

Questions for prospective ACT Politicians on policy relating to people affected by Autism Spectrum Disorders

Speaking Out for Autism Spectrum Disorders in the ACT (SOfASD ACT – formerly the ACT ASD Political Action Group) regards the outcomes for people with Autism Spectrum Disorders (ASD) the Australian Bureau of Statistics report¹ describes as particularly poor. The evidence shows that policies and practices of both the ACT and the Commonwealth Governments, policies and practices that treat the rapidly growing group of people with disability due to Autism Spectrum Disorders as merely part of the general population of people with a disability, results in disproportionate disadvantage for people with Autism Spectrum Disorders. The ASD community regards the substantial gap between outcomes observed for people with ASD and others, both people with other disabilities and the population generally, as alarming, unnecessary and unacceptable. The ASD community expects Governments to address this disparity in outcomes immediately.

People in the community in the ACT who are affected by ASD want to know what a new ACT Government will do to remedy the substantial disadvantage particularly for people with ASD that Governments have caused or allowed to develop.

ACT-VASD prepared the following list of questions for politicians and political parties who are contesting the ACT Election in 2012. The questions are put in the context of the ACT Government's existing services and the needs of people with Autism Spectrum Disorders (ASD) in the ACT, their families and carers.

All these questions are important to our community.

In preparing your answer, please provide a numbered list of responses, with the numbers corresponding to the questions below. Please answer all questions if you can. Once you have answered the questions, you can provide additional information if you feel it will strengthen your case **in the ASD community**. As always, political spin will be regarded negatively by most members of the ASD community, many of whom are particularly sensitive to and wary of such practices.

We look forward to your initial response, and any further response or policy development you may choose to offer on these issues during the election period.

1 Autism/ASD diagnostic service in the ACT

The ACT Government separates its service for diagnosing Autism Spectrum Disorders from diagnostic services for other childhood and developmental condition/disorders². In its Budget submissions, Autism Asperger ACT suggests a preferred approach to diagnostic services for ASD in the ACT. The ACT Government has not acknowledged or responded to the suggestion from Autism Asperger ACT.

1 <http://www.abs.gov.au/ausstats/abs@.nsf/mf/4428.0>

2 see “assessment” at http://www.dhcs.act.gov.au/therapyact/services/autism_services

1. Will your party improve (rationalise) the diagnostic service that the ACT Government offers (funds) for children in the ACT? What will it do to improve diagnosis of paediatric and developmental disorders?

2 Early Intervention

The ASD community is divided about how to approach politicians about some issues. Some in the community are concerned that raising the issues below may be too confrontational. Some people in the community are deeply discomforted by any prospect of tension. On the other hand, some people in the ASD community are keen to express outrage that many children with ASD in the ACT cannot access best practice early intervention.

Clearly, we cannot meet all the expectations of the ASD community. So we note that views on how best to raise the following issues with politicians and Government are divided. However, this group regards it as essential that the issues below are raised and discussed.

While views on how to approach politicians and the Government are divided, there is generally agreement that:

1. the Commonwealth Department of Health and Ageing published best practice guidelines on early intervention for children with ASD; and
2. many children with ASD in the ACT cannot access early intervention for their ASD that could be described as best practice.

After it published its best practice guidelines, the Commonwealth Government implemented its *Helping Children with Autism* (HCWA) package federally in 2008. HCWA package was meant to compliment services that state/territory governments provide. But the services most families access in the ACT still fall well short of “best practice”: HCWA funds up to about 1 hour per week of therapy when the Commonwealth Government itself advises³ that children with ASD need at least 20 hours per week of intensive ASD-specific early intervention for 2 years (or more).

Unfortunately, the limited therapy service that the ACT Government funds for children with ASD are fundamentally incompatible with services available to children with ASD through the Commonwealth's HCWA package. Rather than develop services that are compatible with HCWA, the ACT Government insists instead that its therapy staff diverge from preferred professional practice and that the families they service accept this less-than-ideal service model.

2. Will your party develop and fund a therapy model for children with ASD that is compatible with the Commonwealth's national Helping Children with Autism package?

3. Will your party ensure children with ASD can access best practice early intervention in the ACT?

On 7/1/2010, the Senior Manager Therapy ACT advised⁴ the ACT Minister for Health, the Chief Executive, Deputy Chief Executive, Executive Director Policy and Organisational Services (cc. Minister for Disability, Housing and Community Services) that

Autism is not a curable condition and early intervention services can only work to provide improved coping mechanisms for both the individual and the family.

There is a growing body of evidence that best practice early interventions help a proportion of people with ASD improve sufficiently to lose their diagnosis of ASD. Some would see a person

³ See [http://www.health.gov.au/internet/main/publishing.nsf/content/D9F44B55D7698467CA257280007A98BD/\\$File/autbro.pdf](http://www.health.gov.au/internet/main/publishing.nsf/content/D9F44B55D7698467CA257280007A98BD/$File/autbro.pdf)

⁴ File No. M10/8.

who loses their ASD diagnosis as having been cured in some sense. So saying “Autism is not curable” can be misleading.

Nor is all the treatment provided for people with disease, injury, disorders, etc. directed at curing people. Treatment that normalises or improves functioning for a whole lifetime is extremely valuable for people with ASD, their families and carers.

This advice, that “early intervention services can **only** work to provide improved coping mechanisms ...”, that early intervention for children with ASD is not effective, contradicts the bulk of published research showing early intervention for children with ASD is beneficial. The Senior Manager Therapy ACT contradicts advice from national and international experts who state that best practice early intervention for ASD provides substantial improvements for many children with ASD; early intervention for ASD is widely regarded as cost effective.

The ACT Government's particularly negative attitude of to children with ASD and the policy that results from it denies some of the most vulnerable and disadvantaged children in the ACT services that are essential for their future.

*4. Do you accept Therapy ACT's view of early intervention for children with ASD, that “early intervention services can **only** work to provide improved coping mechanisms”, that is their claim that early intervention for ASD cannot reduce a child's dysfunction or improve long-term outcomes significantly ... as expressed in advice provided to Ministers and top level staff?*

To our knowledge, ACT Government does not fund a comprehensive early intervention program for any child with ASD that uses any credible treatment/therapy options, that is those listed on the FaHCSIA website⁵ as based on either “established research evidence” or “emerging or best practice evidence”.

The Ministerial advice also says:

It would be inequitable to provide intensive service to some children and not to others, and those not included in the pilot program could be expected to demand a similar level of service.

Therapy ACT (hence the ACT Government?) uses this so-called “equity” principle to avoid funding best practice early intervention for children with ASD, thereby denying essential disability services for many children with ASD in the ACT. We are not aware of the ACT Government using this so-called equity argument to deny best practice services to children with other disabilities. This is not an equity principle; it is prejudice and discrimination (albeit, *lawful discrimination*) against children with ASD.

5. Will you take steps to ensure children diagnosed with ASD in the ACT can access best practice early intervention for their ASD, instead of focusing services funded for ASD on “coping mechanisms”?

3 School-age: education and other needs

The Australian Bureau of Statistics reports nationally that, for students with ASD in Australia:

- 88% experience some restrictions in education; 3% of children were not able to attend school because of their disability and 47% needed to attend either a special class in a mainstream school, or a special school.

⁵ See http://www.fahcsia.gov.au/sites/default/files/files/disability-and-carers/hcwa_tables.pdf which is available from <http://www.fahcsia.gov.au/our-responsibilities/disability-and-carers/program-services/for-people-with-disability/helping-children-with-autism/early-intervention-service-providers>

For children with autism who were attending school, 82% reported 'having difficulty' at school, the majority of whom had difficulty with communication, learning and fitting in socially.

- Children with autism need a high level of support to attend school, with 41% needing a counsellor or disability support person and 51% requiring special tuition. Of those children with autism attending school, 24% did not receive any additional support (excluding attending a special school or attending special classes in mainstream schools).

The difficulties students with ASD experienced in the education system continue after they leave school. Of people with ASD who have finished school, 77% have not completed any post-school qualification. This lack of tertiary qualifications among people with ASD is substantially worse than the level of tertiary qualifications observed both for the rest of the population with disability and for people with no disability.

The United Nations *Convention on the Rights of the Child* says education is a right for all children yet the right to education is not protected under Australian or ACT law.

Education helps ensure people have economic and political rights. Economic rights are observed through employment rates. The ABS reports that:

As with restrictions in education, autism also correlates with restrictions in participating in the labour force. In 2009, the labour force participation rate for people with autism was 34%. This compares with 54% labour force participation rate for people with disabilities and 83% for people without disabilities.

Note that outcomes for students with ASD are substantially worse than outcomes for people with a disability more generally. The ACT Government prefers to implement generic disability policy rather than policy that addresses the specific needs of any sub-group of the disability population. For example, the main disability program in the 2012-13 Budget is to help people with a disability generally through ensuring all bus stops are wheelchair accessible.

If generic disability policies and programs were to raise the level of labour force participation for people with a disability from 54% to 83% (the level of the rest of the population), then the proportional improvement for people with ASD would be just 53% (up from 34%) ... which is still abysmal.

6. Do you have any evidence that outcomes for people with ASD in the ACT are different from the outcomes reported for people with ASD at the national level?

7. Will you or your party improve education services and outcomes for students with ASD in the ACT?

The ACT Government's public education system offers variable access for students with ASD to ASD-specific learning support units (LSU-As) across the Territory. Families report that access equity varies substantially with location and with preferences of the schools that have LSU-As.

Parents/families of students with ASD perceive (or observe) inequity in respect of access to the very limited placements, especially at High School level. There are reports/concerns that some public High Schools are inappropriately selective of the students with ASD they allow into their LSU-As.

8. What will you do to ensure students with ASD can access an appropriate education setting regardless of location within Canberra?

There are parents/families in the ACT with concerns over the quality and effectiveness of education and outcomes in some of the LSU-As. Teachers who are responsible for LSU-As should have an appropriate standard of training for the role. Similarly, teachers with students with ASD in their classrooms need to have been trained to teach students with ASD.

9. What will you do to ensure that all ACT Government schools deliver effective education programs to all students with ASD?

Recently, the ACT Government changed the law to allow schools to exclude students with ASD for up to three weeks whenever they feel like it. The practice of excluding a student with ASD when the school cannot manage the student's behaviour is of particular concern.

The ACT Government says it does not provide, and schools cannot access, behavioural services needed to ensure students with ASD can function in schools. Officials told the ACT Select Committee on Estimates (25 May 2010) ...

We do not actually use the ABA intervention method ...

see <http://www.autismaspergeract.com.au/node/126>.

Some schools require students with ASD to attend on a part-time basis because the school lacks the resources or skill needed to educate fully a students with ASD enrolled in the school. This practice denies the student with ASD effective education.

10. What will you do to ensure students with ASD can access effective education?

11. Will you change the current policy so students with ASD cannot be excluded, suspended or expelled due to their behavioural challenges or other issues that the school should be managing with appropriate services and support?

*Please be aware that some ACT Public Servants claim **incorrectly** that anyone who advocates the availability of ABA as a part of an ASD service actually believes that ABA should be used exclusively. Some ACT Public Servants also claim incorrectly that “ABA turns children into little robots”. Be aware instead that any program for people with ASD of any age that excludes the use of ABA **as an option** for addressing challenging behaviour and other behavioural challenges (that are for many an essential element of their disorder) is fundamentally incomplete.*

4 Post-school transition

12. Is it your party's intention that parents/carers of people with ASD cease work (or moves to part-time employment) when a student diagnosed with ASD (or any severe/profound disability) leaves school? If not, what will you do so that parents/carers will no longer be likely to need to give up their employment when the person in their care leaves school?

5 Employment and Community Access

As shown previously, labour force participation for people with ASD is abysmal.

No new supported employment places have been created in recent years despite growing numbers of students with severe and profound disability leaving school.

13. What will your party do to improve participation of people with ASD in the labour force?

6 Supported Accommodation

The ACT has a chronic lack of supported accommodation for people with ASD.

14. What will your party do to ensure people with ASD can access the accommodation support services they need?

7 Community Access and Respite

Since few adults with ASD are employed, they need community access and respite services. Many families cannot access the respite services they need for children with ASD.

Supply of these services falls well short of demand.

15. What will your party do to meet demand for these services?

8 Access to services

People with ASD depend on a range of services. Unfortunately, many of these services are inaccessible. For example, there are several community access services in the ACT. But these services are not funded to pick-up clients and return them to their home/residence. These services are only accessible to people with a disability who have their own transport, who can use public transport or who can access “specialist disability transport”.

People who are severely disabled by their ASD cannot access these forms of transport.

So people who are severely disabled by their ASD often depend on family members to provide access to services.

16. Does your party see access to services for people with ASD as an issue? What will you do to address this issue?

9 Autism/ASD Awareness

ACT Government policy is that services for people with a disability, including services for people with ASD, should be provided in mainstream settings as much as possible. While this is a laudable policy, it lacks credible implementation and support from the ACT Government.

17. What will you do to develop awareness of mainstream service providers and of the community generally as to how mainstream services can meet the needs of people with ASD?

Problems abound with services for people with ASD, particular in the health, welfare and disability service sectors ... and the poor appreciation of ASD-related issues in the development of government policy is especially daunting.

18. Will you take particular steps to inform the health, welfare, disability service and government policy development sectors about specific needs of people with ASD, their families and carers?

10 Human Rights protections

Australian and ACT law does not protect the rights of people with ASD.

19. What will your party do to protect basic rights such as the right to life (health and safety) for people with ASD while they are in the care of service providers?

20. What will your party do to protect rights of people with ASD such as the right to treatment and rehabilitation, the right to primary and secondary education, the right to freedom from discrimination, the right to economic security, etc?

21. What will your party do to protect the rights of carers to economic security and participation in the labour force? What will your party do to ensure family carers are not required to work endless hours caring and supporting a person with severe or profound disability in the family home?

11 The National Disability Insurance Scheme (NDIS)

A series of reports show outcomes for people with a disability in Australia are particularly poor. For example, Australia ranks last in the OECD for poverty of people with a disability.

Above, we high-lighted reports that show people with ASD fare substantially worse than people with a disability more generally. People with ASD fare worse because disability policies and service providers do not recognise nor address the needs of people with ASD.

In the ACT, people with ASD and their associates are concerned that the NDIS will not recognise nor address the needs of people with ASD.

22. What will you do to ensure the NDIS meets the needs of people with ASD?

The ACT is a small jurisdiction. There is a substantial risk that the NDIS will be implemented mainly through national service providers; and the ACT community will have little or no influence over services provided via the NDIS in the ACT.

23. Do you believe people with ASD need service providers that are locally based and administered? If so, how will you ensure services funded through the NDIS are locally based and administered?

Full NDIS implementation is still a long way off. Even the NDIS trial will start after the next election. As yet, the eligibility for NDIS benefits of people who are severely or profoundly disabled by ASD is unknown.

24. What will you do to address the substantial unmet service needs of people with ASD in the interim?

Please email your response to these questions to bob@buckley.id.au.



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