved with these ASD children and adults, but also a general awareness campaign to educate the community. Spend time with these families and understand their frustrations and what support services they desperately need. I fear that as my son gets older and heads toward adult life, that his genuine inability to not understand social faux pas will cause him to make a mistake and end up labeled a criminal and be thrown into a world that would send him over the edge and unable to understand or cope. I want medical and legal professionals to seriously understand our concerns about being able to make serious life changing decisions for our kids. I worry about when my son is an adult and potentially fathers a child he cannot physically and financially deal with. Can I make that choice to have him sterilised so he does not potentially harm or neglect a child of his own out of not being able to understand how to deal with it? Will we be left raising a child in our older years that he cannot? Will any children of his have Autism as well and perhaps of a more severe degree? Who will take care of him when we are not here? How can we of a low income family provide for him for after we are gone as well as our retirement and other children? Do they get a lesser inheritance because it is all tied up for the care of our ASD son, as well as having to be his legal carer as well? These beautiful ASD children will be adults one day, and although they are high functioning and able to integrate relatively well in society, the lack of support services and education may have them ending up in mental health or correctional facilities where they don't have to be. Please help us educate our children so they can find work and be valued members of society. They are not all violent, severely retarded individuals, but are golden souls that do not judge but see only the good in other people.	Tue, Mar 30, 2010 8:16 PM

83.	<p>The amount of money that we get is nothing to what we should be paid for. What is this government going to do for me and my child. I would like to know who do I vote for this year. I like to see the children with ASD get what is need. It's about time that the Government give back to the children of the future.... More schools for child with ASD. More support and funding for these children. More packages for children of all ages to fit into community. What happens to these children when we are not here to look after these children anymore. who is going to look after my child when I am dead. it's time the government takes a stand and step up to all children with ASD.</p>	<p>Mon, Mar 29, 2010 4:09 PM</p>
84.	<p>They already know that there are serious gaps in service delivery to families and individuals affected by ASD. They also already know there isnt enough \$\$ being spent on better educating the educators about ASD and the impact that ASD has on individuals and their families.</p> <p>Our children spend such a long period of time in school settings, whether this be Early intervention settings, kinder, child care, primary school, secondary school, university..... there are so many teachers out there that just dont "get it", and for those that do their hands are often tied because of budget constraints.....please stop dragging this out so another generation of families, educators and caring professionals (speechies, ots etc) have to flounder thro with inappropriate knowledge about Autism Spectrum Disorders AND financial support to best implement programs so that the best outcomes are achieved for all concerned. Thankyou</p>	<p>Mon, Mar 29, 2010 9:22 AM</p>
85.	<p>Again.....the Autism specific secondary school for the outer east of Melbourne, staffed by professionals who understand Autism and its dynamics.</p>	<p>Mon, Mar 29, 2010 9:13 AM</p>
86.	<p>Accommodation - life time is critical. Suggest this government has its priorities wrong. Too much on sport (Grand Prix) etc. too little on the most vulnerable. Overdue to catch up after years of neglect.</p>	<p>Sun, Mar 28, 2010 11:38 PM</p>
87.	<p>Pleae provide them with my comments made throughout this survey. If they have any suggestions and/or solutions We are open to hearing them. Ms Cindy May 0409 548 436 (personal) 0458 324 172 (work)</p>	<p>Sun, Mar 28, 2010 9:00 AM</p>
88.	<p>All children on the ASD need to be addressed not just early intevention (up to 7 years) consider all ASD children</p>	<p>Sat, Mar 27, 2010 4:56 PM</p>
89.	<p>Intervention and support services for school aged children and teens.</p> <p>SOCIAL SKILLS PROGRAMS</p> <p>Supported access to services for families in regional areas - travel and accommodation costs for visits to city areas are huge!!!</p>	<p>Fri, Mar 26, 2010 4:59 PM</p>
90.	<p>The first biggest hurdle is diagnosis.....long waiting list for pulic (especially) and private is very expensive!! Once you have that diagnosis.....where to go from there?? Our first child was diagnosed four (4) plus years ago, and only recently (while going through diagnosis number two) we found out about services that have been available to us all along but we didn't know they existed!! Then, the paperwork and waiting list to then access these is ridiculous. I see respite as an important issue for all immediate family/co-inhabitants of people with ASD, epecially parents and siblings. Educating the educators (at any level) is extremely important. How can we educate these children for every day living if the ones educating them don't understand ASD and the pros and cons?!?!</p>	<p>Thu, Mar 25, 2010 8:39 PM</p>
91.	<p>Support for us as families generally as we are the backbone of our children. As a parent/carer, if I am not supported mentally and physically, then I can not function to the best of my ability to cope with my children with ASD and then the government would then have to intervene to support myself in hospital whilst I am suffering from a breakdown.</p>	<p>Thu, Mar 25, 2010 11:13 AM</p>
92.	<p>Mansfield Autism Statewide Services is an organisation that has been in operation for over 40 years</p>	<p>Thu, Mar</p>

	helping families of children with an Autism Spectrum Disorder between the ages of diagnosis and 18. It delivers an exceptional program for eligible families across rural and regional Victoria but is in dire need of more funding in order to employ more staff and expand its services to reduce its embarrassingly long waiting list and adequately meet the needs of the children and families they service. Why keep funding new and relatively unknown programs, when the established, legitimate programs already on offer are barely meeting the needs?	25, 2010 8:31 AM
93.	It is not just the ASD person that is affected by their condition. It is a whole family problem. I should not have had to cry at a compulsory job network interview before i was put in touch with emergency respite services. As a single mother, I should not have to pay \$000's for education that is suitable. Is the ASD P-12 that was whispered for Ferntree Gully a reality, if not, why not.	Wed, Mar 24, 2010 9:10 PM
94.	The community to be made more aware of Autism. The Premier and Minister both need to visit intervention programs, special schools and classes and spend a whole day there and they can witness how these schools, kinders etc run. Also by try being a parent for a day for a child with autism and try accessing information from government groups and see how they appreciate getting the run around or to be told your child has a disability but because he is able to dress himself he is fine, too bad that he doesn't speak though!!!! How is that fair? Then ask Mr Brumby and Minister Neville to find those parents who are actually ripping off our system and the poor innocent families who are struggling receive no help at all from the government. When is it going to be fair, when I ask????	Wed, Mar 24, 2010 8:32 PM
95.	They need to sit with families and experience first hand what the effects are on the family, both financially and emotionally are, what the affect on the family balance is. Educate teachers in primary schools and the lower years to be aware of the symptoms of ASD. What to do and assist with the education of the child, specific teachers and classes to assist the children, educate the parents, through advertising. It all takes money to start, but it needs to start somewhere. Brumby sit with the parents and learn first hand, don't listen to those without the child, listen to the people who teach and look after these children.	Wed, Mar 24, 2010 8:28 PM
96.	Respite for parents, Autism specific schools to 18 years of age!	Wed, Mar 24, 2010 12:46 PM
97.	There should be one policy for ALL asd categories recognized by everyone. People with asd's and their carers/families shouldn't have to keep proving how much suffering their condition is causing them. Going through the diagnoses should be enough evidence to warrant automatic admission into the program for students with disabilities, centrelink funding, companion cards etc.. This is a life long disability and should be recognized as just that a disability. Early intervention is fantastic and much needed, but intervention services should be offered to ALL newly diagnosed individuals. It has been very much a slap in the face to be told by the education dept that my son doesn't fit the criteria for the program for children with a disability. He is disabled! His grades and the fact that he keeps getting new diagnoses and put on medications like anti depressants should be proof enough that he isn't coping with the system. Another slap in the face is when I get told that my disabled son doesn't meet the criteria for a disabled persons card ie the companion card. They say he doesn't meet the dhs act, hmm yes he does. Its all about how you fill out the forms. I know other kids with school funding (level 3) and a companion card same age as my boy but with only an aspergers diagnoses. How does this happen? My son has 5 diagnoses is on meds and can't get help! Even he cries "why wont anyone help me?" What am I meant to say. Because your not suffering enough? Because your not inconveniencing the school system enough? The system isn't equal its not fair and there are many individuals suffering because of it.	Wed, Mar 24, 2010 10:40 AM
98.	Employment opportunities for adults with ASD, in particular those individuals who don't fit into the ID category, who are intelligent but different and find life with ASD challenging. Recognizing the relationship between ASD and mental health issues-depression.	Wed, Mar 24, 2010 8:48 AM
99.	The service system for children and adults with ASD is in crisis! Those in need wait while those in crisis get the majority of supports to stop relinquishments (for those under 18) or to reduce applications via the Disability Service Register. ISP are not the answer as families with packages have no services to purchase - initial support must come via basic funding for services to exist so that families with ISP can then purchase the services. Without basic service funding most services have become or are becoming 'casualised' - casual staff are used to fill shifts thus further reducing knowledge about ASD and most importantly the individual with ASD. Use of casual staffing also reduces stability and continuity of support.	Wed, Mar 24, 2010 8:31 AM
100.	we are all struggling and wxhausted with the lack of support and insufficient expertise resources are	

limited whilst living in the country seriously it increases waiting times for paediatricians and ei services

come live in my house mr brumby and see what i have to deal with im a carer to four people to asd and one with esrf on dialysis plus another with behaviour mobility and renal complications when doo i get a break never

101.	The PSD criteria needs to be seriously revamped so that parents don't have to wait until they are desperate to receive support for their child at school. My son did not receive funding until he was 4 years behind academically, if he didn't have to wait for so long he wouldn't have been so far behind.	Tue, Mar 23, 2010 8:24 PM
102.	Mr Brumby and Minister Neville, if you don't put money into improving life outcomes for people with ASD, there is going to be a massive social crisis in a few years' time. I promise I'll vote for you if you put up the cash.	Tue, Mar 23, 2010 8:21 PM
103.	1) Early identification and diagnosis of autism within a child 2) A swift program of services to be delivered to a child diagnosed with ASD, a comprehensive early intervention program including speech therapy, behavioural therapy and Occupation Therapy, including social skills. 3) A change of attitude in our autism specific schools, to quickly identify children who can be integrated into mainstream school and assist children to enter into mainstream as soon as possible. 4) To measure the effectiveness of what autism specific schools are doing, we need to measure there success. 5) Help support children with ASD in a mainstream educational setting with highly qualified integration aides and teachers who are specialists in educating a child with ASD. 6) Employment opportunities for ASD adults. 7) Supported living accommodation for ASD adults.	Tue, Mar 23, 2010 7:50 PM
104.	diagnosis for asd is very expensive and is out of reach of many up to 500 dollars so substantial financial support is needed	Tue, Mar 23, 2010 3:46 PM
105.	I would like free diagnosis. We paid out a lot of money for this and I am aware there are many who just cannot afford to have their children diagnosed. There are many who cannot even afford the difference between medicare rebate and the psychologists fees for ongoing counselling. This counselling is so important for families, many women coping on their own with no support of husband. It could prevent suicide. I would like more funding for more psychologists at AUtism Victoria.	Tue, Mar 23, 2010 10:27 AM
106.	Facility based respite should have a much higher priority than it currently has.	Tue, Mar 23, 2010 9:21 AM
107.	I would like to see state schools accepting students with ASD. It does not happen and most often it is not the school's fault - they are reluctant to accept such a student because of lack of funding. I would also like to see the same level of funding in the independent/catholic/private schools (for ASD students) as in the state schools - there should not be a disparity of funding based solely on the type of school. In fact, it would ease the demand on state schools.	Tue, Mar 23, 2010 8:37 AM
108.	Specialised School that these children can reach their full potential without interruption. Because ASD children have emotional immaturities, the school age would be prep to 20 yrs before moving onto university, etc	Tue, Mar 23, 2010 8:04 AM
109.	It really saddens me that we are being forced to choose. Things have been let go for too long and we are at crisis point. I would like to tell them to pull their finger out and get moving. Autism isn't going away and the numbers are escalating.	Mon, Mar 22, 2010

		10:50 PM
110.	If families are not supported well, they will fall apart with the care of their children. The consequences of this are financially catastrophic (since finance is the only language they understand)	Mon, Mar 22, 2010 7:48 PM
111.	Evidence based research on successful biomedical treatments that are being implemented in mainstream medicine in the United States and the United Kingdom. An educational program for Peads.and G.P.s about ASDs and common biomedical issues.	Mon, Mar 22, 2010 12:02 PM
112.	Funding to access intervention services / specialists to assist those with Autism over the age of 6, their Families and Carers.	Wed, Mar 17, 2010 11:07 PM
113.	Disability Client Services (Intake) at DHS should have an efficient eligibility assessment service within the department. At the moment we have to jump through hoops to obtain funding for our son to be placed in a day program to teach him social, self-care etc. skills. There should be a specific program involving suitable employers to help them to take on ASD people with advanced mathematical, statistics skills. Job programs should be formulated and jobs reserved for people with these very high skills (our son has gained these, yet are wasted) yet who need the clear guidelines and instructions typical of ASD. Such employers do exist in the USA and Denmark and are desperately needed here.	Tue, Mar 16, 2010 8:28 AM
114.	more aides for kindergatens, my child found it very hard to get one full time.	Mon, Mar 15, 2010 11:32 AM
115.	more help and support for these beautiful children and their parents we need a better understanding for the public so people dont stare at our kids and make them blowup worse some people are just damn ignorant dont stare at my child it upsets him and ends up in an episode im different not contagious	Sat, Mar 13, 2010 9:37 AM
116.	Education is my concern and awareness in the schools. Make children aware about autism so there is no bullying. Have a class based on the kids with autism and have children know about their behaviours and differences.	Fri, Mar 12, 2010 8:29 PM
117.	Families of children with ASD are in crisis - once our children are of school age there is limited support for intervention. These children need OT support to develop litererecy skills and handwriting, they need speech support for communication and to prevent behaviours of concern developing due to frustration. they need ongoing support with social skills development. Parents need greater support and siblings are suffering as families simply cannot manage with the limited support available. Depressin is common amongst parents and siblings of children with ASD. The present situation is just way too hard for most families. More needs to be done URGENTY.	Fri, Mar 12, 2010 5:08 PM
118.	There is so much fragmentation now with FaHCSIA money (a good thing that allows families access to services they may not be receiving otherwise), Disability Services, ECIS, Respite brokerage as only a few areas, not connected, not funded to be connected and a maze of confusion for families who are already so stressed. Ongoing need to be deemed eligible for many different service streams is harrassment and traumatic for families. Fully funding ECIS could help pave the way for families to be better prepared to be their child's advocate and to make life changes that help sustain the family, extended family and community.	Fri, Mar 12, 2010 4:17 PM

119.	<p>There seems to be funding available for children with disabilities that require ramps and sight support, Can we consider the actual support aides our children need. Often our children have poor motor skills, it would be fantastic to help them with laptop in schools and support with programs to help with words and sentence building.</p>	<p>Mon, Mar 8, 2010 11:39 AM</p>
120.	<p>A school with small class sizes (e.g. 4-5 children) for children with Asperger's Syndrome or High Functioning Autism. These kids have great difficulty integrating into the school system and their IQ is too high for them to go to a special school. It would be great if they had their own school whereby they could grow and flourish at a rate which reflects their needs not everyone else's.</p> <p>Also, help for parents with respite and accomodation services. Parents need a break from the constant repetitive behaviours (physical and verbal) and there needs to be respite for children with High Functioning Autism and Asperger's in order to support the families who care for them.</p>	<p>Sat, Mar 6, 2010 7:09 PM</p>
121.	<p>Given that a recent study suggests an incidence of approximately 1 in 64 school aged children (Baron-Cohen et al., 2009)* it is imperative that Autism services, support and research is funded appropriately in Australia.</p> <p>While it has been acknowledged that current funding for people with ASD is insufficient in almost all areas, there are two areas that if funding injections are received, will have knock-on benefits for the Australian population.</p> <p>1) Early intervention services: Families funding their child's therapy by scientific (peer-review) research based methods such as Applied Behavioural Analysis desperately need to be financially supported by the government. Other families which are unable to fund these resources for their children are unfairly disadvantaged and require access to government funding for appropriate early intervention.</p> <p>Funding by government will actually SAVE money in the long term through reduced life time dependency on government services (and increased community integration) of these individuals with ASD.</p> <p>2) Basic research: There is a dearth of basic research into the causes and possible targeted treatments for autism in Australia which must be rectified. Investment of government funding into Autism targeted basic and clinical research will reap benefits in the future in terms of reducing government costs due to earlier diagnoses, specific treatment strategies and reduced social effects (e.g. including stress-related health problems of families struggling to cope with caring for family members with ASD).</p> <p>I am very willing to meet with Premier Brumby and Minister Neville to discuss these points both from the view of a parent of a child with autism and as a neuroscientist actively conducting research into the causes of autism.</p> <p>Please do not hesitate to contact me for any future discussions on these issues.</p> <p>Elisa Hill, PhD, Ion Channels and Disease Laboratory, Howard Florey Institute, Parkville, Victoria 3010. elisa.hill@florey.edu.au</p> <p>*Prevalence of autism-spectrum conditions:UK school-based population study Simon Baron-Cohen,* Fiona J. Scott,* Carrie Allison,* Joanna Williams, Patrick Bolton, Fiona E. Matthews and Carol Brayne, The British Journal of Psychiatry (2009) 194, 500–509.</p>	<p>Sat, Mar 6, 2010 5:35 PM</p>
122.	<p>set up services at mainstream schools for kids with ASD. This way they can find it easier to adapt and be able to be accepted by peers.</p>	<p>Fri, Mar 5, 2010 6:47 PM</p>
123.	<p>Where to start: there needs to be more places available for facility based respite for children and teenagers. this needs to be purpose built and peolpe trained to work with children with Autism to work there. more funding for these children to attend local kinders and child care settings. appropriate levels of support for a child to attend school. i could go on!!!!</p>	<p>Fri, Mar 5, 2010 11:29 AM</p>
124.	<p>more support for parents with aspergers.</p>	<p>Fri, Mar 5, 2010 9:17 AM</p>

125.	Services should not be based on age or when you were diagnosed. I vote for whatever party says they'll give me the support I need. I have no parents to advocate for me, no-one to manage my condition or to assist me finding appropriate services and next to no funding simply because I'm not a child. It's incongruous you'd rather me spend the rest of my life on a pension rather than saving money in the long term by helping me now with the services I need.	Fri, Mar 5, 2010 1:11 AM
126.	I am a mother of a child with ASD i am currently working for an early intervention program offering a prep class for ten children with disabilities in a mainstream school i have studied cert IV in disabilities and am currently doing my bachelor of education. I have worked in child care centres, kinders, primary schools and early intervention centres for the last 4 years. I would like them to know how hard they make it for kids with asd to get funding for education support(aides) in these settings especially primary school, it gets harder every year for these families to get funding when it is quite obvious they need help. I see these children wander aimlessly through the playground with little or no idea how to join in, i see them in lessons with no idea what is being said to them or what they must do and then most times punished for it, IT IS HEARTBREAKING....these kids and their families are desperate for help. I want them to know that the length of time it takes to get funding information through is a joke its march and the class i am in is still waiting, meanwhile we work with scrap paper donated pencils and second hand equipment, school started 5 weeks ago it is UNACCEPTABLE and i beleive all funding should b approve before school starts, procedures need to change.The government goes on about a quality education for all kids.... WHAT ABOUT KIDS WITH ASD!!!!!!!!!!	Thu, Mar 4, 2010 4:50 PM
127.	I would like the guidelines for best practices report written by M Prior and J Roberts (http://www.health.gov.au/internet/main/Publishing.nsf/Content/mental-pubs-e-autbro) to be acted upon. The recommended minimum hours of intervention offered throughout Australia falls disgustingly short of the recommend minimum hours offered.	Thu, Mar 4, 2010 4:17 PM
128.	Occupational and speech therapy supports at schools. education of educators and fellow students. access to support for families made easier. Accommodate the needs of high functioning ASD kids. They will be the ones who solve the problems of the human race in the future BECAUSE they are both brilliant and quirky!	Thu, Mar 4, 2010 3:08 PM
129.	First and foremost funding the professionals to understand autism, in the medical and educational field. Getting the correct information and diagnosis in the beginning is critical, and getting the runaround with incorrect diagnosis, compounds the problem. We went from a family with a disabled child to a disabled family at breaking point, because we couldn't get services needed in the first place. Next the services need to be there and accessible to all who need it. Speech, OT, social skills, music, drama, and teenage social services are needed. But reassuring carers that their child will be looked after when they are gone is also paramount, therefore Independant and Supported accommodation services need great funding. State govt getting behind the N.D.I.S. would be a good start.	Thu, Mar 4, 2010 9:25 AM
130.	ASP teenagers struggle to get employers to understand their limitations. Housing is also a problem if they want out move out and be independant. My lot are all bright so with assistance have managed but i imagine some struggle with daily interactions and being accepted. Thye are warm and loving peole and can become frustarted as are taken advantage of because of their condition.	Thu, Mar 4, 2010 8:57 AM
131.	If the goveremnt is going to stop children with any form of disability attending 'special schools' then they must provide training and support for teachers to be able to deal with and support the child in their class appropriately. It is not fair on the child, the teacher, or the other children in the class to expect a teacher to cope with children with complex needs without formal training or support. ASD comes with many social issues and school is one of the most social places a child can be if they are not guided correctly then school can be a very negative place and many of these children are seen as 'naughty' when in fact the world around them makes no sense. Even where behaviour is not an issue these children still need support to follow instructions and organise belongings or deal with sensory issues. This is very difficult for a teacher to provide for a child effectively without additional support.	Thu, Mar 4, 2010 8:08 AM
132.	All areas from preschool through to early adult support services are very important. Cahms services are struggling to respond to even the most critial of needs. I liken it to calling cahms in crisis. Child is on the bridge ready to jump off and the next question is 'how windy is it'. We shouldn't be concerned with mitigating risk to services by assessing how damn windy it is. Or how long can we hold off not responding. As a result of the extreeme lack of people and \$ my family is now split up. One adult living in one home with one child and the other parent living 200km away in another home. All to maintain safety and emotional security for a younger sibling. When our house was burning down emotionally that is services offered more assessments and a waiting list. They could not offer consitant ongoing appropriate support. In terms of education the concept of creating bigger schools with large classrooms of a 100 children and 5 teachers is lunicy for children with ASD. I can't be more blunt. It wont work, it will create stresses of the scale and it is an	Thu, Mar 4, 2010 6:54 AM

educational environment that would terrorise children with ASD. We are fortunate to receive a financial package from DHS. This has been a life saver. Its been the wicket keeper for us. Too little too late but it stopped the whole house from burning down. We would have preferred support that held our family together. not came in after it fell over. We don't know if it can come back together whilst our son needs care and support. There is no effective out of home care and support so we do it. But at a huge cost to our family and our own resources. If I didn't have a well paid job and the package we wouldn't be in a position to run two houses and our son would be institutionalised or on the street. School supports have far too many hurdles in front of families. YOU need to jump over the assessment hurdle. For education this is double the height that DHS set. Why should there be a higher standard of criteria in schools than DHS set?? then once you jump over the education hurdle you have to get that done by June in one year. Before you receive funding for the next year. So what happens in the meantime. No support for school to then support a child. In our case our child was assessed privately as having an ASD when he was 13 and three months. This was after CaHMs in our region said they would put him on a priority wait list for assessment and that would be 12-18 months away. Not good enough. At school our child couldn't get over one assessment criteria. He was too well behaved in the classroom. he smiles when he's stressed because he's learnt that people don't notice him too much if he is well behaved. So when he comes home from school all wound up because internally he's at breaking point we cop it. School thinks all is ok and it is with his behaviour in class. in the playground he's been bullied and in the classroom he's been sitting still smiling and not learning. Supports need to be skilled and on the ground and adequately funded to meet the real need. Not funded to respond when the house has already burnt to the ground. Far better to put \$ into support to ensure families can stay together and the child gets to reach their full potential which can be amazing. our child has skills in areas that are lightyears ahead but in these areas the school can't contain him can stretch him or provide the tools to extend his learning.

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133. We NEED to know the root cause, so that we can then tackle the symptomatic difficulties that are faced. No more treating - just cure which can only be obtained through understanding the reason ASD occurs in the first place.
- Wed,
Mar 3,
2010
10:23
PM
-
134. Funding is need to support the child through each stage. Statistics show us that the more support in the early years for high functioning ASD children - when they become adults they will not be such a burden on the states health services/pensions. It will save the government \$ in the future. The older the ASD child gets - the less funding and support services are available. At a time when they are trying to deal with all the typical adolescent issues plus ASD- to access support means long waiting lists, when you finally get some service it is limited and expensive. Support is required in all aspects- school program (teachers require training); adequate funding to provide high functioning children with Aides; support for families who are struggling with their child/children; professionals who are trained in dealing with ASD clients- who understand ASD and are prepared to give a diagnosis; respite support for families who often live on a razor's edge as they manage their child with minimal if any support; access to holiday programs, recreational programs; support services at school - which are currently overloaded and under resourced; social skill groups in and out of the school program; assistance with transition through each stage of the child's education ; easier access to services; services linked- information readily available; simplify the entire process so that the parents don't have to leap through hoops to be eligible for funding. Life with an ASD child is hard enough without making the paperwork red tape a logistic nightmare. Funding is given to light the West Gate; colour trees blue; print glossy magazines - but when it comes to education funding/supporting disabilities it is harder to obtain. What is going to happen in the future when all these children with disabilities carers are no longer able to support them? Where are they going to go? Who is going to care for them? What is your plan?
- Wed,
Mar 3,
2010
9:13 PM
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135. Enormous effort must go into establishing mandated minimum standards, checklists and processes for ASD children in primary and secondary schools. I think this is imperative. There should be equal educational opportunity for all ASD kids regardless of where they go to school. Families should not have to school hop and keep on hoping for something to improve for their kids. Families should not have to work tirelessly to educate principals and staff on how to deal with their ASD child. It is disgraceful. The battles that go on for us over school are frightening. ASD children currently do not access the same educational opportunities as their peers. Funding should go to establishing across the board processes for ASD kids at school - staff training, Prof devpt, training in education degrees, satellite classrooms for ASD kids, curriculum adaptation, etc, etc, etc.
- Wed,
Mar 3,
2010
9:03 PM
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136. Adults with high functioning ASD are a wasted resource. If money was directed to them to allow their expertise to be used instead of wasted, they would become a valuable community Asset instead of a rotating liability.
- They only have to look at the billions of dollars Temple Gradin has saved the live stock industry.
- How much genius is rotating in the community because of lack of domestic support for Adults with ASD?
- How much genius is rotating in the community because of lack of support in selling their individual genius to the
- Wed,
Mar 3,
2010
7:05 PM
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people in power in business, government and the work place in general?

137.	demystify the public perception of ASD spectrum.	Wed, Mar 3, 2010 5:47 PM
138.	<p>Suitable employment opportunities that allow people on the spectrum to achieve their best outcomes, as well as offer flexibility of workplace accommodations, employment conditions (hours, etc) and other support services necessary to help people gain employment (the traditional recruitment/interview process is a major barrier), and deal with workplace issues that crop up during the course of normal employment.</p> <p>Getting more people on the spectrum able to earn some income has the positive side effect of directly contributing to the tax base, as well as reducing Government expenditure on welfare such as Newstart and Disability benefits. It also enhances the quality of life for the ASD person themselves, and with appropriate support, provides more opportunities to learn social and other life skills.</p>	Wed, Mar 3, 2010 4:30 PM
139.	every child deserves an education. it is the governments responsibility to see that this happens. many times families are moving their children to private schools or smaller public schools but the funding does not go with the child. by finding solutions that suit their child the families are saving governments millions of dollars and i feel they should allow funding to go wit the child and not punish families because they have found a better solution for their child. if it is deemed a child neds funding then see that he gets it whether he is in private education or not.	Wed, Mar 3, 2010 1:39 PM
140.	Integration Aides should be well-educated in ASD. I have a Certificate in Integration Aide but only know a lot about ASD since I have two AS children myself. Other Integration Aides who do not have this knowledge don't "get" what ASD is about. The "getting" what it is about is the key to handling the situation.	Wed, Mar 3, 2010 1:05 PM
141.	That just because a child turns 16 does not mean all things are solved!!! That ASD is for life!! Thanks heaps for the survey too.	Wed, Mar 3, 2010 10:50 AM
142.	Funding at school needs to increase so that higher functioning children are not missing out. My oldest son hates "catholic" school but knows he'd get no help at state school because of his scores on the relevant assessments for funding allocation. We are looking at private school for secondary education because we do not believe the state system will give our kids what they need. Private school would not be necessary and our lives would not be put on hold financially if the state system could provide an appropriate setting for our kids.	Wed, Mar 3, 2010 10:46 AM
143.	The Moomba Park Primary School/CISCA model is excellent and should be properly funded and rolled out across the State asap.	Wed, Mar 3, 2010 10:10 AM
144.	<p>Make it easier to get DSR's!! It is so hard to get help!!</p> <p>Help the primary schools and secondary schools by running social skills programs and providing specialists like OT's and Speech Therapists.</p> <p>Provide extra funding to the schools who are ASD friendly!!</p> <p>Look at family situations like finances, no. of children with an ASD, family support, etc when deciding who to help!!</p>	Wed, Mar 3, 2010 9:16 AM
145.	Early Diagnosis and then services once diagnosis confirmed asit is a puzzling time	Tue, Mar 2, 2010 11:02 PM
146.	I understand the importance of early intervention and eearly diagnosis and I knew where to go then for help even though it was limited. Now I have almost finished in primary education and I do not know what is important for me to be addressing with my girls and there are not the services and supports out there to help in the same way as the early post diagnosis time. How are they meant to make the transition from education	Tue, Mar 2, 2010 10:06

to employment? Am I meant to keep being their advocate a tjob interviews? Where is the next place to go for help? PM

While I applaud all the State and Federal government initiatives in early intervention, there must be continuity of care that is not disrupted by transitions from one stage to another. This does not exist as far as I know and while I have a good knowledge of ASD, I feel isolated and alone in managing. I can deal with each new crisis as it arises but there must be a better way of helping my girls and preparing them better for the challenges of teen and adult life rather than going from crisis to crisis.

I have always been prointegration in educational settings. I recently made the decision to transfer one of my girls to a segregated specialsit setting. My decision was made because I could see there were not enough supports and never would be at her mainstream school. I made this decision when she was in grade 5 after spending years advocating for services at school, educationg new teachers myself every year, trying to keep the school accountable for what it was doing in the absence of any standards for education of children with ASD in mainstream settings and being worn down by a system that could do what it liked in spite of setting goals and having an individual plan. Our goals barely changed over the 5 years, little progress was made and if the school didn't really want to carry out anything we discussed in meetings, there was no consequence apart from my discontent. I had to deal with a school principal who was a bully and frequently intimidated me. I am not an unassertive parent and I am told I am a good advocate for my family but I found it a struggle. I am very happy with the care my daighter is receiving in her new school and I cannot understand why it is not possible for her to recieve the same education in a mainstream setting.

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147. That the Department of Human Service Disabilty Client Services Staff do not know that all aspects of Autism fall within the Target Group thus causing parents/carers a lot of stress and forcing us to appeal and have to go to our local member and then not fulfilling what they told the local member that they would do