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**Results from consultation survey to inform a submission into the Federal Senate Select Committee on Autism**

Prepared by ACU Engagement for the Australian Autism Alliance

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**Our respondents**

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## Who did we hear from?

3,884 completed surveys:

- 769 autistic adults responding on behalf of themselves; and
- 3115 parents/carers responding on behalf of an autistic person they care for
- (including 257 autistic adults who are also parents/carers of autistic people and completed the survey in both contexts)

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## Basic Demographics

### Autistic Adults

- 565 (73.5%) female
- 59.3% aged 25-44
- 87.1% born in Australia
- 91.7% do not speak another language at home

### Parent/carer on behalf of autistic person

- 2219 (71.2%) responding on behalf of a male
- 2737 (87.8%) responding on behalf of a person aged under 18 years.
- 95.1% born in Australia
- 93.1% do not speak another language at home

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## Diagnosis

**Autistic Adults**

- 66.7% had a formal autism diagnosis and a further 9.6% were in the process of getting a diagnosis
- The majority were diagnosed as adults (77.2%)
- 77.0% reported waiting less than 12 months for a diagnosis
  - BUT 79.2% report that the diagnostic process was undertaken via the private system

**Parent/carer on behalf of autistic person**

- Almost all parents/carers were responding on behalf of a person with a formal autism diagnosis (96.2%) or in the process of getting a diagnosis (2.6%)
- 75.2% reported waiting less than 12 months for a diagnosis
  - BUT 69.8% report that the diagnostic process was undertaken via the private system



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## Advantages of Diagnosis (top 5)

### Autistic Adults

Helped me understand myself	91.9
Helped me understand my needs	82.5
Helped me deal with feelings of being different/inadequate	80.7
Helped me to explain my needs to others	75.4
Helped me find ways to improve my life/situation	69.3

### Parent/carer on behalf of autistic person

Allowed them to access support	90.7
Helped them understand themselves	49.6
Helped me/them understand their needs	45.2
Helped them deal with feelings of being different/inadequate	40.4
Helped me/them find ways to improve their life/situation	39.1



## Disadvantages of Diagnosis (top 5)

### Autistic Adults

People making assumptions about me based on myths (e.g. autistic people are good at maths, have a special talent)	52.6
People assuming I am incompetent / incapable of things	43.9
Experiencing stigma and/or discrimination	41.4
Makes me concerned that my other health needs will be overlooked/overshadowed	35.7
Being labelled / defined solely in terms of my autism	25.7

### Parent/carer on behalf of autistic person

People making assumptions about them based on myths (e.g. autistic people are good at maths, have a special talent)	61.0
People assuming they are incompetent / incapable of things	52.4
Experiencing stigma and/or discrimination	48.0
Being labelled / defined solely in terms of their autism	47.0
Makes me/them feel that I can't change my situation/ have less options	24.3



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**NDIS**

**Autistic Adults**


- 263 (34%) had applied to the NDIS for support:
  - 168 (63.9%) had received funding
  - 42 (5.2%) were deemed ineligible
  - 53 (6.6%) had an application pending
- 506 (66%) had not applied
  - 168 (33.2%) thought they would not be eligible
  - 115 (22.7%) did not think they needed support
  - 80 (15.7%) needed information or support to apply

**Parent/carer on behalf of autistic person**

- 2711 (87%) had applied to the NDIS for support:
  - 2475 (91.3%) had received funding
  - 107 (3.9%) were deemed ineligible
  - 129 (4.8%) had an application pending
- 404 (13%) had not applied
  - 90 (22.3%) thought they would not be eligible
  - 54 (13.4%) did not think they needed support
  - 109 (26.9%) needed information or support to apply

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## Autism knowledge of planner

	Autistic Adult (n=155)	Parent/carer on behalf of autistic person (n=670)
Good	18.1	31.8
OK	38.7	39.3
Poor	37.4	24.9
Unsure	5.8	3.7
Prefer not to say	0	0.3

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## NDIA planning process was easy to understand?

	Autistic Adult (n=155)	Parent/carer on behalf of autistic person (n=670)
Agree	28.4	33.7
Disagree	61.3	57.5
Unsure	10.3	7.9
Prefer not to say	0	0.9

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**Education:  
Primary and Secondary**

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**School attended**

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Only asked of parents/carers of school-aged children:

- 96.7% currently enrolled in primary or secondary school:
  - 72.2% mainstream school
  - 10.9% special school
  - 9.0% dual school (mainstream and special)
  - 3.3% home school
  - 2.2% distance ed

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## Disclosure and adjustments

99.0% had disclosed their child's diagnosis to the school

Adjustments made	Percentage
Providing adjustments such as curriculum, assessment and exam conditions	32.0
Providing an education aide to meet the student's needs	31.2
Establishing clear routines and avoiding changes	28.0
Making adjustments to sensory environment (noise, light, smell, textures)	21.3
Establishing support outside of the classroom (e.g. during recess / lunch times / excursions)	22.3
Identified a person/teacher at school for me to contact/exchange information about my child's needs and progress at school.	35.1
Having robust and effective methods to deal with bullying	10.3
Providing information/education to other students on how to support/assist the student at school	8.3
Establishing a process by which they can leave the classroom without explanation if they need to take a break	19.1
Providing professional development in autism for school leaders and educators	12.4
Providing regular parent, student, teacher communication and meetings	28.7
Providing autism accessible environments such as quiet rooms/spaces for students	23.8
Promoting mental health and well-being, such as support including buddying and mentoring for autistic students	9.6

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## Education: Post-secondary

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## Further education

### Autistic Adults


- 29.1% (224) were enrolled in further study
  - 33.5% a Bachelor degree
  - 25.9% a post-graduate degree
  - 17.9% a Certificate (I, II, III or IV)
  - 13.4% Advanced Diploma, Associate Degree, Diploma

### Parent/carer on behalf of autistic person

- 29.1% (376) were enrolled in further study
  - 31.9% a Bachelor degree
  - 3.3% a post-graduate degree
  - 40.7% a Certificate (I, II, III or IV)
  - 11.0% Advanced Diploma, Associate Degree, Diploma

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## Disclosure and Adjustments

### Autistic Adult

- 51.3% had disclosed their diagnosis to the institution
- 33.0% had an adjustment (inclusion) plan
- The most common adjustment was adjustments to assessment/exam procedures (28.6%), with no other adjustment endorsed by more than 10%.

### Parent/carer on behalf of autistic adult

- 84.6% had disclosed their diagnosis to the institution
- 59.3% had an adjustment (inclusion) plan
- More likely to report adjustments being made:
  - 42.9% adjustments to assessment/exam procedures
  - 27.5% providing a disability support person
  - 19.8% providing a quiet room/area
  - 19.8% establishing a process by which they can leave the classroom without explanation if they need to take a break

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**Employment**

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**Autistic Adults**


- 411 (53.4%) currently held a paid job
  - 40.4% full-time
  - 32.8% part-time
  - 24.6% casual
- 148 (19.2%) were on a disability support pension
- Of those not in paid employment 59.4% would like to be employed

**Parent/carer on behalf of autistic adult**

- 107 (28.4%) currently held a paid job
  - 25.2% full-time
  - 43.0% part-time
  - 29.9% casual
- 199 (52.9%) were on a disability support pension
- Of those not in paid employment 57.5% would like to be employed

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## Disclosure

### Autistic Adult

Of the 705 currently or previously employed


- 214 (30.4%) had told their employer that they are autistic
- Most common reasons for non-disclosure:
  - concern that they would be judged negatively (59.4%)
  - Not confident that this will help (42.3%)
  - don't believe they will understand or that anything will change (41.3%)
  - Don't think I would be believed (fear of having diagnosis/self-identification questioned) (41.1%)
  - concern that they would lose the job or have their hours reduced (30.6%)

### Parent/carer on behalf of autistic adult

Of the 192 currently or previously employed

- 114 (59.4%) had told their employer that they are autistic
- Most common reasons for non-disclosure:
  - concern that they would be judged negatively (54.7%)
  - Don't want to be seen as different (45.3%)
  - concern that they would lose the job or have their hours reduced (32.1%)
  - Don't want to identify as autistic (30.2%)

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## Adjustments (IF disclosed)

	Autistic Adult (n=214)	Parent/carer of autistic adult (n=114)
Adjusted lighting and/or sound levels and/or other sensory (smells, textures)	8.4	5.3
Identified a person in the organisation to support you / them, if required.	13.1	27.2
Provided a quiet room/area	10.3	12.3
Provided information and/or training to others in the workplace on how to support you / them at work	5.6	14.9
Provided information and/or training to others in the workplace on how to support you / them at work	10.3	37.7
Provided a set work routine and avoided changes	25.7	26.3
Allowed you / them to work flexible hours	11.7	15.8
Changed the work flow/process while still achieving required outcomes	18.2	13.2
Changed the communication method to suit your / their preferred way of communicating (e.g. providing written rather than verbal instructions)	30.4	24.6
Other (SPECIFY)	31.8	21.9
None (EXCLUSIVE)	8.4	5.3

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### Current housing situation

	Autistic Adults (n=769)	Parent/carer of autistic adult (n=376)
Living with parents/guardians	17.5	72.1
Living with family/dependants	36.7	5.9
Living alone	11.8	3.5
Living alone with some assistance from a support worker	2.6	1.9
Sharing a home with friends	3.4	1.6
Sharing a home with other occupants (e.g. shared housing program)	.9	3.7
Owning a home	27.9	2.7
Renting a home	26.4	2.7
Provided with housing funding assistance	1.0	0.3
Prefer not to say	1.1	0.3
Other	10.3	5.6

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### Supports needed to live in preferred housing situation

	Autistic Adults (n=769)	Parent/carer of autistic adult (n=376)
Support in finding affordable housing options	20.4	50.0
Support in finding accessible housing options	10.0	28.5
Support in finding housing options where I am safe from violence, abuse, neglect	10.7	39.1
Assistance with personal care (showering, eating, dressing etc)	7.2	29.3
Assistance with shopping	17.2	42.6
Assistance with budgeting and paying bills	19.8	60.1
Support finding others of my own choosing to live with	4.2	32.4
Support finding a place to live on my own	12.1	36.7
Assistance with home management – laundry, gardening, maintenance, etc.	35.2	60.9
Other (please specify)	6.9	13.3
None	2.0	0.5
Unsure	3.7	3.5

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Justice



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## Ever been involved in the criminal justice system\*

	Autistic Adults (n=769)	Parent/carer on behalf of autistic person (n=3115)
Yes	33.4	5.9
No	63.5	92.9
Unsure	1.3	0.7
Would rather not say	1.8	0.5

\* as a victim, witness or accused

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## Knowledge and understanding of the police and/or courts and/or prison about autism


	Autistic Adults (n=257)	Parent/carer on behalf of autistic person (n=185)
Good	3.1	12.4
OK	9.3	24.9
Poor	65.4	55.7
Unsure	22.2	7.0

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### Accessed the health system in the last 12 months

	Autistic Adult (n=769)	Parent/carer on behalf of autistic person (n=3115)
GP / family doctor	96.5	95.0
Mental health practitioner (psychologist, psychiatrist, mental health support worker)	69.7	62.6
Dentist / dental hospital	48.8	59.6
Emergency department of a hospital	35.1	27.7
Complementary and alternative medicine practitioner (e.g. chiropractor, osteopath, kinesiologist)	26.4	14.5
Admitted to hospital	19.4	12.7
Did not visit/use any of these health professionals or health system	1.6	1.7

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## Autism knowledge and understanding

...of GP	Autistic Adult (n=742)	Parent/carer (n=2960)
Good	22.5	34.9
Ok	34.1	41.8
Poor	32.6	19.6
Unsure	10.8	3.6

...of mental health practitioner	Autistic Adult (n=536)	Parent/carer (n=1949)
Good	55.4	76.2
Ok	28.4	18.4
Poor	14.4	4.6
Unsure	1.9	0.8

...of hospital emergency department	Autistic Adult (n=270)	Parent/carer (n=863)
Good	8.5	22.0
Ok	24.1	36.8
Poor	45.9	34.0
Unsure	21.5	7.2

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## Mental Health

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### Mental health concerns

	Autistic Adult (n=769)	Parent/carer on behalf of autistic person (n=3115)
Yes, diagnosed	75.2	38.1
Yes, but no diagnosis	8.1	13.8
No	12.4	40.5
Unsure	3.5	6.8
Prefer not to say	0.9	0.7



### Have been able to get appropriate support

	Autistic Adult (n=769)	Parent/carer on behalf of autistic person (n=3115)
Yes	57.3	56.6
No	29.1	31.7
Unsure	8.9	6.7
Haven't tried to get support	3.6	4.4
Prefer not to say	1.1	0.6



## Usefulness in addressing mental health needs

...of GP	Autistic Adult (n=324)	Parent/carer (n=650)
Very useful	52.5	48.6
Somewhat useful	44.1	44.5
Not at all useful	3.1	6.0
Unsure	0.3	0.9

...of psychologist	Autistic Adult (n=310)	Parent/carer (n=815)
Very useful	62.9	65.4
Somewhat useful	32.9	29.7
Not at all useful	4.2	3.8
Unsure	0	1.1


...of psychiatrist	Autistic Adult (n=188)	Parent/carer (n=271)
Very useful	54.8	66.8
Somewhat useful	37.8	27.7
Not at all useful	6.9	4.1
Unsure	0.5	1.5

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## Social and Recreational Activities




### Receive support to access social and recreational activities

	Autistic Adult (n=769)	Parent/carer on behalf of autistic person (n=3115)
Yes, funded by NDIS	13.4	31.8
Yes, funded by another agency	0.3	0.6
Yes, but unfunded (e.g., family support)	8.3	20.4
No, but would like to	37.3	39.4
No, and don't want/need to	40.7	7.7

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### Feel socially isolated

	Autistic Adult (n=769)	Parent/carer (n=3115)
Strongly agree	32.9	36.2
Agree	34.6	37.2
Neither agree or disagree	16.6	13.5
Disagree	10.8	9.1
Strongly disagree	4.2	3.4
Unsure	0.9	0.6

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## Advocacy

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### Know where to get support

	Autistic Adult (n=769)	Parent/carer on behalf of autistic person age 18+ (n=375)	Parent/carer on behalf of autistic person age <18 (n=2731)*
...if they are experiencing violence, abuse or neglect	57.0	38.9	51.1
...if they are experiencing discrimination or exclusive practices – such as lack of opportunities to access education, accommodation, recreation and leisure	31.1	17.3	30.3
...with the law, with tenancy, with Centrelink or with having enough money to meet their needs	41.1	20.8	31.2

\* or I know on their behalf

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