



Centre for Health and
Social Research



Australia's Attitudes & Behaviours towards
Autism; and

Experiences of Autistic People and their
Families

Autism and Education

Research Report for AMAZE

Sandra Jones, Muhammad Akram, Nicole Murphy, Paul Myers and
Natasha Vickers

Released 26 September 2018

Research Background

In July 2015, Amaze released its *Strategic Directions 2040*, a 25-year plan with a social impact goal: Amaze aims for a society that respects the dignity of every person on the autism spectrum and offers them real opportunities to participate and contribute.

Within this strategy Amaze seeks to achieve three key outcomes:

- Community understanding of autism in Victoria increases over time;
- Attitudes and behaviours towards autistic people by the Victorian community (government, private and social sectors) improves over time;
- Opportunities for meaningful participation and valued contribution increase for autistic people.

Against these outcomes, Amaze determined success indicators and outputs to measure progress, including conducting a *Community Attitudes and Behaviours Survey* to establish baseline data of awareness and understanding of the key facts about autism, plus undertake a companion survey of a *Study of Experiences of Autistic People and their Families*, also known as the “Experiences Survey”.

This report outlines the research findings from both surveys in relation to General awareness, knowledge and understanding of autism & Social Isolation

Key Facts

Have Australians heard of Autism?

The majority (97.9%) of respondents reported that they had heard of autism; 1.0% (n=24) said that they had not and 1.1% (n=26) that they were not sure.

Australia's Personal Connection with Autism?

The overwhelming majority of respondents reported that they have contact with an autistic person (86.1%); 22.2% (n=355) a lot of contact, 63.1% (n=1008) a little contact, and 13.9% (n=222) no contact at all.

One in four have an autistic relative (13.5% a close relative and another relative); 19.3% a friend; 15.4% an acquaintance; 5.1% a co-worker or colleague; and 23% someone else.

Autism Community Perceived Community Understanding of Autism

The majority of respondents (87.3%) agreed that most people in the community have heard of autism, but few perceive that most people know how autism might affect someone's behaviour (15.8%) and even fewer (3.7%) that they know how to support autistic people (see Figure 3).

Study 1 - Community Attitudes and Behaviours towards Autism

The Community Attitudes and Behaviours towards Autism survey was conducted to identify community attitudes and behaviours relating to autism. One of the key outcomes of this research is to better understand the attitudes and behaviours of the community and establish a baseline from which we are able to track changes over time to measure progress against Amaze's strategic outcomes.

To our knowledge, this is the first study of its kind to examine the attitudes and behaviours towards autism in Australia.

Findings – Autism and Education

What do Australians know about Autism and Education

Prevalence: More than half of the respondents (62.2%) agreed that the number of autistic people is increasing, and a further 31.2% were unsure. Respondents were less confident that the number of girls with autism is increasing (38.5% said this was true and 53.2% were unsure).

Impact: Of concern, 17.7% believed that schools can refuse to enrol a student with autism (and 34.2% were unsure) and that 13.9% believed that autistic people should go to Special Schools (. Almost one in five believed it was true or were unsure whether people with autism grow out of the condition (Figure 1).

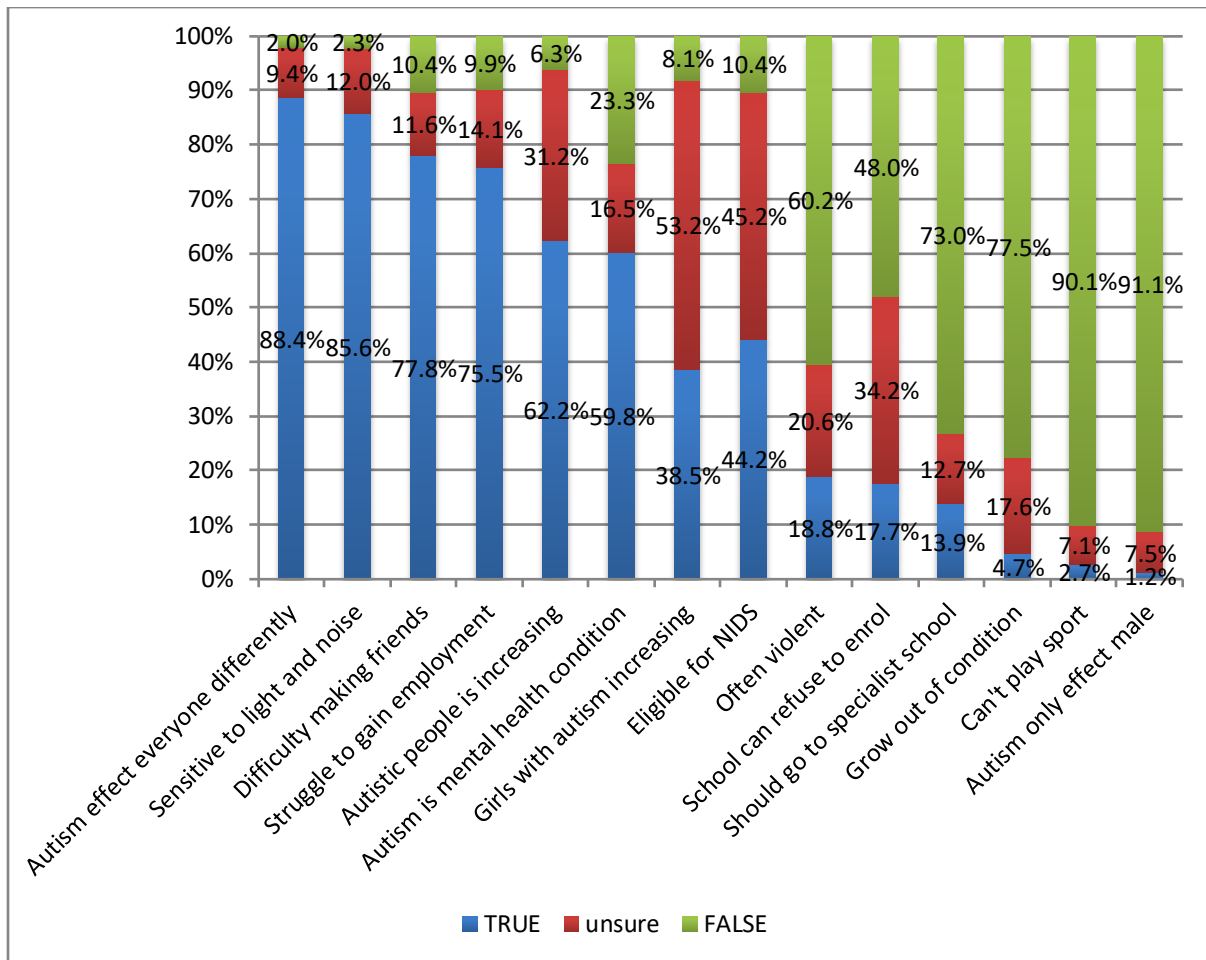
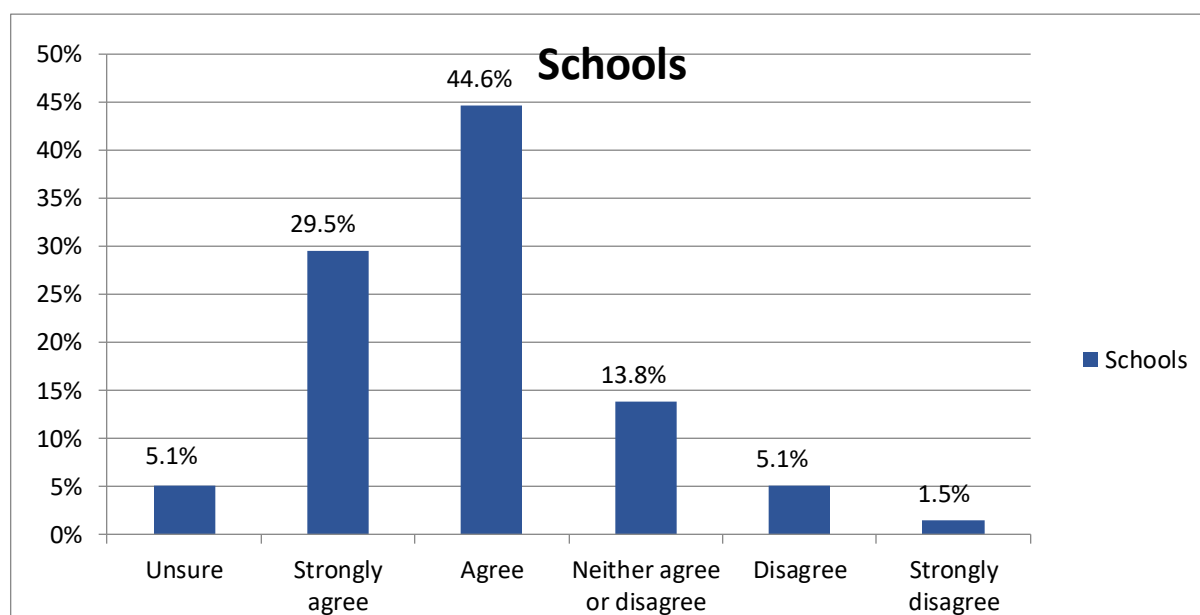


Figure 1: What do they 'know' about autism?

Younger respondents were more likely to believe that autism affects everyone differently ($p < 0.05$) and less likely to believe that people with autism should go to a specialist school ($p = 0.002$).

Do they think schools should make adjustments for autistic people?



Nearly three-quarters of the respondents 'agree' or 'strongly agree' that schools (74.1%) should make adjustments for autistic people; with only a small proportion (6.6%) disagreeing or strongly disagreeing with this statement. Less than one-quarter of respondents were 'unsure' or 'neither agree nor disagree' for the school policy questions (Figure 3).

Figure 2. Should schools make adjustments for autistic people?

How would they feel about autistic people entering their lives?

The situations that respondents were concerned or very concerned with were if an autistic person was appointed as their boss (20.1%) and if a close relative married an autistic person (20.1%). Interestingly, respondents were less likely to be concerned or very concerned with an autistic child moving in next door (5.5%) or being a classmate (8.1%) than if an autistic adult moved next door (12%) or became a colleague (10.3%) (Figures 3 and 4).

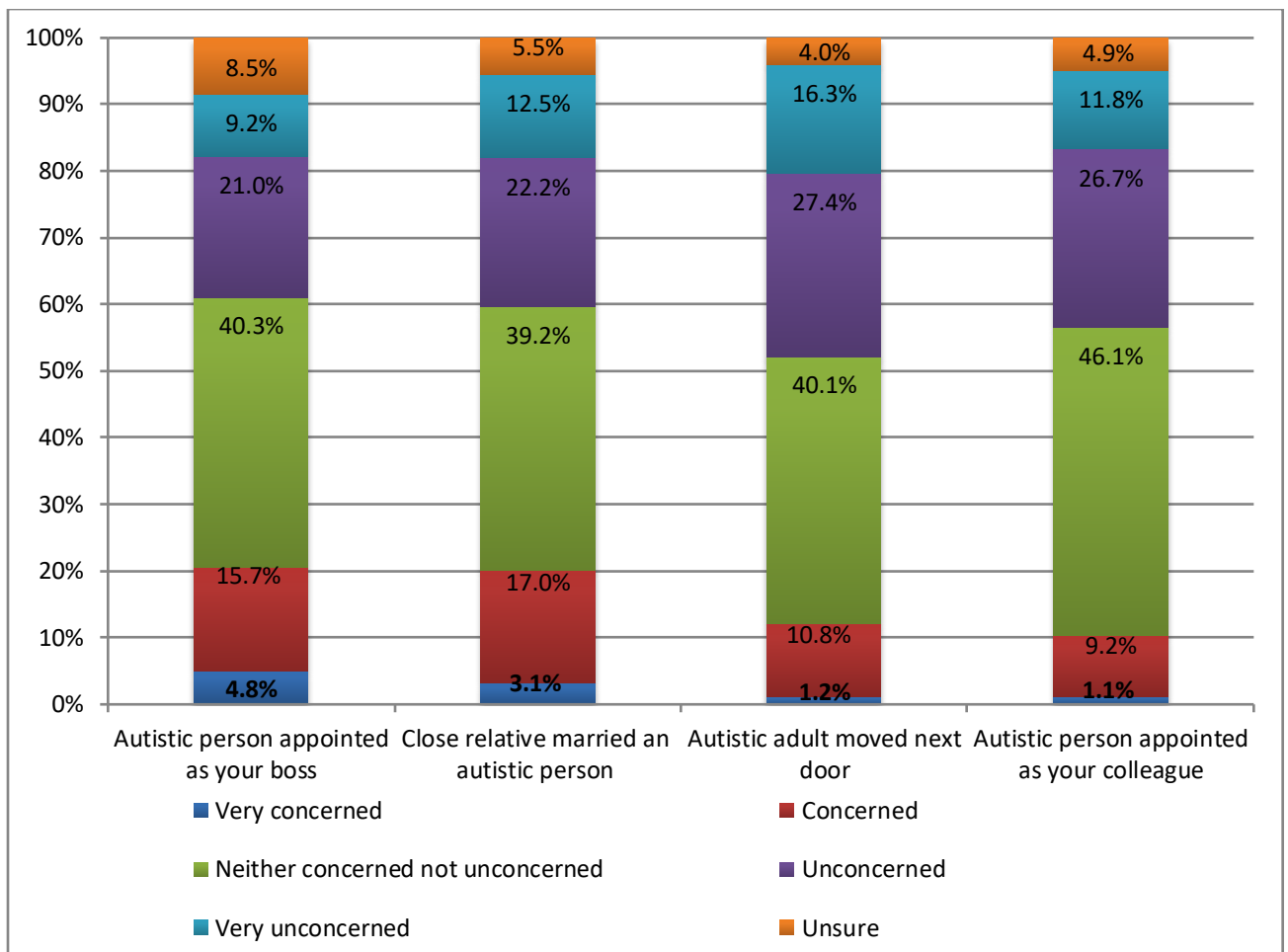


Figure 3. How would they feel about an autistic adult entering their lives?

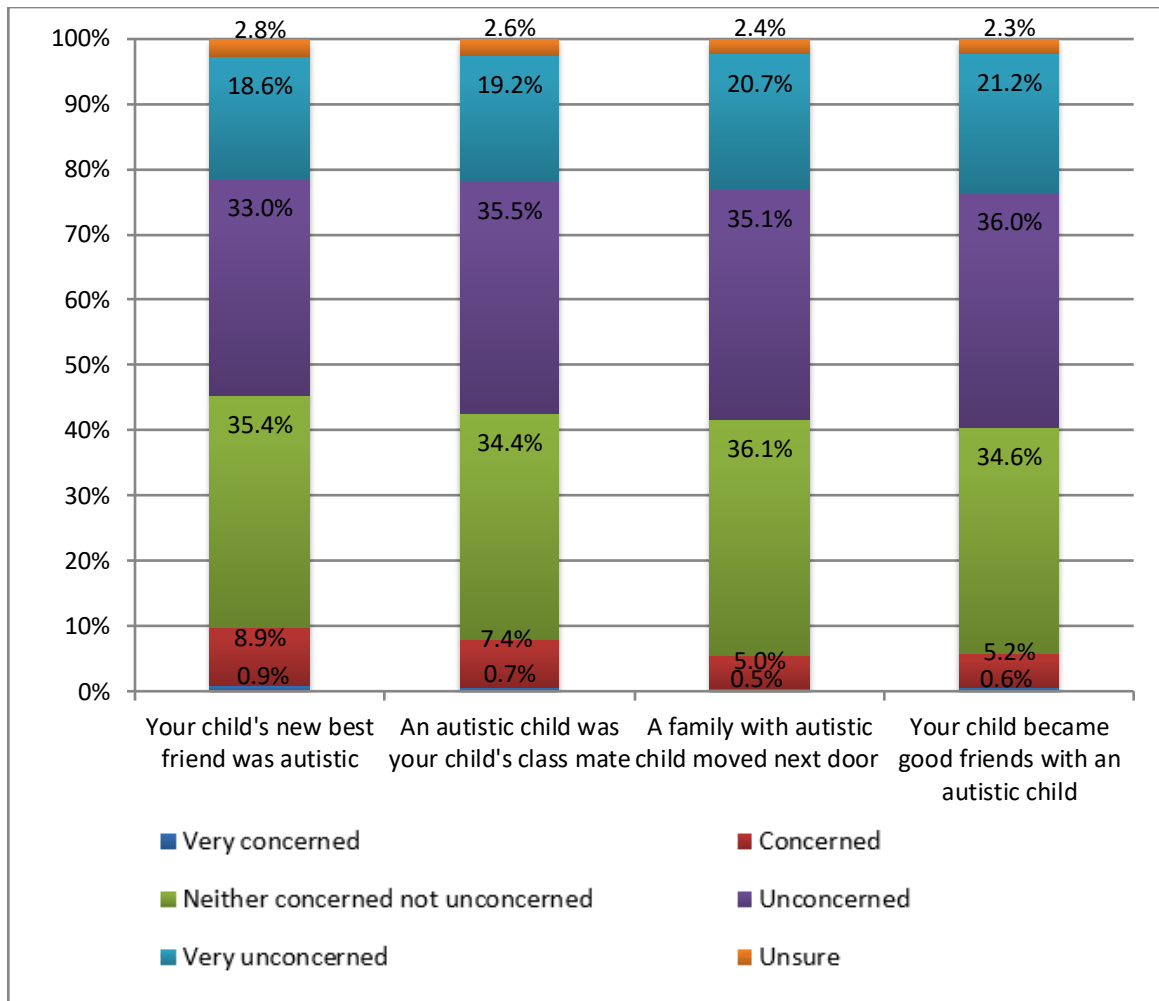


Figure 4. How would they feel about an autistic child entering their lives?

The data suggest that people are more comfortable with the concept of interacting with an autistic child than an autistic adult; and more comfortable with distal than proximal relationships. To illustrate the former, 5.5% said they would be concerned or very concerned if an autistic child moved in next door, but 12.0% if an autistic adult moved in. To illustrate the latter, 10.3% would be concerned or very concerned if an autistic person was appointed as their colleague, but 20.5% if an autistic person was appointed as their boss, and 20.1% if a close relative married an autistic person.

Study 2 - Experiences of Autistic People and their Families Survey

The Experiences survey seeks to better understand the experiences and challenges faced by autistic people, their family members and carers. The survey aimed to collect data from approximately 1,000 autistic people and/or family members/carers of an autistic person. Participants were to be recruited from subscribers to Amaze's information and communication publications.

The collected data will be used to help build understanding of the needs of autistic people, their families and carers. Results will be used to develop educational and support materials, public reports, media communications, advice to government and academic publications on the lived experience of people on the autism spectrum and their family members/carers. The results of the research will not be disseminated directly to participants.

The responses made by autistic people have been presented in italic text and break out boxes to distinguish between their experiences and those of their families/carers.

Findings – Autism and Education

Adjustments made at School?

Respondents with a child currently in education were asked whether the school had made each of ten specific adjustments (see Figure 3). The only adjustment reported by more than half of respondents was to identify a person/teacher at school for them to contact/exchange information about the child's needs and progress at school (58.1%); although this suggests that a substantial proportion of schools have not taken even this minimal step. The only other modifications reported by one-third or more of respondents were establishment of clear routines and avoidance of changes (43.4%), provision of an education aide to meet the student's needs (39.7%), and modification of the curriculum (33.2%) (see Figure 5).

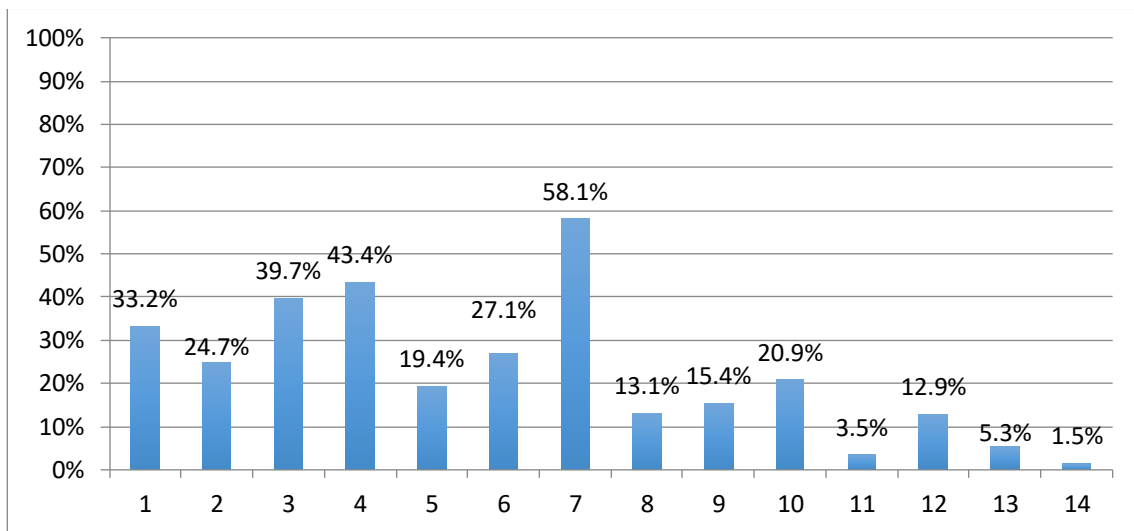


Figure 5: Adjustments made at school attended

1. Modification of the curriculum
2. Changes to assessment/test/exam procedures
3. Provision of an education aide to meet the student's needs
4. Establishment of clear routines and avoidance of changes
5. Adjusted sensory environment (noise, light, smell, textures)
6. Establishment of support outside of the classroom (e.g. during recess/lunch times/excursions)
7. Identified person/teacher at school for me to contact/exchange information about the child's needs & progress
8. Robust and effective methods to deal with bullying
9. Provided information/education to other students on how to support/assist the student at school
10. Established a process by which they can leave the classroom without explanation if they need to take a break
11. Other
12. None of the above
13. Unsure
14. Attends an autism / ASD specific school

Just under one-quarter (23.3%, n=178) reported that their family member/person they care for has had to change schools due to the school not being able to support their autism. This was more common amongst students of secondary school than primary school age (44.% compared to 19%, $p < 0.001$).

Experience of being treated unfairly in education?

Respondents reported being treated unfairly in both social situations and formal situations. Over a quarter (26.1%) reported that they had been treated unfairly (moderately or a lot) in education. These figures are substantially higher if we include those who were treated unfairly 'a little').

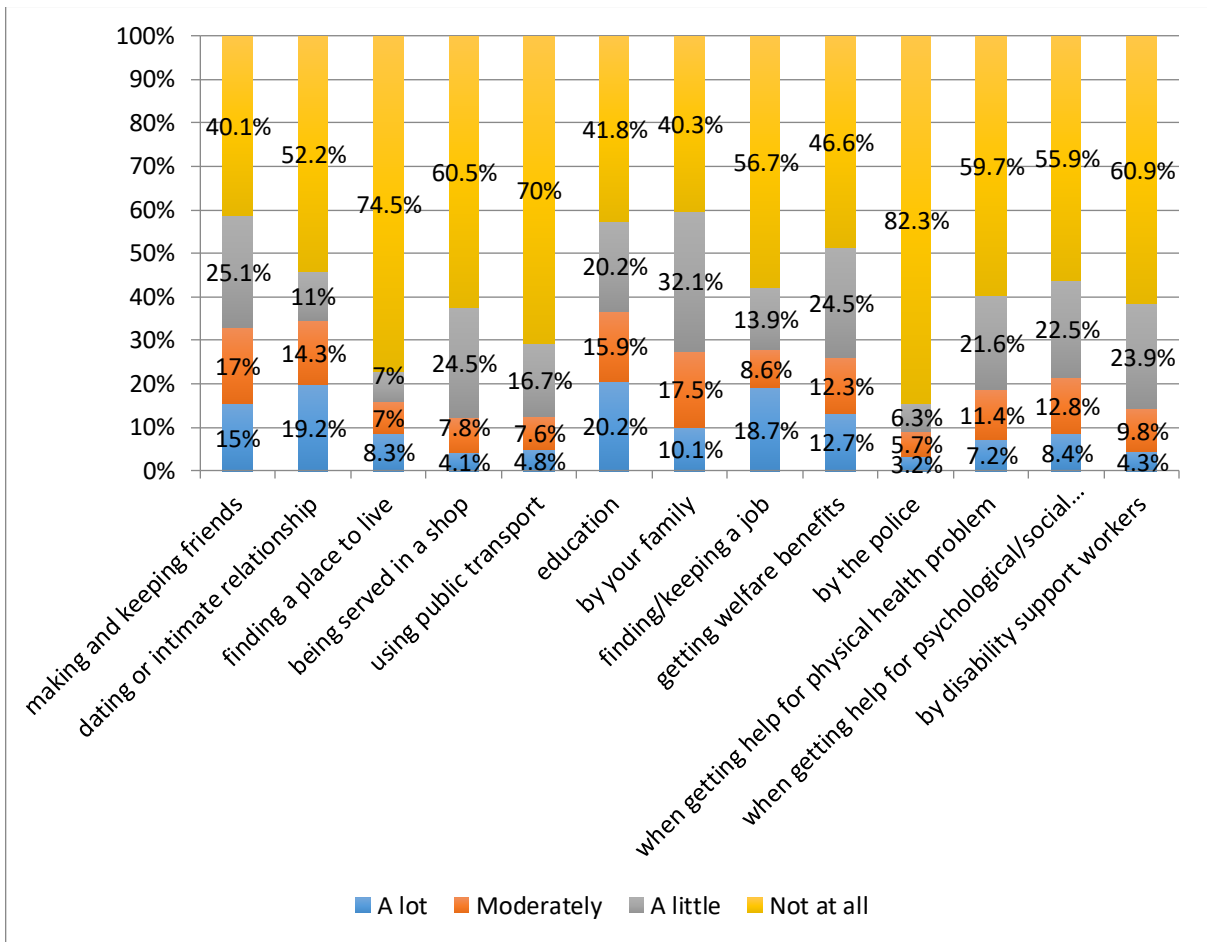


Figure 6: Experiences of being treated unfairly in the past year

Responses from autistic people

Autistic people were most likely to report being treated (moderately or a lot) unfairly in the past year in education (16%).

Methodology

Community Attitudes and Behaviours Survey

Sample

The sample consisted of adults aged 18 years and older recruited through a mixed-mode approach, including both online and telephone surveys conducted via the Social Research Centre's Life in Australia panel.

The Life in Australia panel was established in November 2016 by the Social Research Centre and is Australia's first probability-based online survey panel that are generalisable to the Australian adult population and that sampling errors and confidence intervals can be accurately calculated. Life in Australia Panel members were randomly recruited via their landline or mobile phone and provided their contact details so that they can take part in surveys on a regular basis.

A dual-frame RDD sample design was employed to undertake recruitment of the Life in Australia Panel, with a 30:70 split between the landline RDD sample frame and mobile phone RDD sample frame. For the landline sample, an alternating next/last birthday method was used to randomly select respondents from households where two or more in-scope persons were present. The phone answerer was the selected respondent from the mobile sample. Only one member per household was invited to join the Life in Australia panel.

Members of the panel are Australian residents aged 18 years or more and all active members of the panel (n = 3,204) were invited to take part in the survey via email, SMS and telephone, with reminders over a 2-3 week period. Of these, 75.7% (n = 2,424) participated in the survey. The majority of participants completed the online survey via email (76.7%), followed by via the telephone (13.1%) and SMS (8.6%).

The demographic characteristics of the respondents are reported in Table 1. The sample is consistent with the Australian population by gender; SEIFA quintile; state of residence; capital city vs other; and Australian vs overseas-born. The sample was more highly educated than the underlying population (40% with bachelor or higher degree compared to 23% of the population); and, while the overall age distribution was not significantly different, there was a greater proportion of people aged 55 and over in the sample than in the underlying population.

Table 1: Demographic characteristics

		N (%)	Australia	p-value
Gender	Male	1125 (46.4%)	49.8	0.79
	Female	1289 (53.2%)	50.2	
	Other	4 (0.16%)		
	Missing	6 (0.24%)		
Age	18-24	177 (7.3%)	12.3	0.34
	25-34	306 (12.6%)	19.1	
	35-44	328 (13.5%)	17.5	
	45-54	408 (16.8%)	16.9	
	55-64	534 (22.0%)	14.8	
	65-74	462 (19.1%)	10.9	
	75+	202 (8.3%)	8.4	
	missing	7 (0.3%)		
Highest educational qualification	Bachelor or higher	695 (39.8%)	23	0.03
	Trade/certificate/diploma	831 (34.3%)	31.1	
	Year 12 or equivalent	275 (11.3%)	18.3	
	Year 11 or less	353 (14.6%)	25.1	
Household structure	Person living alone	430 (17.7%)		
	Couple only	786 (32.4%)		
	Couple with kids	779 (32.1%)		
	Single parent with kids	148 (6.1%)		
	Others	260 (10.7%)		
	Missing	21 (0.9%)		
Country of birth	Australia	1749 (72.1%)	72	1.0
	Other	659 (27.2%)	28	
	Missing	16 (0.7%)		
Socio-Economic Indexes for Areas	Quartile 1 – Most disadvantage	302 (12.5%)	16	0.95
	Quartile 2	421 (17.4%)	18	
	Quartile 3	475 (19.6%)	20	
	Quartile 4	535 (22.1%)	22	
	Quartile 5 – Least disadvantage	668 (27.5%)	24	
	Missing	23 (0.9%)		
Region	Capital city	1610 (66.4%)	67	1.0
	Rest of the state	792 (32.7%)	33	
	missing	22 (0.9%)		
State	NSW	701 (28.9%)	32.0	0.99
	VIC	606 (25%)	25.2	
	QLD	480 (19.8%)	20.1	
	SA	221 (9.1%)	7.1	
	WA	275 (11.3%)	10.9	
	TAS	65 (2.7%)	2.2	
	NT	18 (0.7%)	1.0	
	ACT	58 (2.4%)	1.6	

Analysis

Descriptive statistics have been used to summarize survey data. The summary statistics are reported as frequencies and percentages for all categorical variables. To examine the relationship between two variables measured at the nominal or ordinal level of measurement, bivariate tables (or contingency tables) were prepared and this data is presented graphically using simple and multiple bar diagrams. To test the association between variables (such as age group) chi-square tests were performed for all categorical data. Statistical significance was set at a p-value of <0.05. All analyses were performed in Statistical software R (R Core Team 2017) version 3.4.0

There were no significant differences by age, gender, education level or state of residence for the majority of the questions; where such differences were identified they are explicitly stated in the results.¹

Experiences of Autistic People and their Families Method

Data collection for the Amaze Experiences survey was conducted by the Survey Research Centre (SRC). The sampling frame for the Experiences survey was persons aged 18 years and over who are autistic and/or are a family member/carer of an autistic person, and who subscribe to the Amaze mailing list. Respondents were recruited to participate in the online survey via email invitation, and two subsequent reminder emails. Data were collected between 3 July and 21 July 2017.

Invitations to complete the online survey were sent to 14,334 subscribers. A small proportion of the sample was found to be unusable due to the email address no longer existing or being incorrect (bounces - 1.36%) or because the email was no longer in use / the named respondent was not known (email refusals - 0.5%). A very small number of respondents chose to opt out of participating in the study.

Of those subscribers sent an invitation 1,353 completed the survey with an average duration of 14.9 minutes. A further 109 respondents attempted to undertake the study but were terminated due to not meeting the selection criteria outlined above. The final participation rate was 9.43% (of all sample members approached). Table 1 provides an overview of survey statistics.

Table 1 Survey Statistics

	Total
Invited to complete survey	14,334
Total interviews achieved	1,353
Failed screener	109
Bounced email	196

¹ As there were only 18 respondents from the Northern Territory, these were excluded from the analyses by state of residence.

Email refusal (e.g. person not known, email no longer in use)	73
Opt outs	3
Participation rate (%)	9.43

As it was expected that participants may fit more than one selection criteria, i.e. they identified as autistic and/or a family member and/or a carer to an autistic person, a selection process was undertaken to randomise the selected reference for response.

Sample

Due to the very small number of respondents from outside of Victoria, the analyses were conducted on those living within the state (n= 1297). The demographic characteristics of the respondents are reported in Table 2.

Slightly more than two-thirds (68.4%) identified as a family member of an autistic person, 49.4% as a carer of an autistic person, and 75 as an autistic person. Due to the randomization process described above, 57 autistic people completed the survey in relation to themselves and the remainder answered in relation to the autistic person they care for. Three-quarters of parents/carers (73.7%) provide care for one person, 18.2% for two people, 5.2% for three people, and 2.1% for between four and six people. For the majority of these respondents (81.4%) the oldest person they provide care for is under the age of 18 years (including 19.8% whose oldest child was under the age of six years and 49.9% whose oldest child was under the aged 6-12 years).

Table 2: Demographic characteristics

Sample Characteristics		N (%)
Sample size		1297
Gender	Male	130 (10.0)
	Female	1161 (89.5)
	Other	2 (0.15)
	Missing	4 (0.3)
Age	18-24	19 (1.5)
	25-34	151 (11.6)
	35-44	603 (46.5)
	45-54	365 (28.1)
	55-64	108 (8.3)
	65-74	38 (2.9)
	75+	6 (0.5)
	missing	7 (0.5)
Highest educational qualification	Masters or higher	331 (25.5)
	Bachelor	373 (28.8)
	Diploma	187 (14.4)
	Certificate	252 (19.4)
	Other	39 (3.0)
	missing	115 (8.9)
Household structure	Person living alone	16 (1.2)
	Couple only	43 (3.3)
	Couple with child(ren)	973 (75.0)
	Single parent with child(ren)	207 (16.0)
	Others	49 (3.8)

	Missing	9 (0.7)
Country of birth	Australia	1025 (79.0)
	Other	254 (19.6)
	Missing	18 (1.4)

Analysis

Descriptive statistics have been used to summarize survey data. The summary statistics are reported as frequencies and percentages for all categorical variables. To examine the relationship between two variables measured at the nominal or ordinal level of measurement, bivariate tables (or contingency tables) were prepared and this data is presented graphically using simple and multiple bar diagrams. To test the association between variables (such as age group) chi-square tests were performed for all categorical data. Statistical significance was set at a p-value of <0.05; and differences are only reported in the text where they were statistically significant. All analyses were performed in Statistical software R (R Core Team 2017) version 3.4.0