

To
 The Hon. Shane Rattenbury
 Minister for Mental Health
 GPO Box 1020
 Canberra ACT 2601

Date 15 July 2018

Statement of Intent

Mental Health Services for Autistic People

This document describes our intention to provide a short report to the ACT Government on gaps that autistic people¹ or people with autism spectrum disorder (ASD) currently experience while accessing or trying to access mental health services in the ACT. The report aims to inform the development of the vision and the workplan of the recently established Office for Mental Health and Wellbeing, and will be submitted by November 2018.

We observe that autistic people in the ACT currently appear to lack the right to appropriate and effective mental health services. We expect the ACT Government to recognise and address the right of autistic people in the ACT to access appropriate and effective mental health services. We ask that the new Office for Mental Health and Wellbeing advise the ACT Government on how best to ensure the rights of autistic citizens to effective mental health services and to improve mental health services for autistic people in the ACT.

Autistic citizens in the ACT are often denied, or find it challenging to gain, then maintain access to appropriate mental health services. Refusal or denial of mental health services may be more likely for autistic people, particularly when they have a known history of distressed behaviour (also called problem or challenging behaviour, or behaviour(s) of concern). The lack of necessary supports in the ACT is especially concerning for autistic people (including children and adolescents) with more extreme distressed behaviour, also because there is a flow-on effect that impacts on the physical and mental health of family members and carers. The consequences for children, young people and adults who do not receive timely, appropriate mental health services when they are most needed can be severe including misdiagnosis, entry to the justice system, self harm and removal from their families. At best they struggle to attend their place of work or study and to maintain relationships and housing.

Research and experience show autistic people often have comorbid mental health conditions (e.g., anxiety, depression), more often than the general public. Hence autistic people have greater needs for appropriate and effective mental health services, yet they often cannot access them in the current system.

Areas of particular concern include:

¹ Many autistic people prefer identity-first language to person-first language (person with ASD), see <http://autisticadvocacy.org/ab:ut-asan/identity-first-language/>

- Mental health services refusing service based on ASD diagnosis, without an effective referral to another service, in the absence of a mental health safety net
- Medical/health staff who are unaware or dismissive of ASD diagnoses
- Lack of ASD training for mental health staff (and for health staff generally)
- Staff shortages and workforce planning for specialist mental health services in the ACT, public and private (e.g., not enough paediatric psychiatrists, developmental neurologists, behaviour specialist services)
- Confused and conflicted responsibility between ACT Health and NDIS (results in delays and exclusion from services)
- Inappropriate responses in emergencies involving autistic people
- Lack/shortage of accommodation suitable for autistic people with extremely distressed behaviours, including children and adolescents. Currently, parents may be forced to relinquish care of the child in order to get appropriate accommodation and care.
- Lack of support for families caring for autistic people with extremely distressed behaviour
- Lack of support for autistic people in forensic settings
- Lack of supportive environments for autistic people when accessing health services (reduced noise/light/people traffic)
- Need for holistic mental health supports for autistic students across all their environments, including school settings, living arrangements, therapy and care (the cross-directorate structure of the Office for Mental Health and Wellbeing will be helpful in addressing this)
- Need to recognise and register professional behaviour support in relation to distressed behaviour and extremely distressed behaviour
- Need for systemic case management so autistic people cannot just drop off the health and mental health service systems

A particular concern is **CAMHS (Child and Adolescent Mental Health Service)** refusing treatment for autistic children and adolescents because of their ASD diagnosis. Families are told CAMHS cannot treat or house them because CAMHS clinicians were not trained to treat autistic patients/clients, and their treatment is outside of CAMHS' responsibilities. The option for clients who can afford it or get NDIS funding is long waiting lists for private services, if available - services that may also decide to not treat autistic clients, in particular those with extremely distressed behaviour.

Increasing rates of ASD require long-term planning

Autism used to be described as rare but **ASD diagnoses have increased substantially** in recent times. This highlights the importance and timeliness of ensuring that mental health services for autistic people are adequate now and into the future. The Australian Bureau of Statistics reports² that in 2015, **2.8% of Australian children aged 5 to 14 years** were autistic

² <http://www.abs.gov.au/ausstats/abs@.nsf/Latestproducts/4430.0Main%20Features752015> . These data indicated ASD diagnoses increased at 12.4% per year from 2012 to 2015 or 42.1% over the three years. Currently, the number of autistic Australians at least doubles each 5 years. There is also evidence that there are high rates of undiagnosed ASD associated with psycho-social disability and

(see table below). At this rate, ASD is now more common in children than intellectual disability (note: 30-50% of autistic children also have intellectual disability).

Age (years)	ASD diagnoses
0-4	0.4%
5-9	2.8%
10-14	2.8%
15-19	1.8%
20-24	1.2%
25-29	0.7%
30-34	0.2%
35-39	0.2%
40+	0.1%

ASD diagnoses are at substantially higher rates among children. The lower rates for older Australians with an ASD diagnosis does **not** result from substantial numbers of people being "cured" or losing their diagnosis, but is due to substantial under-diagnosis of ASD in the past. The growing number of children in the 5-9 and 10-14 ASD cohort means there will be a larger number of adults with ASD diagnoses in the future.

Without targeted and appropriate interventions, autistic people are at risk of poor outcomes in adulthood; they are likely to have poor employment prospects and a reduced ability to live independently. The long term outcome of not supporting ASD children and young adults is that these people are likely to require frequent and ongoing access to mental health and community services throughout their lifetime.

We are families who are unable to access the appropriate services that our children need, in particular, mental health services. We are also concerned that autistic adults cannot access the mental health services they need in the ACT.

Support for our advocacy comes from:

- *Speaking Out for ASD* (SofASD) in the ACT
- *Autism Aspergers Advocacy Australia* (known as a4)
- Dr Alexander YC Lim (Psychiatrist, Managing Director of ZedThree Specialist Centre)

Autistic people in the ACT and their families need better mental health services. We intend to provide a report with supporting evidence that makes the case for improving mental health services for autistic people.

Thank you for your consideration.

homelessness. ASD diagnosis rates in the ACT appear to be below the national average (<http://sofasd.org.au/d7/node/142>), but we do not know why this is the case.

Kind regards

[Redacted]

Fiona Brammall - Founder of *Canberra Autism Spectrum Parents and Relatives (CASPAR)*

[Redacted]

Bob Buckley - Chair of *Speaking Out for ASD (SOfASD)*; Convenor of *Autism Aspergers Advocacy Australia (a4)*

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Michelle Halton - Parent of Autistic/Bipolar Teenager; Social Worker and Teacher

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Dr Alexander YC Lim - Psychiatrist; Managing Director of ZedThree Specialist Centre

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Dr. Ulrike Troitzsch (contact) - Parent of Autistic Child

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