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**The Hon Bill Shorten MP**  
**Parliamentary Secretary for Disabilities and Children's Services**  
**Parliamentary Secretary for Victorian Bushfire Reconstruction**

Parliament House  
CANBERRA ACT 2600

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MC10-008549

6 JUL 2010

Mr Bob Buckley  
[bob@buckley.id.au](mailto:bob@buckley.id.au)

Dear <sup>Bob</sup>~~Mr Buckley~~

Thank you for your correspondence on behalf of Autism Aspergers Advocacy Australia about the prevalence of Autism Spectrum Disorder (ASD) and on a more personal note about your son.

I would, once again, like to assure you the Commonwealth Government is committed to providing services that meet the support needs of people with disability, their families and carers. The Government's aim is to offer practical support to enable people with disability to participate as fully as possible in community life, both socially and economically.

I enjoyed our discussion at the meeting on 16 June 2010 about the issues you captured in your brief dated 1 April 2010. I feel that our meeting was informative and beneficial, not just for me as Parliamentary Secretary for Disabilities and Children's Services, but also for the Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA) in hearing your views on assistance for people with ASD. As discussed with you, FaHCSIA will be further exploring options for funding of activities undertaken by peak bodies.

Your earlier email sought clarification on my press release of 7 May 2010 regarding the parent workshops and professional development provided under the Helping Children with Autism (HCWA) Positive Partnerships initiatives. The statement that "a further \$10.5 million will be provided to Australian Autism Education and Training Consortium (AAETC) to support their ongoing delivery of the Positive Partnerships initiatives" refers to \$10.5 million from within existing funding and is not in addition to the \$190 million provided for the overall HCWA package.

The AAETC is working with state and territory education authorities and other key stakeholders to ensure co-location of professional development and parent/carer workshops. The AAETC is employing other strategies to build synergies between the professional development and parent/carer components, such as fostering networking between the local personnel who provide post-workshop support to parents and teachers, and developing newsletters to promote local community involvement in Positive Partnerships. Parents and teachers nationally are also able to access materials and resources developed by the AAETC through the Positive Partnerships website at [www.autismtraining.com.au](http://www.autismtraining.com.au).

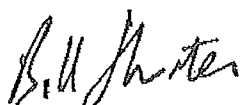
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In reference to your later email regarding after school care, and specifically YouthLinx, I understand the Department of Education, Employment and Workplace Relations (DEEWR) will be replying to you.

If you would like to receive updates on disability issues, please send a blank email to [officeofbillshorten@fahcsia.gov.au](mailto:officeofbillshorten@fahcsia.gov.au) with 'subscribe to mailing list' in the subject line.

Once again, thank you for taking the time to write to me on behalf of Autism Aspergers Advocacy Australia and meeting with me to discuss your brief.

Yours sincerely

A handwritten signature in black ink, appearing to read 'Bill Shorten', written in a cursive style.

**Bill Shorten**

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## CORRESPONDENCE ACTION SHEET 2010

ACTION: ☒ Reply ☐ NFA ☐ Refer to: .....

SURNAME OF AUTHOR: ..... BUCKLEY .....

SOURCE: Category 1 Category 2 Category 3 Category 4  
 (URGENT/VIP) (MP/SENATOR) (CONSTITUENT/PEAK) (GENERAL PUBLIC)

☐ 1 week ☒ 2 weeks ☐ 3 weeks ☐ 4 weeks

SUBJECT: Brief - ASD Prevalence  
 obo A4 - Autism Aspergers  
 Advocacy Australia

BRANCH: Mental Health  
 & Autism Branch

## REPLY FOR:

## DIRECT

## INDIRECT

Minister for FaHCSIA  
 Adviser  
 Minister for the Status of Women  
 Minister for Housing  
 Adviser  
 Parliamentary Secretary Shorten  
 Shorten Adviser  
 Parliamentary Secretary Stephens

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## MCU Use Only

Referral (Macklin/Adviser)  
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 Referral (Shorten)  
 Referral (Dept)

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OUTPUT GROUP:

5-1

Coding Officer (Name & Date)	Comments	Referred from:
Sord 17/5/10	Note PSO request for 2 wk turnaround	

S. 22  
irrelevant

**From:** Thomson, Julia  
**Sent:** Friday, 14 May 2010 11:06 AM  
**To:** Cole, Mitchell  
**Subject:** FW: Brief for Bill Shorten [SEC=UNCLASSIFIED]

Can you put forward for corro? It can say that I will meet him. It should also refer the respective parts to ACT gov, DEEWR...

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**Sent:** Friday, 14 May 2010 9:05 AM  
**To:** Thomson, Julia  
**Subject:** Brief for Bill Shorten

Hi Julia

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I would like to meet sometime to talk about its contents.

regards  
Bob Buckley

mobile: 161 418 677 288

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Convenor: <http://a4.com.au/>  
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AUTISM  
ASPERGER ACT

14/05/2010

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irrelevant

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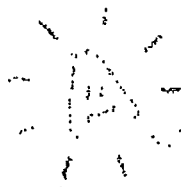
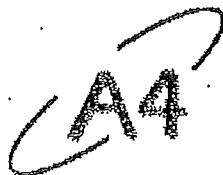
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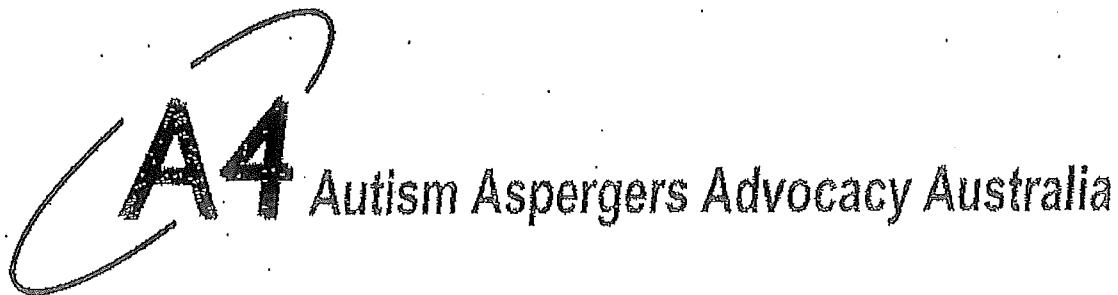
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Director:  
<http://autismaus.com.au/>



**AUTISM  
ASPERGER ACT**



16/05/2010



## Brief for Bill Shorten

1/4/2010

### ASD Prevalence

ASD prevalence more than doubles every 5 years (see Annex A). Science expects that the future will continue like the past. If ASD prevalence continues to double every 5 years ...

- ASD will be more prevalent than intellectual disability by 2013
- 50% of boys will have ASD in 25 years
- the impact of increasing ASD prevalence will have a greater effect on the nation than the ageing population and global warming combined
- the economic cost of ASD nationally was estimated (conservatively) to be between \$4.2 billion to \$7.3 billion in 2007; by 2025 the economic cost to Australia will be between \$33.6 billion to \$58.4 billion annually

We ask that ASD research be significantly better funded. Key research questions are:

1. Why is ASD prevalence doubling every 5 years?
2. How can we reduce the impact of rising ASD prevalence?
3. What will stop the growth in ASD prevalence?
4. What is the real cost of ASD to the community?

### ASD challenges more generally

A4 raised challenges for the Commonwealth Government relating to people with ASD, their families, carers and others through its initial two issues of so called "Shorten Curlies" (see Annex B). Members of A4 would like to see the Government's response to the challenges described in A4's "Shorten Curlies".

### Issues in the ACT

The following are issues that affect us locally but relate to issues for the Commonwealth Government.

#### Respite

The ACT Government has a Standing Committee inquiring into respite. This follows the ACT Government Auditor's "disappointing" report on Respite in the ACT that found a number of "issues" with respite services in the ACT.

There is a massive shortage of support, services and resources for people with disability in the ACT. Families ask for respite in response to the massive pressure they are under to compensate for the lack of a wide variety of essential services.

The Auditor's report says there were no deaths in respite over the period it reviewed. However, Jack Sullivan was a citizen of the ACT who died in an ACT Hospital after an "incident" in respite that was funded by the ACT Government. The "incident" occurred in NSW where Jack was in respite ... because an appropriate respite service for Jack was not available in the ACT. Neither the ACT nor the NSW Coroner has investigated Jack's death. Nor did the ACT Coroner report on a previous death of Stephen Moon, a young man with severe ASD, who died in a group home shortly after the Gallop Report (which was about the deaths of 3 young men in ACT group homes). In both these cases (Jack Sullivan and Stephen Moon), the relevant services had complete information on the care needs of the individuals ... but they died anyway.

This Standing Committee Inquiry closely follows the latest ACT and NSW special education inquiries. The ASD Association in the ACT gets no help from either the Commonwealth or the Territory Government to respond to this plethora of Inquiries.

### Education

Families are experiencing significant cuts to disability support in education.

- Teachers lack essential skills and professional support for teaching students with ASD. For example, parents are frustrated that they go along to their Parent/Carer component of HCWA Positive Partnerships, only to find that teachers of their children are not accessing their component of HCWA Positive Partnerships effort due to limited places offered/selected and also due to the huge cost of teacher replacement being a barrier to teacher training.
- Schools do not use appropriate behavioural services and support for students with ASD.
- Students with (or suspected of having) ASD in mainstream schools are excluded from national standard (benchmark) testing.
- The leaving age from Black Mountain Special School is being reduced.
- The ACT Government legislated to allow schools to exclude students for up to 3 weeks without referral to the Department. This is an increase from 1 week (5 days) previously. Before this legislation, we were aware that school exclusions ate into the annual leave of mothers in the ACT.

We notice that FaHCSIA and ACT Department of Disability, Housing and Community Services funds groups like Advocacy for Inclusion<sup>1</sup> in the ACT to *undermine* the message of Autism Asperger ACT before the ACT Inquiry into special education ... and with the public generally. Autism Asperger ACT gets no funding from the ACT Government and the funds it gets from FaHCSIA are for specific contracted services ... that do not include advocacy.

### Post school

Many people with ASD have few choices after they leave school: there are very few employment opportunities for them.

The primary means of support for people with a disability in the ACT is the Individual Support Package (ISP). An ISP provides a family with about 1/6-1/4 of what it costs the Government to try to address minimally the needs of a person with a severe disability.

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1 see <http://www.advocacyforinclusion.org/educationpp.html>

Families are expected to meet fully the needs of their adult-child from these funds without access to the economies of scale that are available to Government. According to the ACT Government, no new ISPs have been awarded since 2007 nor will there be any new ISPs until at least 2012.

There are two typical post-school trajectories for people with ASD. For those whose ASD most obviously affects behaviour, their family needs to care for them 24/7 ... often with little or no clinical service or respite. Some of the higher function people diagnosed with ASD go on to tertiary education, wherein they may succeed. Despite succeeding in tertiary education, few of them subsequently get or remain in a job.

There is a chronic lack of suitable accommodation for adults with ASD. In the UK, a recent report found that higher functioning adults, many of whom have not been diagnosed, are homeless or in basic hostel accommodation. Their prospects for adult life are poor. Indications are that the situation is similar in Australia.

The Government is kicking people with higher needs out of nursing homes even when the nursing home is the most appropriate place available for them.

Many families require a member to give up their job so they can provide much more than full-time care for their family member. Some family members are left alone to manage chronic challenging behaviour and even violence. They have no real alternative.

At present, state funded services for adults with ASD have massive gaps and inadequate service provision in all areas including residential options, medical, transport and so on.

Government funding and services need to reflect changes across the lifespan so that no one is left out.

### **Therapy services**

Therapy services for people with ASD in the ACT are minimal ... for many people they are non-existent.

For young children, the HCWA package addresses a small part of their needs. But in the ACT, HCWA early intervention is incompatible with Government therapy services (which are even more inadequate). There is little access to HCWA Medicare items.

For older children, we don't even have a waiting list for many essential services. People just miss out entirely ... or it is up to the family to bring in expertise from beyond our region.

### **Behavioural expertise for treating ASD**

Most people with ASD need clinical level behaviour services. There is a massive world-wide shortage of expertise in behavioural intervention. Growing ASD prevalence exacerbates the skill shortage.

### **ASD and mental health services**

Recently, Prof. Patrick McGorry (Australian of the year) complained about the dearth of mental health services in Australia.

However, Governments should know that many of their mental health services exclude people with ASD and deny them essential services. In the ACT (and Qld), public mental health services will avoid treating (or even responding to crises) if the person involved has a pervasive developmental disorder (or developmental delay).

If services are bad for people with mental health, they are much worse for people with multiple diagnoses that include ASD. People with ASD do not get the treatment they need for their ASD. Rarely can these people get treatment for their co-morbid mental health conditions such as anxiety, depression, psychosis, etc.

People in Australia need access to essential treatment for their ASD. President Obama's health reforms in the USA may give US citizens with ASD the right to essential treatment. Australians with ASD also need the right to treatment either in the health system or through a national disability insurance scheme that includes specifically treatment and rehabilitation for ASD.

For example, the Government's Mental Health Respite Program targets mental illness and intellectual disability. The program omits people with autism spectrum disorders despite the severe and pervasive nature of these condition and reports showing people with ASD have higher levels of severe or profound disability.

### **In conclusion**

People with ASD in the ACT cannot access essential services. They experience massive inequity and discrimination (albeit lawful under Australia's deficient discrimination laws).

Australia needs to do much better.

### **Acknowledgements**

This brief includes material and ideas directly from Karna O'Dea, Peter Hill, Myrna Domingues, Helen Steinhardt and Bernardette Wilson. Ideas from many other sources have been included but responsibility for its content lies entirely with its editor, Bob Buckley.

R. Buckley  
Convenor

## Annex A

### Warning over growing ASD numbers

Data from Centrelink show more than 1% of Australian school-age children have a confirmed diagnosis of Autistic Disorder or Asperger's Disorder. These data, presented at the APAC'09 conference in Sydney, show the number of children diagnosed with autism spectrum disorders (ASD) more than doubled over the preceding 5 years. Similar diagnosis levels have been confirmed in the USA.

Back in 2004, a peer reviewed paper published data that the Australian Bureau of Statistic (ABS) collected for its Survey of Disability, Ageing and Carers (SDAC) showing the number of Australians with ASD more than doubled in the 5 years from 1998 to 2003. The number of Australians *estimated* to have ASD on the basis of the ABS SDAC rose from 13,000 in 1998 to 30,000 in 2003. We await the results of the latest data collection in the SDAC data series<sup>2</sup>. Other data collections show prevalence of ASD is growing rapidly.

The diagnosis rate for ASD has doubled every 5 years over a 20 year period. In the early 1990s, the prevalence of ASD was said to be 1 per 1,000. The prevalence of ASD now exceeds 1 in 100, so ASD diagnoses increased 10 fold over 15-20 years.

The following table shows how the percentage of children with ASD will increase over time *if this pattern continues*.

Year	children		
	male	female	total
2009	1.6%	0.4%	1%
2014, +5 yrs	3.2%	0.8%	2%
2019, +10 yrs	6.4%	1.6%	4%
2024, +15 yrs	12.8%	3.2%	8%
2029, +20 yrs	25.6%	6.4%	16%
2034, +25 yrs	51.2%	12.8%	32%
2039, +30 yrs	102.4%	25.6%	64%

ASD affect adults and children: ASD are said to be life-long. Many people diagnosed with ASD experience severe or profound disability through their life; they need life-long 24/7 support and supervision.

Analysis of the ABS SDAC 2003 data shows 87% of people with autism spectrum disorders have severe or profound disability.

Many people who are diagnosed with ASD need substantial levels of support.

If diagnosis rates continue to double every 5 years, in 20 years the effect on the community and the Australian workforce will be substantial. In 25 years, supporting such a high level of disability in the community would be challenging and the situation for males in 30 years is inconceivable.

*If this growth of ASD diagnoses continues*, if outcomes for people with ASD remain particularly poor and governments continue doing very little, the effects of ASD on our

<sup>2</sup> The survey was due in 2008 but the ABS deferred data collection until the end of 2009.

nation and our community could soon be greater than either our ageing population or global warming.

At the very least, Government should immediately fund research into why diagnoses of ASD are increasing. We should know the nature of the challenge due to ASD and how best to tackle it. Surely we need to know, right now, what happens for children when they become adults with ASD, how rates of ASD diagnoses for Australian children could slow down, whether severe/profound disability persists with increasing prevalence of ASD, and what policy and actions are needed.

Notice that with 1% if children diagnosed, almost 2% of parents are affected by ASD. In many cases, this could influence extended families and friends. Even if ASD issues do not impact on imminent state and federal elections, the influence of the issue should grow over the next decade.

*This timely warning is due to Esther Woodbury, President of the Community Living Project in Canberra, pressing for projections of the number of people with disabilities/ASD who will need specialised accommodation and support in the foreseeable future.*

Bob Buckley  
A4 Convenor  
24/2/2010

## Annex B

### The Shorten Curlies

This is a new column in A4 Updates for describing possible or perceived challenges, anomalies, inequities and policy glitches that are ASD-related – in other words “curly” issues for our federal government. This column raises challenges and issues that A4 members feel the federal government could or should address. A4 will share these “curlies” with government and report the ensuing dialogue or outcomes as they emerge.

The column is named for The Hon. Bill Shorten MP, Parliamentary Secretary for Disability, who is a member of the Government likely to consider such issues.

If the title of this column gives you any discomfort, try seeing it as a metaphor: try to imagine a game of curling with the Parliamentary Secretary smoothing the way and improving the chances that our “spectrum coloured” curling stone (symbolising treatment, services and support for people with ASD) will reach its target (representing a goal of equitable outcomes for people with ASD). And if you like obscure sport metaphors, you might see ASD currently as a skeleton event in the Winter Olympics with participants speeding head-first down a slippery and twisting course ... an event with far too few winners in the end.

**SC#1. ASD and accessing CSTDA-funded services:** A4 commends the federal government for supporting people with ASD through Carer's Allowance and through the CSTDA (Commonwealth State/Territory Disability Agreement). A4 also appreciates the valuable data collection and reporting that is part of these schemes.

Table 1 below shows the number of Australians with autism spectrum disorders (ASD) using data collected both by the Australian Bureau of Statistics (ABS) through the 2003 Survey of Disability, Ageing and Carers (SDAC) and by Centrelink for the purpose of paying Carer's Allowance. These data show comparable ASD prevalence in their common age ranges even though the ABS data was collected 4 years previously.

In Australia, most disability services are provided through the Commonwealth State and Territory Disability Agreement (CSTDA). The Australian Institute of Health and Welfare (AIHW) reports on data collected by state and territory governments relating to disability services provided through the CSTDA. Table 1 shows the latest published data for younger Australians.

Table 1: People with ASD and people with ASD accessing disability services.

Ages (years)	ABS SDAC 2003	Carer Allowance 2006-7	CSTDA 2006-7	c.f. CSTDA and Carer Allowance
0-4	1200	2189 to 3515	1136	35% to 50%
5-9	8200	10071	3632	36%
10-14	10800	10055	2723	27%

15-19	3900	-	2552	-
20-24	-	-	1584	-
25-29	-	-	663	-

The right-most column of Table 1 compares the best available estimates of the number of Australians with ASD to those who receive disability services through the major disability service mechanism agreed between the levels of Government. These data show that fewer than half the people diagnosed with ASD access disability services funded through the CSTDA.

This issue arises from the following points:

- a) ASD is highly disabling: the AIHW reports that 87% of people with ASD have severe or profound disability<sup>3</sup>;
- b) people with ASD usually need disability services that are substantial, complex/comprehensive and ASD-specific;
- c) the bulk of disability services (apart from those services for people with ASD that are part of the Education and Health systems, and the recent federal HCWA early intervention and playgroups) are offered and provided as disability services via the CSTDA-related system; and
- d) these data indicate that many people with ASD do not access the CSTDA-related disability service which are the very services intended to address their substantial disability-related needs;

The low CSTDA numbers suggest that adults, as well as children, with ASD are not accessing disability services that they need.

CSTDA services are provided through state-based schemes yet the AIHW reporting on their website is national. We now know the number and age of people diagnosed with ASD in the different states and territories. The AIHW should at least show the number of people in each state and territory who access the disability services available in the state.

This problem goes beyond the issue that most families cannot access any disability services. Of those who access a disability service, many families suggest the disability services funded that they do access are neither adequate nor effective for their ASD. The services people access through the CSTDA should better address growing, specific and distinct needs associated with ASD.

**SC#2. PDD-NOS and Carer's Allowance:** As indicated above, A4 commends the federal government for supporting people with Pervasive Developmental Disorders (PDD), including ASD, through Carer's Allowance. However, A4 suggests there is an anomaly in the Carer's Allowance scheme relating to the Pervasive

Developmental Disorder called "Pervasive Developmental Disorder not otherwise specified" (PDD-NOS).

Formal diagnosis of any type of Pervasive Developmental Disorder under the DSM-IV, including PDD-NOS, is a clinical diagnosis that requires the diagnosed person has "severe and pervasive impairment".

The qualifying conditions for Carer's Allowance recognise all disorders in the DSM-IV Pervasive Developmental Disorders category except PDD-NOS. This exclusion of PDD-NOS from Carer's Allowance appears inconsistent and discriminatory.

While it is possible that a child with PDD-NOS can qualify for Carer's Allowance the nature of their disability may not be reflected clearly in Centrelink's client database.

In other schemes, such as its HCWA package, government recognises and supports all the ASD diagnostic types in the DSM-IV Pervasive Developmental Disorders category, including PDD-NOS.

**SC#3. Disability discrimination in Australian Law:** Australia is among the first countries to ratify international law. Australia is signatory to international law that disallows disability-related discrimination, especially in relation to children.

Australia could complete processes required under these agreements so that Australian Law protects children with a disability from discrimination such as that suggested in SC#2 above.

A4 recognises that the government departments responsible for Australian Law do not answer to the Parliamentary Secretary for Disability – though our members would appreciate any influence exerted in that direction.

**SC#4. Nature and cost of Best Practice early intervention for ASD:** The federal government's Helping Children with Autism (HCWA) package is Australia's biggest assistance initiative ever offered for people with autism spectrum disorders.

The nature of "best practice early intervention for ASD" is a subject of dispute among alleged experts in the field. The Department of Health and Ageing (DoHA) advises that Best Practice for young children with autism is "20+ hours per week of intensive ASD-specific early intervention for a minimum of 2 years". Intensive means one-on-one delivery or delivery processes that use very low staff/client ratios.

Using advice from an academic and clinical "expert reference group", FaHCSIA created a Provider Panel and the HCWA early intervention component is essentially face-to-face clinical interventions. The cost of a HCWA Panel Provider is at least \$100 per hour so the cost of best practice using services from Panel Providers is at least 20x\$100 per week for 48 weeks per year – a minimum annual cost of at least \$96,000.

The HCWA package can provide a family with up to \$6,000 per year so families would have to find \$90,000 from other sources or find complementary and compatible services. Very few families can find this level of funding.

In contrast, families advise that they expect programs providing 30+ hours per week "intensive ASD-specific early intervention", exceeding DoHA's "best practice" recommendation for children with autism, can be provided practically for \$40,000 to \$60,000 per year. But even at this lower cost, few families can afford such a program. They need help from government and/or from their community to get early intervention for their child.

Families recognise that

- There are insufficient clinicians with the required expertise in ASD to deliver anything like best practice on a face-to-face basis for all the young children diagnosed with ASD in Australia.
- The cost of a clinician model using face-to-face delivery for 20+ hours per week over at least 2 years is excessive, and challenging politically
- Practical and affordable service models for ASD early intervention are essential
- The \$6,000 per year that HCWA provides needs to be augmented so that effective early intervention is provided for as many Australian children with ASD as possible.

One practical approach is for clinicians to supervise less experienced staff to provide "intensive" face-to-face intervention for young children with autism. This approach has been shown to be capable of delivering outcomes among the best known for children with ASD. But Australian graduates in allied health areas do not get adequate ASD-specific training, and they are not taught to supervise delivery using junior staff and assistants. Very few allied health graduates are employed after graduation in situations where they develop these skills.

But the HCWA package does not fund early intervention services using this model: a model recognised as having the strongest evidence for its effectiveness.

In some areas, such as the Australian Capital Territory, early intervention services funded through the CSTDA are not compatible with services available through the HCWA Panel. Families of children newly diagnosed with ASD have to choose between extremely inadequate service models.

Families are also concerned that many clinicians lack the skills they need through their careers to interpret and adopt methods from quality research. Some clinicians appear rigid and inflexible in their approach, becoming increasingly out-of-date in their methods in relation to ASD.

Some people argue that the families themselves can be trained to provide most of the 20 hours per week of early intervention. While there is evidence that family involvement can benefit an effective program of early intervention, there is no real evidence that families can meet the clinical needs of a child with ASD. Nor is there evidence that anyone benefits from making families responsible for meeting their child's ASD-related clinical needs. Demonstrably, there are many families where

the child's needs are not met through this model. The extra burden on a family can contribute substantial additional family dysfunction. This "parent is clinician" model is considered completely inappropriate for most clinical disorders – why are children with ASD and their families singled out for this (lawful) discrimination/injustice?

A4 members are encouraged to use this forum to raise further challenges for the federal government. Please send your suggestions for this column to [editor@a4.org.au](mailto:editor@a4.org.au).

## The Shorten Curlies: volume 2

This is A4's second group of challenging ASD-related issues for the Australian Government. The previous A4 Update explained the origin of the column and introduced an initial four "curly" issues relating to ASD in Australia.

As yet we do not have a response from the Government to the initial set of "curlies" ... nor an acknowledgement that they received them.

SC#5. **Education outcomes for students with ASD.** It is clear from Table 2 in the AABASD (2007) report, *The Prevalence of Autism in Australia: Can it be established from existing data?* (see <http://autismaus.com.au/index.php?page=research>) that education departments around Australia have relatively poor data relating to students with ASD. The ASD rates reported from state education departments vary rather erratically from more credible sources (especially, Centrelink). Apparently, state education departments do not know what outcomes students with ASD achieve or how effective education services are for students with ASD. From this one can infer that state education departments do not know what resources they need to provide so they ensure equitable outcomes for students with ASD.

Indications are that a high proportion of people with ASD in their post-school years receive a Disability Support Pension. This suggests that the available education does not prepare people with ASD effectively for employment and/or post-education employment services are ineffective for people with ASD.

Education Departments should monitor and report education outcomes for people with ASD.

It appears that an increasing number of students with ASD get tertiary qualifications but are still unable to get jobs. While some do get jobs, their jobs do not make effective use of their training and skills.

SC#6. **Schools excluding students with ASD.** Education systems/bureaucrats in Australia (and elsewhere in the world) decided that students with disabilities should be "integrated" or "included" in mainstream education settings. Rather than offer segregated education, funding for educating students with a disability would be used to provide the required service for the student in a mainstream setting.

Many people regard this inclusion model as desirable and appropriate.

SC#8. **Workforce development.** Australia needs an increasing number of clinicians to deliver best practice intervention, treatment, rehabilitation and support for people with ASD. For example, students with ASD need clinical support in school to address their behaviour challenges rather than allowing schools to exclude students with ASD (see above).

Since the 1990s, Australia has not had the workforce capacity needed to deliver the level of service required. The number of Australian children diagnosed with an ASD has more than doubled each 5 years since then and service capacity is hugely behind demand.

A particular concern is that tertiary education institutions need to significantly improve their training quality and increase the quantity of allied health professionals needed to provide ASD-specific clinical services for people with ASD.

SC#9. **ASD Peak Body.** According to the FaHCSIA website:

In Australia there are several national disability peak organisations that contribute to government policies about disability issues affecting Australian families and communities, to carry information between government and the community on social policy issues and to represent constituent views.

See <http://www.facsia.gov.au/sa/disability/progserv/providers/AustralianDisabilityEnterprises/Pages/DisabilityPeakBodies.aspx>

None of the groups listed represents people with autism spectrum disorders. The website says the Department funds most of these organisations "to be the peak body ..." for specific disability groups. The webpage even lists two different deafness groups.

People with ASD are a distinct disability group. We hope that Governments recognise that now that over 1% of Australian children are now diagnosed with ASD, ASD is by definition at least a severe and usually life-long disorder, and people with ASD have ASD-specific needs distinct from other types of disability (people with ASD may also need some generic (specialist?) disability services).

People with ASD need ASD-specific representation: it would help if the Government were to contribute to funding such representation as it does with so many other disability peak bodies.

While this model often works well for students with a disability, the unfortunate reality for many students with ASD is that placements in mainstream schools have not worked out as intended or desired. Governments have not provided sufficient funding and resources, nor ensured students with ASD are prepared adequately, for effective education in mainstream schools. For students with ASD, Governments use inclusive education as a cheap and often ineffective option for students with ASD.

For example, the ACT Government sought recently to allow schools to exclude students for 10 days ( without telling the Education Department ... up from 5 days. The ACT Opposition wants schools to be able to exclude students for 20 days. The ACT Government does not show how this will improve education outcomes for children with ASD. The experience of parents is that an excluded student's behaviour does not improve; rather it deteriorates as the student learns that bad behaviour helps them avoid the school setting that they hate. The student spends an increasing amount of time out of school. A parent may need to stop working so the family's economic situation deteriorates. Stress and mental health issues in the family escalate.

Many students with ASD do not get the support they need in mainstream schools. Consequently, students with ASD are excluded too often from the school where they are enrolled. The issue is raised in several recent media reports.

<http://www.theaustralian.news.com.au/story/0,25982712-13881,00.html>

<http://www.abc.net.au/news/stories/2009/08/26/2667147.htm>

<http://www.abc.net.au/worldtoday/content/2009/s2645607.htm>

A few families complain formally but most do not. The Australian Human Rights Commission reports some conciliations arising from these complaints result in increased resource allocations (see

[http://www.hreoc.gov.au/disability\\_rights/decisions/conciliation/education\\_conciliation.html](http://www.hreoc.gov.au/disability_rights/decisions/conciliation/education_conciliation.html)). Those students whose parents do not complain miss out on an effective education. In Australia, students do not have a right to an education, or even a right to attend school.

SC#7. **ASD research.** The cost of ASD to the Australian community is large.

With the apparent increase in the number of people affected, the apparent cost is also growing substantially. Despite the considerable cost of ASD to the community, Australia spends very little on ASD research.

Recently, the US Government recognised ASD prevalence now exceeds 1% of children and this realisation apparently provoked the US Government to increase its ASD research.

As yet, the Australian Government has not explained why it is not funding ASD research at an appropriate level. More recently, it put \$190 million into its Helping Children with Autism package over a 5 year period yet it did not increase ASD research.

The latest Australian data suggests more than 1% of Australian school-age children are now diagnosed with ASD. ASD prevalence has more than doubled every 5 years since the 1980s. Surely, this growth in a severe disorder deserves serious investigation.

222  
irrelevant

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**From:** Thomson, Julia  
**Sent:** Friday, 21 May 2010 8:35 AM  
**To:** Cole, Mitchell  
**Subject:** can you put these through for urgent corro? [SEC=UNCLASSIFIED]

Julia Thomson  
Office of the Hon. Bill Shorten MP  
Parliamentary Secretary  
Disabilities and Children's Services  
Victorian Bushfire Reconstruction  
Ph: (02) 6277 4778; Mobile: 0417 140 404

21/05/2010

000020

**Buchanan, Sarah**

**From:** Bob Buckley [bob@buckley.id.au]  
**Sent:** Friday, 21 May 2010 8:30 AM  
**To:** Julia.Gillard.MP@aph.gov.au; Thomson, Julia  
**Subject:** Fwd: Email to the Prime Minister [SEC=UNCLASSIFIED]

FYI ... and I will send a copy to Minister Macklin if I can navigate the complex communication process ...

regards

**Bob Buckley**

mobile: +61 418 677 288

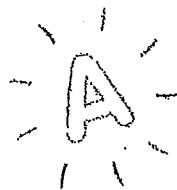
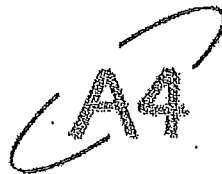
Band/Bass: <http://paverty.com.au/>

Convenor: <http://a4.com.au/>

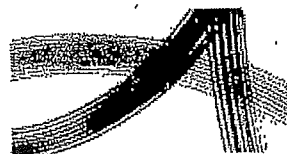
Vice-President:

<http://autismaspergeract.com.au/>

Director: <http://autismaus.com.au/>



**AUTISM  
ASPERGER ACT**



----- Original Message -----

**Subject:** Email to the Prime Minister [SEC=UNCLASSIFIED]

**Date:** Fri, 21 May 2010 08:12:18 +1000

**From:** [info@pm.gov.au](mailto:info@pm.gov.au) <[info@pm.gov.au](mailto:info@pm.gov.au)>

**To:** [bob@buckley.id.au](mailto:bob@buckley.id.au)

Thank you for your message to the Prime Minister at [www.pm.gov.au](http://www.pm.gov.au).

Below is a copy for your records.

Responses prepared to your message will generally be emailed to you. If you have supplied a postal address, a response may be sent to you via Australia Post. In some cases, your message may be forwarded to other Federal Ministers for their consideration.

This is an automatically generated email. Please do not reply to this email as this address is not monitored. If you have any problems with this service please contact the Web Administrator through the site feedback service at [http://www.pm.gov.au/Site\\_Feedback](http://www.pm.gov.au/Site_Feedback)

Submitted on 21 May 2010

Title: Mr

First Name: Bob

Last Name: Buckley

Email Address: [bob@buckley.id.au](mailto:bob@buckley.id.au)

21/05/2010

Street Address: 27 Fairbridge Cres  
Suburb/City: Ainslie  
State: ACT  
Postcode/Zip: 2602  
Country: Australia  
Subject: cut disability service  
Comment:

Dear Prime Minister Rudd

My son is 18 years old he is severely disabled by his Autistic Disorder. He attends Black Mountain School, the only "special school" in the ACT for students his age.

Both my wife and I work. My son needs constant supervision. We need after school care for my son. There are very few after-school care services for students like my son. We use the GRCS Disability Service in Gungahlin which is the only available service we could access.

Recently, the GRCS Disability Service told us that the Commonwealth funding for their after school care program was cut. As I understand it, there is no direct government funding at any level for after school care for students like my son. It seems the origin of the service we use was that GRCS Disability Service recognised a need and scabbled around among the discombobulated system of pitiful grants and managed to raise some funding for a few students from a Commonwealth program called YouthLink.

Last year, the Commonwealth cut the YouthLink program so the arrangement for my son's after school care is ending.

Can you tell me why the Commonwealth Government cut my son's after school care service? Did the Commonwealth Government consult or even notify clients in the community about its decision to cut this crucial service for people with disabilities and their carers?

Why do Governments make the provision of disability services so complicated? Rather than fund essential services like after school care for older students with a disability, we depend on the ability and efforts of a few visionary volunteers to create a support organisation and to navigate the chaotic government grants system for a service to even exist. It seems we are very lucky that we are close enough to GRCS Disability Service as many other places have no comparable service.

When I went looking for information about what happened to the YouthLink program, I found very vague references to it on the FaHCSIA website. When I rang FaHCSIA, I was referred to DEEWR. But DEEWR referred me back to FaHCSIA. I do not know why YouthLink was cut and not replaced.

In any case, I ask that the Government ensure that after school care is available for students with a disability who need supervision while their carers are at work. Please ensure the scheme is properly sustainable with ongoing funding.

Sincerely

Bob Buckley

21/5/2010

Mobile: 0418 677 288

Email: [bob@buckley.id.au](mailto:bob@buckley.id.au)

21/05/2010

**Buchanan, Sarah**

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**From:** Bob Buckley (A4 Convenor) [cnvnr@a4.org.au]  
**Sent:** Thursday, 20 May 2010 7:54 AM  
**To:** Thomson, Julia  
**Subject:** question on media release

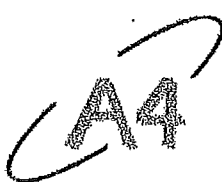
Hi Julia

Can you answer the following? If you cannot answer it, can you pass the question on to Bill or an appropriate person or should I contact someone else?

Bill Shorten's press release *Teachers and Parents to Continue Benefiting From Autism Workshops Until 2012* (7/5/2010) says (see [http://www.billshorten.fahcsia.gov.au/internet/billshorten.nsf/content/teachers\\_parents\\_autism\\_works](http://www.billshorten.fahcsia.gov.au/internet/billshorten.nsf/content/teachers_parents_autism_works)

An extra \$10.5 million will be provided for the Positive Partnerships program, bringing total funding for 2008-2012 to \$20.7 million.

Is this an **extra** \$10.5 million to the \$190 million Helping Children with Autism package ... or is it an **extra** \$10.5 million for AAETC to continue their contract that comes from the original \$190 million Helping Children with Autism package?



regards  
**Bob Buckley, Convenor**  
<http://a4.org.au/>  
mobile: +61 418 677 288

**Autism Aspergers Advocacy Australia**

21/05/2010