

Summary of 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 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.

59% were aged 25-44.

315 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.

88% responded on behalf of a person aged less 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:

74% were diagnosed under DSM-5.

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

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

77% were diagnosed as adults.

96% were responding on behalf of a person with a formal autism diagnosis, and a further **3%** were in the process of getting a diagnosis. Of the **2996** with a diagnosis:

74% were diagnosed under DSM-5.

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

31% report that they were previously (incorrectly) 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.

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.

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.

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.

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

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

83% did not receive information on other supports 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.

36% reported that the NDIA provided enough information in advance for them to understand the planning process.

60% said they needed more support to engage with the NDIA and understand what they would need to do in their planning meeting.

Housing and Independence



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

13% would like to live more independently.

34% said that they would need additional support to live independently.

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.

20% Assistance with budgeting and paying bills.

17% Assistance with shopping.

Of the autistic people reported on by parents/carers, **72%** live with parents/guardians.

28% would like to live more independently.

65% said that they would need additional support to live 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 autistic person is safe from violence, abuse, and neglect.

Education: Primary and Secondary



Of the parents/carers reporting for an autistic person aged less than 18:

99% disclosed their child's diagnosis to the school.

37% felt that their child had been discriminated against at school or when seeking to access an education.

97% had a child currently enrolled in primary or secondary school.

72% were enrolled in a mainstream school.

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:

34% were completing a Bachelor degree.

26% were completing a postgraduate degree.

51% had disclosed their diagnosis to the institution.

33% had an adjustment plan.

35% indicated that the adjustments made were mostly or completely adequate.

27% 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).

Of the autistic people aged over 18 reported on by parents/carers, **24%** were enrolled in further study. Of those:

41% were completing a Certificate qualification.

32% were completing a Bachelor degree

85% had disclosed their diagnosis to the institution.

59% had an adjustment plan.

30% indicated that the adjustments made were mostly or completely adequate.

31% indicated that the adjustments made were only partly or not at all adequate.

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



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%*

* The autistic person (OR they themselves on that person's behalf)



Employment

Of the autistic adults responding on behalf of themselves:

- 53%** currently held a paid job.
- 19%** were on a disability support pension.
- 40%** Of those in paid employment 40% were employed full-time.
- 59%** Of those not in paid employment 59% would like to be employed.

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.
- 42%** Not being confident that this will help.
- 41%** Not believing they will understand or that anything will change.
- 31%** Concern that they would lose the job or have their hours reduced.

Of the 214 who had disclosed:

- 32%** said that no adjustments had been 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.

Social and recreational activities

Of the autistic adults responding on behalf of themselves, **37%** indicated that they don't receive support to access social and recreational activities but would like to; and only **14%** 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:

- 45%** Sporting activities.
- 65%** Social or recreational activities.
- 48%** Volunteering activities.

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

- 28%** currently held a paid job.
- 53%** were on a disability support pension.
- 25%** Of those in paid employment 25% were employed full-time.
- 58%** Of those not in paid employment 58% would like to be employed.

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.
- 45%** Not wanting to be seen as different.
- 32%** Concern that they would lose the job or have their hours reduced.

Of the 114 who had disclosed:

- 22%** said that no adjustments had been made.
- 5%** said that adjustments had been made to the sensory environment.
- 15%** said that information had been provided to others in the workplace on how to support them at work.



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.
- 49%** Dentist / dental hospital.
- 35%** Hospital emergency department.

Reported autism-related challenges in accessing healthcare were:

- 91%** Anxiety caused by the environment.
- 87%** Health professionals' lack of understanding about autism.
- 84%** Sensory sensitivities.
- 77%** Communication difficulties.

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 practitioner.
- 63%** Mental health practitioner.
- 60%** Dentist / dental hospital.
- 28%** Hospital emergency department.

Reported autism-related challenges in accessing healthcare were:

- 94%** Anxiety caused by the environment.
- 91%** Sensory sensitivities.
- 85%** Communication difficulties.
- 82%** Health professionals' lack of understanding about autism.

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:

- 29%** had not been able to get appropriate support for this condition.
- 67%** 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:

- 32%** had not been able to get appropriate support for this condition.
- 49%** 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:

- 65%** rated the knowledge and understanding of the police and/or courts and/or prison about autism as poor.
- 57%** 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:

- 56%** rated the knowledge and understanding of the police and/or courts and/or prison about autism as poor.
- 52%** reported that they were not adequately supported to have their say.



Of the autistic adults responding on behalf of themselves:

- 68%** feel socially isolated.
- 61%** have lost friends because of the way those friends have responded to their autism.
- 65%** are criticised for their management of their daily organisation and planning due to their autism.
- 48%** feel sometimes unable to leave the house because they are worried about people behaving negatively towards them because of their autism.
- 42%** have 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.