

27 Fairbridge Cres
Ainslie ACT 2602
mobile: 0418 677 288
email: bob@buckley.id.au

The Hon Ms Julia Gillard MP, Prime Minister
PO Box 6022
House of Representatives
Parliament House
Canberra ACT 2600

Dear Prime Minister

Subject: **Season's greetings and United Nations on autism**

I wish you greetings of the season.

I write to you today as a father of a 21 year-old son with severe Autistic Disorder and as a volunteer advocating for people affected by autism spectrum disorders in Australia. I am writing during this holiday, as advocacy for people affected by autism is not part of my job. No one in Australia is funded to act as a systemic advocate for the growing number of Australian whose lives are significantly affected by autism spectrum disorders since the Government does not fund a peak body and the community lacks the capacity to raise funds for itself.

According to its website, on the 12/12/2012, the United Nations

Assembly called on all States to enable persons with autism, developmental disorders and associated disabilities to learn life and social development skills to facilitate their full and equal participation in education and as members of the community.

The Australian Government has a long way to go. In its report on autism¹ from the 2009 Survey of Disability, Ageing and Carers (SDAC), the Australian Bureau of Statistics said,

- “The 2009 SDAC showed an estimated 64,600 Australians had autism. This is an increase of 34,200 from the 2003 SDAC, or more than double the prevalence identified in 2003.”
- “The majority of people with autism (85%) are identified in the survey because they reported having difficulty learning or understanding.”
- “In 2009, 12% of children with autism attended school and did not experience any educational restrictions. Of the remaining 88% who did experience some restrictions, 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.”

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

- “Of people with autism who had finished school, 77% had not completed a post-school qualification. This is well above the rate for both the rest of the population with disability and people with no disability”.
- “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.”
- “Of people with autism, 74% reported having a profound or severe core activity limitation (that is, they need help or supervision with at least one of the following three activities - mobility, communication or self-care).”
 - “According to SDAC 2009, the greatest challenges for people with autism lay with communication. There were 68% of people with autism reported having a profound or severe communication restriction, meaning they either cannot understand or be understood by others at all, or has some difficulty being understood or understanding others (it may be they communicate more effectively using sign language or some other non-verbal form of communication).”
 - “Mobility was the next most significant area of restriction, with 63% of people with autism having a profound or severe mobility restriction”.
- “About one third of people with autism need assistance with self-care, mobility, communication and cognitive or emotional tasks on a daily basis”.
 - In 2009, “there were 15,400 people with autism needing more help with communication (understanding or being understood by others) and 22,600 needing more help with cognitive or emotional tasks (managing their emotions and/or behaviour).”
 - “The bulk of care was provided by informal carers (relatives or friends), particularly in the core activity areas of self-care, mobility and communication.”
 - “Formal care providers provided less than one third of the care with these core activities. In the case of communication, formal care providers provided less than 10% of the care received on a daily basis with 2,200 people receiving daily assistance from formal care providers.”

The ABS report concludes:

One of the key goals of both the National Disability Strategy and National Disability Agreement is to increase the economic and social participation of people living with disabilities. People with autism struggle with social engagement – it is the nature of their disorder. In 2009, the data indicates they were also struggling with economic participation, with lower levels of post-school qualifications and labour force participation compared to other people with disabilities.

Autism is a very restrictive condition requiring a high level of support on a daily basis. While schools in Australia are providing some support to help children with the condition, 2009 data indicates more needs to be done to help them into further education and to the labour force.

It is undisputable that the number of Australians, especially children, who are diagnosed with autism has grown substantially over the last two decades (the ABS SDAC estimates 13,400 in 1998, 34,200 in 2003 and 64,600 in 2009 ...

similar growth is seen in children registered for Carer Allowance with Centrelink from 2005 to 2012, see <http://a4.org.au/a4/node/389> and <http://a4.org.au/a4/node/622>). The Government increased funding for the *Helping Children with Autism* (HCWA) package in the 2010-11 Federal Budget to meet increasing diagnoses and registrations.

None-the-less, the Australian Government's response to autism is disappointing.

- the Health Department told the Senate Community Affairs Committee (see Question E11-184) "The Department does not collect data on autism prevalence. The Department is not aware of any evidence of any major shifts in prevalence of autism in Australia."
- the Government's Departments for Health and FaHCSIA advise that a child with autism needs intensive autism-specific early intervention ... then Australian Governments refuse to provide the treatment they say children need. They advise children need 20 hours per week of early intervention then fund at most one hour per week. They advise that children need evidence-based early intervention for their autism yet they do **little or nothing** to train the required workforce or ensure families can access appropriate services.
- successive Attorneys-General refuse to even discuss the rights of people with autism in Australia (see <http://a4.org.au/a4/node/619>, <http://a4.org.au/a4/node/396> and <http://a4.org.au/a4/node/438>).
- There is no discernible response from the Australian Government to the ABS report on autism quoted above.

I recognise that any improved outcomes from the Government's *HCWA* package will take time to flow through. When the *HCWA* package was announced, the Prime Minister at the time said the initial announcement was "just the beginning".

Since 2007, Labor Governments ...

- initially implemented *HCWA* to meet its election promise, then allowed the *HCWA* initiative to ossify ... FaHCSIA and DEEWR resumed their *generic* approach to disability (for example, moving their focus to a more generic *Better Start* scheme ... I anticipate that both *HCWA* and *Better Start* will be absorbed in the NDIS Early Intervention, to the detriment of children with autism). Generic approaches to disability do not recognise/address the distinct needs of people with autism; so people with autism miss out on essential services and the consequent outcomes are abysmal (shown clearly in the education and workforce participation outcomes reported by the ABS for people with autism – see above).
- lied in its National Disability Strategy document about the number of Autism Specific Early Learning and Care Centres (ASELCC). Labor Governments at both Federal and State/Territory level said there are eight, but there are only six ASELCCs.
- promised in 2009 then broke Bill Shorten's promise of an Autism Register ... or at least work on an Autism Register appears to be at a standstill. In the scheme of things this promise is small, but it is symbolic for the autism community.

While I recognise that your Government's efforts to create a National Disability Insurance Scheme (NDIS) may offer some help for some people with autism and

their families/carers, I am concerned that the NDIS omits and distracts from key issues for people with autism, including:

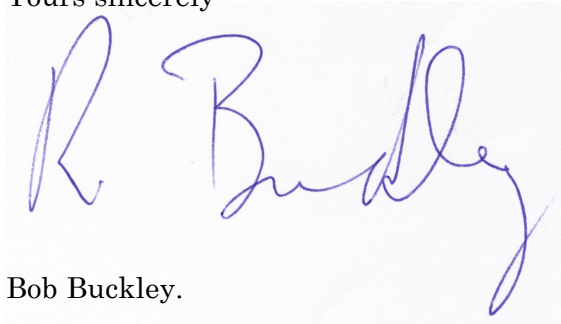
- basic human rights (including the right to life through safe disability services)
- adequate and appropriate early intervention
- effective education
- formal supports and accommodation for adults with autism
- workforce participation and employment.

As yet, the Australian Government's actions are not sufficient to improve significantly outcomes for its citizens with autism.

I now need to join my family in their seasonal celebrations.

Please, when you get a chance, think about the above. Please let me know what is Australia's additional response to the United Nations General Assembly's call on all states to ensure people with autism "learn life and social development skills to facilitate their full and equal participation in education and as members of the community"?

Yours sincerely

A handwritten signature in blue ink, appearing to read "R Buckley". The signature is written in a cursive style with a large initial "R" and a long, sweeping tail on the "y".

Bob Buckley.

25/12/2012