

Summary of results from consultation survey to inform a submission into thé Federal Senate

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Our participants



769 autistic adults responded on behalf of themselves.

Including 257 who are also parents/carers of autistic people and completed the survey in both contexts).

74% were female.

were aged 25-44. **59%**

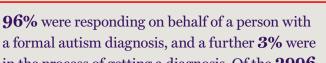
3115 parents/carers responded on behalf of an autistic person they care for.

Including 257 who are also parents/carers of autistic people and completed the survey in both contexts).

71% responded on behalf of a male.

responded on behalf of a person aged less 88% than 18.

Diagnosis



Of the 769 autistic adults responding on behalf of themselves, 67% had a formal autism diagnosis and a further 10% were in the process of getting a diagnosis. Of the **513** with a diagnosis:

were diagnosed under DSM-5. **74%**

reported that the diagnostic process was **79%** undertaken via the private system.

report that they were previously (incorrectly) **58%** diagnosed with another condition before their autism diagnosis.

were diagnosed as adults. **77%**

a formal autism diagnosis, and a further 3% were in the process of getting a diagnosis. Of the 2996 with a diagnosis:

were diagnosed under DSM-5. **74%**

70% reported that the diagnostic process was undertaken via the private system.

report that they were previously (incorrectly) 31% diagnosed with another condition before their autism diagnosis.

NDIS



Of the autistic adults responding on behalf of
themselves, 34% had applied to the NDIS for
support. Of those, 64% had received funding.

34%	Of the 221 with an NDIS Plan, 34% reported
	that their NDIS funding is adequate.

66%	reported that it is difficult to access disability support services after receiving NDIS funding
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Of the **42** whose applications were unsuccessful:

36%	did not receive an explanation of why they
	were ineligible.

86%	did not receive information on other supports
	that may be available to them.

Of the **155** who had attended a planning meeting:

18%	reported that their planner had a good understanding of autism.
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32%	reported that the NDIA provided enough information in advance for them to understand
	the planning process.

65%	said they needed more support to engage with the NDIA and understand what they would need to do in their planning meeting.
	need to do in their planning meeting.

Of the autistic people reported on by parents/carers, 87% had applied to the NDIS for support. Of those, **91%** had received funding.

37%	Of the 2604 with an NDIS Plan, 37% reported
	that their NDIS funding is adequate.

68%	reported that it is difficult to access disability support services after receiving NDIS funding.
	support services after receiving ND13 funding

Of the **107** whose applications were unsuccessful:

31%	did not receive an explanation of why they were ineligible.
	were mengible.

did not receive information on other supports 83% that may be available to them.

Of the **670** who had attended a planning meeting:

32%	reported that their planner had a good understanding of autism.
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36%	reported that the NDIA provided enough information in advance for them to understand
	the planning process.



Housing and Independence

Of the autistic adults responding on behalf of themselves, 28% own and 26% rent their home; 18% live with parents/guardians.

The most commonly endorsed forms of support needed were:

35%	Assistance with home management – laundry, gardening, maintenance, etc.
20%	Support in finding affordable housing options.

21	7%	Assistance with budgeting and paying bills

Assistance with shopping.

Of the autistic people reported on by parents/carers, 790/ live with parents/guardians

72% live with parents/guardians.		
28%	would like to live more independently.	

The most commonly endorsed forms of support needed were:

61%	Assistance with home management – laundry, gardening, maintenance, etc.
60%	Assistance with budgeting and paying bills.
50%	Support in finding affordable housing options.
43%	Assistance with shopping.
39%	Support in finding housing options where the

and neglect.

autistic person is safe from violence, abuse,

39%

Education: Primary and Secondary



Of the parents/carers reporting for an autistic person aged less than 18:		97%	had a child currently enrolled in primary or secondary school.
99%	disclosed their child's diagnosis to the school.	72%	were enrolled in a mainstream school.
37%	felt that their child had been discriminated against at school or when seeking to access an education.	42%	indicated that the adjustments made by the school for their child were mostly or completely adequate.

Education: Further education



Of the autistic adults responding on behalf of themselves, 29% were enrolled in further study. Of those:		Of the autistic people aged over 18 reported on by parents/carers, 24% were enrolled in further study. Of those:	
34%	were completing a Bachelor degree.	41%	were completing a Certificate qualification.
26%	were completing a postgraduate degree.	32%	were completing a Bachelor degree
51%	had disclosed their diagnosis to the institution.	85%	had disclosed their diagnosis to the institution.
33%	had an adjustment plan.	59%	had an adjustment plan.
35%	indicated that the adjustments made were mostly or completely adequate.	30%	indicated that the adjustments made were mostly or completely adequate.
27%	indicated that the adjustments made were only partly or not at all adequate.	31%	indicated that the adjustments made were only partly or not at all adequate.
63%	indicated that no support was provided to assist in their transition from secondary school to further study (and only 11% that an ok or good level of support was provided).	42%	indicated that no support was provided to assist in their transition from secondary school to further study (and only 24% that an ok or good level of support was provided).

Advocacy C	Autistic adult respondents	Autistic people aged over 18 reported on by parents/carers	Autistic people aged under 18 reported on by parents/carers
Know where to get help if they are experiencing violence, abuse or neglect.	57%	39%	51%*
Know where to get help with the law, with tenancy, with Centrelink or with having enough money to meet their needs.	41%	21%	31%*
Know where to get help if they are experiencing discrimination or exclusive practices.	31%	17%	30%*
Have enough help and support to communicate when they need to speak up about an issue.	41%	42%	38%*
Are confident to speak up for themselves and self-advocate.	40%	14%	16%*

Employment



Of the autistic adults responding on behalf of themselves:

53% currently held a paid job.	
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Only **30%** had told their employer that they are autistic. The most commonly endorsed reasons for not disclosing to their employer were:

59%	Concern that they would be judged negatively.
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42%	Not being	confident	that this	will help.
				- I

31%	Concern that they would lose the job or have their hours reduced.
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Of the 214 who had disclosed:

32%	said that no	adjustments	had l	oeen made.

8%	said that adjustments had been made to the
	sensory environment.

6%	said that information had been provided to others in the workplace on how to support
	them at work.

Of the parents/carers responding on behalf of an autistic person over 18:

28%	currently held a paid job
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59% had told their employer that they are autistic. The most commonly endorsed reasons for not disclosing to their employer were:

55%	Concern that they would be judged negatively.
	concern that they would be judged negatively.

45%	Not wanting to be seen as	different.
45%	Two wanting to be seen as	different.

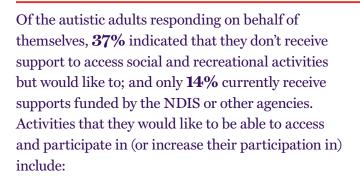
Of the 114 who had disclosed:

22%	said that no adjustments had been made. $$
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5%	said that adjustments had been made to the
J /0	cancary anvironment

15%	said that information had been provided to others in the workplace on how to support them at work.
	tnem at work.

Social and recreational activities



AEO/	Sporting activities.
45%	sporting activities.

48% Volunteering activities.

Of the parents/carers responding on behalf of an autistic person, **39%** indicated that they don't receive support to access social and recreational activities but would like to; and **32%** currently receive supports funded by the NDIS or other agencies. Activities that they would like to be able to access and participate in (or increase their participation in) include:

53%	Sporting activities.
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67%	Social or	recreational	activities

27%	Volunteering	activities.
	Volunteering	activities

Healthcare



Of the autistic adults responding on behalf of themselves, **98%** had accessed one or more healthcare providers in the last 12 months. The most commonly utilised healthcare providers were:

97% General practitioner.

70%	Mental health practitioner.
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Reported autism-related challenges in accessing healthcare were:

91%	Anxiety caused by the environment

87%	Health professionals' lack of understanding about autism.
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Of the autistic people reported on by parents/ carers, **98%** had accessed one or more healthcare providers in the last 12 months. The most commonly utilised healthcare providers were:

95%	General	l practitioner.
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63%	Mental health practitioner
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Reported autism-related challenges in accessing healthcare were:

94%	Anxiety caused by the environment.
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	91%	Sensory se	nsitivities
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49%

85% Communication difficulties.

82% Health professionals' lack of understandi	ıding
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Mental Health

Of the autistic adults responding on behalf of themselves, **75%** reported having a diagnosed mental health condition and **8%** an undiagnosed condition. Of these:

had not been able to get appropriate support for this condition.

More than two-thirds do not have adequate funding to access mental health services (46%) or pay for the services they access from private income (15%) or support from family (6%).

Of the autistic people reported on by parents/ carers, **38%** reported having a diagnosed mental health condition and **14%** an undiagnosed condition. Of these:

had not been able to get appropriate support for this condition.

Approximately half do not have adequate funding to access mental health services (36%) or pay for the services they access from private income (7%) or support from family (6%)



Justice

Of the autistic adults responding on behalf of themselves, **33%** had been involved in the justice system (as a victim, witness or accused). Of these:

rated the knowledge and understanding of the police and/or courts and/or prison about autism as poor.

reported that they were not adequately supported to have their say.

Of the parents/carers responding on behalf of an autistic person, **6**% had been involved in the justice system (as a victim, witness or accused). Of these:

rated the knowledge and understanding of the police and/or courts and/or prison about autism as poor.

reported that they were not adequately supported to have their say.

Inclusion and Exclusion



Of the autistic adults responding on behalf of themselves:

68% ^f	eel socially isolated.
	nave lost friends because of the way those riends have responded to their autism.
03% t	are criticised for their management of heir daily organisation and planning due o their autism.
40% l	eel sometimes unable to leave the house because they are worried about people behaving negatively towards them because of their autism.
42%	nave lost a job due to their autism.

Due to their autism or other people's responses to their autism:

58%	avoided going to pubs/bars.
52%	avoided going to family gatherings.
47%	avoided going to concerts.
46%	avoided going to shops.
45 %	avoided going to sporting events.
45 %	avoided going to the pool or gym.

The main reasons they avoid going to public places are:

92%	Crowds/number of people
82%	Levels of light and noise.

Of the parents/carers responding on behalf of an autistic person:

73%	feel socially isolated.
63%	have lost friends because of the way those friends have responded to their family member's autism.
58%	are criticised for their management of their daily organisation and planning due to their family member's autism.
60%	feel sometimes unable to leave the house because they are worried about people behaving negatively towards them because of their family member's autism.
32%	have lost a job due to their family member's autism.

As a result of their family member's autism or other people's responses to their family member's autism:

61%	avoided going to restaurants or cafes.
59%	avoided going to shops.
52%	avoided going to concerts.
50%	avoided going to sporting events.
44%	avoided going to pubs/bars.
45%	avoided going to family gatherings.

The main reasons they avoid going to public places are:

87%	Crowds/number of people.
58%	Concern over how people would respond to them.