



Senator the Hon Jan McLucas
Parliamentary Secretary for Disabilities and Carers
Parliament House
Canberra ACT 2600

Dear Senator McLucas

Subject: **funding a national secretariat for autism**

Thank you for your letter on 23/12/2010 (your reference: MC10-017712).

We write again about the Government funding a national secretariat to help represent people with Autism Spectrum Disorders (ASD).

As we said in our previous email, Bill Shorten (as Parliamentary Secretary for Disabilities) asked FaHCSIA to find a small amount of funding for a national secretariat for Autism Spectrum Disorders. This did not happen before the last election and he has now moved on to another role.

A4 understands from your letter, that you are responsible for funding for the National Secretariat Program for disability. You say FaHCSIA “manages and administers funds for the National Secretariat Program, an initiative providing financial support for peak bodies to allow them to contribute to government policy and service delivery, and to communicate government information to their membership.”

On numerous occasions, the ASD community has pointed out to the Commonwealth Government that these important purposes are very difficult for the ASD community to achieve without a funded secretariat.

You wrote “there are no funds available to support funding to additional peaks”. Initial funding for a national secretariat for autism could be quite modest. Clearly, Bill Shorten felt the level of funding was within the range of discretionary funding for FaHCSIA or could be included in the next budget.

A4 understands from your response that you do not intend to fund a national secretariat for Autism Spectrum Disorders; therefore that the Government does not want people with autism spectrum disorders, their families and carers “to contribute to government policy” and does not support a peak body for ASD that can “communicate government information to [its] membership” and the rapidly growing ASD community.

It will be one of our goals to change your mind on this issue.

As you mention, the Commonwealth Government funds a number of other organisations through its National Secretariat Program (see <http://www.fahcsia.gov.au/sa/disability/progserv/govtint/policy-unesap/Pages/pl1.aspx>), specifically

- Physical Disability Council of Australia;
- National Ethnic Disability Alliance;

- Women With Disabilities Australia;
- Brain Injury Australia;
- National Council on Intellectual Disability;
- Deafness Forum of Australia;
- Australian Association of the Deaf; and
- Blind Citizens Australia.

The groups listed as part of FaHCSIA's National Secretariat Program do not represent people with autism spectrum disorders. Notice that

- The Government must recognise that the needs of people with disability arising from ASD are distinct from the needs arising from physical disability
- Some ethnic groups have limited understanding of ASD
- There is a 4:1 male-to-female ratio in current ASD diagnoses so women's advocacy groups see ASD more often as a male issue (though there are concerns that ASD may be underdiagnosed in women).
- ASD is not considered as Brain Injury (the ACT Government says ASD is not a mental illness ... though they do not say which part of the body other than the brain they think ASD affects).
- Issues relating to Intellectual Disability are treated distinctly from issues relating to ASD ... about 30% of people with ASD have an intellectual disability.
- Representatives from the (two) hearing and blind citizens groups have minimal interest in ASD issues.

Surely, people with autism spectrum disorders also need representation. People with ASD have rapidly growing numbers of people with severe or profound disability and increasing difficulty in accessing essential services.

You suggest Children with Disability Australia "is funded to contribute to government policies about disability" It is not clear from their website and published information what they actually represent ... and our experience is that their position is heavily ideological and does not properly reflect the varied view of the ASD community.

You refer to the National Disability Services (NDS) organisation. This is an organisation for service providers. Service providers have years of experience in **not providing** services for people with ASD and of providing service for people who are **not diagnosed with ASD**. We see no evidence that NDS represents people with ASD or advocates on behalf of service providers for people with ASD. We do not expect a peak body for service providers to advocate for people with ASD: these are quite different roles.

You say the National Secretariat Program "is reviewed from time to time". When was it reviewed last? You say opportunities will be advertised when they next come up. But without funding for a secretariat, we simply do not have the capacity to continuously monitor Government gazettes, websites and advertising. When will it be reviewed next? Will you notify us?

We object to being repeatedly referred to Government grants that simply do not fund the operations of peak bodies. I ask that you focus on practical

approaches to this issue. If on the other hand, you are aware of (and we have somehow missed) a specific Government grant scheme that is designed to fund national secretariats, please let us know.

You say

“As part of the Helping Children with Autism Package, FaHCSIA has engaged the Australian Advisory Board on Autism Spectrum Disorders in the development of the National Autism Spectrum Disorder Register and has committed to meeting regularly both face-to-face and via teleconference to focus on strategic issues.”

FaHCSIA did not engage the Australian Advisory Board on Autism Spectrum Disorders (AABASD) ... and developing the National ASD Register is not part of the *Helping Children with Autism* package, though it is administered by the same Branch in FaHCSIA.

We are aware of (and I am personally involved with) FaHCSIA's funding to state autism/ASD associations relating to a National ASD Register. FaHCSIA engaged the state associations to work on a National ASD Register. The state associations decided to collaborate on this project through the existing AABASD organisation. FaHCSIA did not fund the AABASD to work on this project.

The National ASD Register is just one example of the need for Government to fund a secretariat for ASD.

We understand FaHCSIA does not contribute to the cost of “meeting regularly [with the AABASD] both face-to-face and via teleconference to focus on strategic issues”.

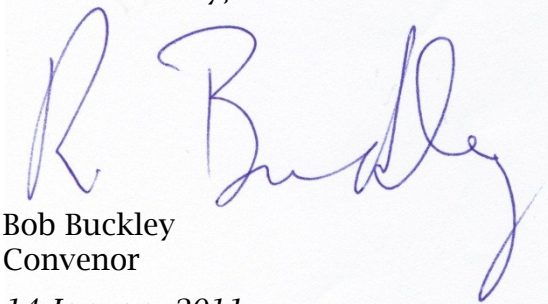
FaHCSIA has no arrangement with or commitment to A4.

The Government does not fund A4, the AABASD or any organisation as a peak body for ASD. Both A4 and AABASD rely on substantial efforts from volunteers to “contribute to government policy” and planning and “communicate government information to [its] membership”.

In conclusion, we hope the information and argument above convinces you to help fund a national secretariat for autism spectrum disorders. If not, we ask ...

- What would it take to convince you and your Government to ensure the growing number of people with ASD get the support they need to contribute to health and disability policy?
- When will the Government next review of the National Secretariat Program? Will you notify us when the review is announced?

Yours sincerely,



Bob Buckley
Convenor

14 January 2011