



*Speaking Out for Autism Spectrum Disorder  
in the Australian Capital Territory*

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Ms Lisa Spencer  
Disability and Community Policy | Health Policy and Strategy  
ACT Health Directorate | ACT Government  
2-6 Bowes Street, Phillip ACT 2606  
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Dear Ms Spencer,

Subject: **ACT Disability Health Strategy**

Thank you and the ACT Health Directorate for the invitation (via email, 12/11/2021) to join you for an ACT Disability Health Strategy (DHS) Roundtable. And thank you for providing the associated document: Stanford, D. (2021). *Future Directions of Disability Health in the ACT: Phase One of the ACT Disability Health Strategy Project*. ACT Health Directorate, Canberra. However, I have some concerns: this is an 83-page document with just one mention of “autism” or “autistic” in its *Appendix 2: European Manifesto on Basic Standards of Health Care for People with Intellectual Disabilities (2004)* contains the sentence:

This includes learning how to support and care for people with intellectual disabilities who have for instance sensory impairments, autistic spectrum disorders, epilepsy, mental health problems, behavioural/forensic problems, physical and complex disabilities, swallowing and feeding problems and age-related problems.

Apparently, people in the health sector in Europe think only about “autistic spectrum disorders” as a possible comorbidity of intellectual disability.

Autism autistic people do not even rate a mention in the Australian or ACT health context. This is remarkable when autism is now the primary disability for 33% of all NDIS participants and 67% of NDIS participants aged 7 to 14 years



(60% in the ACT). Since the 1990s, the number of children diagnosed with autism spectrum disorder (ASD) has increased substantially: autism was considered a rare disorder but now 33% of NDIS participants have autism as their primary disability. Nationally, 3% of Australian school-age children are NDIS participants with autism as their primary disability.

Autism rates vary substantially between states: in Victoria, 6% of school-age children, and 5% in South Australia, are autistic NDIS participants. Under 3% of school-age children in the ACT are autistic NDIS participants- a bit below the national average. By definition, the maximum number of people with intellectual disability is 2.2% of the population ( $IQ \leq 70$ , 2 standard deviations (15 IQ points) below the mean of 100 IQ points), so there are a significant number of children diagnosed with autism spectrum disorder who do not have intellectual disability.

One of the biggest challenges is to understand why autism diagnosis rates for children are ten times the rates for adults. We doubt that suicide and deaths of autistic people account for the much lower number of autistic adults; it is more likely to be a massive problem with autism under-diagnosis in the health sector. A Disability and Health strategy needs to recognise and address this issue.

It seems the whole strategy lacks appreciation of the disability sector. It says little or nothing about the composition of disability in Australia and how it is changing over time. For example, in Australia the number of people with disability is decreasing both overall and as a proportion of the population. However, the number of autistic people is increasing significantly. This should be important information needed to develop a credible disability health strategy.

This Health Strategy document uses numerous references relating to Developmental Disability. And it has Appendix 6 dedicated to Developmental Disability. Interestingly, this term is rarely if ever used in the disability sector. It is unclear what the health sector even means by *developmental disability*.

The NDIS defines Developmental Delay in the actual legislation, but it is meant to be a term used until a more definitive diagnosis is made. NDIS Developmental Delay (defined in the Section 9 Definitions) and Global Developmental Delay (DSM-5) are up to age 6 years.

Also, the strategy does not even consider the likely technology advances that are happening in human genetics and its relationship with disability understanding and services.

The whole strategy document seems to focus on service access rather than on health and well-being *outcomes* for people with disability.

There is one brief mention of the Disability Royal Commission. The strategy simply fails to recognise and respond to the avalanche of abysmal health outcomes for people with disability that have been reported to, and discussed by, the Disability Royal Commission. Health outcomes for people with disability in Australia are catastrophic: premature and unnecessary deaths, excessive and inappropriate use of chemical restraint, undiagnosed and untreated chronic illness, etc. The strategy fails to identify many of the major problems.

The following table shows NDIS participants in from the ACT at June 2021.

	0 to 6	07 to 14	15 to 18	19 to 24	25 to 34	35 to 44	45 to 54	55 to 64	65+
ABI	11	11	11	11	28	28	45	58	20
Autism	248	1324	397	347	167	68	41	11	11
Cerebral Palsy	22	64	30	44	41	35	32	18	11
Developmental delay	656	149			11				
Global developmental delay	124	47							
Hearing Impairment	62	95	31	36	49	34	40	65	23
Intellectual Disability	69	320	165	220	204	159	158	106	27
Multiple Sclerosis				11	11	40	46	58	43
Other	11	11	11	11	11	11	11	26	11
Other Neurological	13	36	13	16	13	34	56	97	80
Other Physical	15	48	14	21	30	68	94	136	102
Other Sensory/Speech	11	63	11	11	11	11		11	
Psychosocial disability		15	11	48	160	246	250	235	83
Spinal Cord Injury		11		11	11	13	14	20	11
Stroke					11	11	25	48	40
Visual Impairment	11	18	11	11	26	18	31	42	16
ALL	1227	2193	684	761	742	757	838	922	460

Note that the value “11” means a number greater than 0 and less than 11.

Note, there are 3 times as many children aged 0 to 6 years with Developmental Delay or Global Developmental Delay compared to autism. It seems most of them are subsequently diagnosed with autism once they have missed their opportunity to access evidence-based early intervention for their ASD. There were 207 children aged 7 to 14 years with DD or GDD when those conditions do not even exist beyond 5 years of age.

These are the small number of people with disability who are NDIS participants. Most people with disability are not NDIS participants. Services for them are abysmal in the ACT. The Strategy paper barely mentions waiting times/lists for diagnosis and allied health services as an issue.

The strategy fails to recognise the problems that need addressing. The diversity of the disability sector is a challenge. Disability rates rise with age so most disability is among the aged. However, people born with disability of various types often have very different needs. It isn't even appropriate to think about autism as homogenous. Autism and intellectual disability are distinct which is a fundamental issue that the health sector mostly fails to appreciate.

We previously identified that ACT Health consistently disregards autistic people. When asked to review ID and autism, it just dropped the autism part.



And it keeps doing that. That is disability discrimination, and “no” the disability discrimination law does not protect autistic people from such discrimination.

The ACT government has a sad history with reviews of disability services. The only real conclusion of the Gallop Inquiry was that the ACT Government will vigorously defend its officials from criticism no matter the accuracy or value of the criticism, and simply ignore the disability issues. Other disability reviews in the ACT have been pointless. It seems likely that the ACT remains consistent in its approach.

Again, thank you for the invitation ... though I’m confused about whether it is still on.

Sincerely

A handwritten signature in blue ink, reading "R Buckley".

Bob Buckley  
Chair, Speaking Out for Autism Spectrum Disorder

14/11/2021

cc: Ms Amanda Charles, Senior Director Office for Disability  
Ms Rachel Stephen-Smith, Minister for Health  
Ms Emma Davidson, Minister for Disability

## Annex A: ACT Government health officials ignore autism

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The following information was included in A4's recent submission to the federal Joint Committee on the NDIS.

### ACT Mental Health & autism timeline

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ACT Health avoids services and support for autistic people as much as possible. This is just the state/territory that A4 (and SOfASD in the ACT) knows most about. We expect other states and territories have similar responses to their autistic citizens.

Following is some of the correspondence and inactivity relating to mental health service and support for autistic youth in the ACT.

July 2018	parents, advocates and a psychiatrist wrote to ACT Minister for Mental Health about autistic patients needing mental health service and supports. See <a href="https://sofasd.org.au/d7/sites/default/files/20180715State%20mentofIntent.pdf">https://sofasd.org.au/d7/sites/default/files/20180715State mentofIntent.pdf</a>	No direct response.
15/11/2018	First Working Group Meeting see FoI result below.	Working group decided to ignore autism; to only consider Intellectual Disability
24/12/2019	<a href="#">SOfASD Freedom of Information request.</a>	See <a href="https://sofasd.org.au/d7/node/232">https://sofasd.org.au/d7/node/232</a>
March 2020	<a href="#">Review of Children and Young People in the ACT Office for Mental Health and Wellbeing</a>	The words “autism” or “autistic” do not appear anywhere in the document.
5/7/2020	<a href="#">Letter from Minister Rattenbury</a> quoting “additional work is required to address issues for people on the Autism Spectrum more specifically” to complement this Position Statement	

August 2020	ACT Standing Committee on Education, Employment and Youth Affairs: <a href="#">report on Youth Mental Health in the ACT</a>	The report says “Routinely, autistic youth who present with anxiety, trauma or depression are denied mental health services for those conditions because of their autism. In the past, CAMHS had a strong interest in autism but now the service excludes many, possibly all known, patients known to be autistic. Many autistic youths with mental illness have nowhere else to go to get the mental health services they need. It seems this is a staff decision rather than an actual policy”
13/4/2021	<a href="#">SOfASD Correspondence:</a> “We will be commencing this body of work in this quarter, rather than earlier in the calendar year, due to competing work priorities.”	By 29/10/2021 – there is no discernible progress.

## Annex B. Short talk given to Disability and Health Sector Consultation Committee (DHSCC) 10/11/2021

### A4's concern about health systems

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*we would like to invite you to talk about the experiences of people with autism and neuro-divergent people in the health system. ...*

*We suggest that you include the following during your 5 minutes introduction:*

- How people with autism and neuro-divergence are currently treated in the health system- a few key points, with some data if possible*
- What you think needs to change in order for people with autism and neuro-divergent people to have better experiences in the health system- a few key points*

Email from Ms Paige Kille on 3/11/2021

*Autism Aspergers Advocacy Australia, known as A4, appreciates this opportunity to speak briefly about autism in the health sector.*

Hospitals and health systems around the country are not prepared for increasing numbers of autistic patients, and their unexpected and often unwanted behaviour. [A recent story in The Age](#) (27/10/21) shows what happens too often to patients with “unwanted behaviour” – such patients are subject to (excessive, sometimes extreme) physical and chemical restraint. This recent media report mentioned “adverse effects of the man’s brain injury”, however, we also observe autistic people are often treated adversely in the health system.

A4 advocated for a young autistic man in NSW who was confined and drugged for over 200 days in hospital because the NDIS was not providing essential disability supports. Further, authorities who were informed of the situation took no real action ... they just asked the hospital who said, “nothing to see here”.

In the ACT, a young autistic man was excluded from a transplant list because he was autistic: health officials decided his life, because he was autistic, was not worth improving or extending. These are not isolated incidents.

Health complaint systems do not work: they just protect the institutions, dismiss complaints and whitewash inappropriate activities. The existing complaints process are a complete waste of our time. There is no regulation or registration of behavioural clinicians. The media is the only option, and it achieves very little.

Autistic people have, by definition, communication, behavioural and likely sensory differences. Too often, health staff refuse to accommodate their differences. Parents advise us that sometimes A&E triage ignores autistic children who don’t show a *normal* response to pain. Autistic children are left in A&E suffering indefinitely, often in very disturbing settings. Many Autistic patients are discharged prematurely, sometimes untreated.





COVID vaccination in the disability sector was a disaster. Needle phobia is common for autistic people. So-called “sensory vaccination units” worked OK for some but failed completely for others. Many severely autistic people are reluctant to get a second jab because their first vaccination experience was traumatic.

Mental health is a particular concern. Autistic people have high rates of mental illness, yet many mental health services refuse to treat mental illness in autistic people. We suspect there are substantial rates of undiagnosed autism among people with persistent or treatment-resistant mental illness. Note that autism diagnosis rates for children are inexplicably ten times the rates observed in Australian adults.

The ACT government asked its health department to review health services for people with Intellectual Disability and people with autism. The ACT Health Department simply dropped the autism part of the review. Subsequently, ACT Mental Health officials told an Assembly Committee “autism is a behavioural disorder” and they don’t treat people with behavioural disorders, so an autistic person with depression, anxiety, or trauma is denied treatment for their mental health because they are autistic. ACT officials promised repeatedly to review their service in relation to autism, but simply do nothing.

Now the NDIS Minister is complaining about the growing burden of autism in the NDIS. 6% of Victorian school age children get NDIS support and have autism as their primary diagnosis, 5% in South Australia, but just 2%, 2.4% in NT, WA and under 3% in Tasmania, NSW and ACT respectively.

It is likely that a majority of autistic adults in Australia are as yet undiagnosed.

The federal government has a [National roadmap for improving the health of Australians with intellectual disability](#) but denies there are increasing numbers of people diagnosed with ASD and ignores their health needs.

Clearly, we need the health sector to recognise autism as a major health issue. We also need health and mental health roadmaps to improving outcomes for autistic Australians. The health service sector needs to engage properly with the autism sector.