



Centre for Health and
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Community Attitudes & Behaviours
towards Autism; and
Experiences of Autistic People and their
Families

**General awareness, knowledge and
understanding of autism and social
isolation**

Research Report for AMAZE

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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

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 - General awareness, knowledge and understanding of autism

Have they 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.

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 relative 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.

What do they 'know' about autism?

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); although only 1.2% believed that autism only affects males, with a further 7.5% unsure.

Impact: The majority were aware that autism affects everyone differently (88.4%), that people with autism may be sensitive to light and noise (85.6%), that they have difficulty making friends (77.8%), and that they struggle to gain employment (75.5%). Of concern, 18.8% believed that people with autism are often violent (and a further 20.6% were unsure) and 17.7% believed that schools can refuse to enrol a student with autism (and 34.2% were unsure). Almost one in five believed it was true or were unsure whether people with autism grow out of the condition (Figure 1).

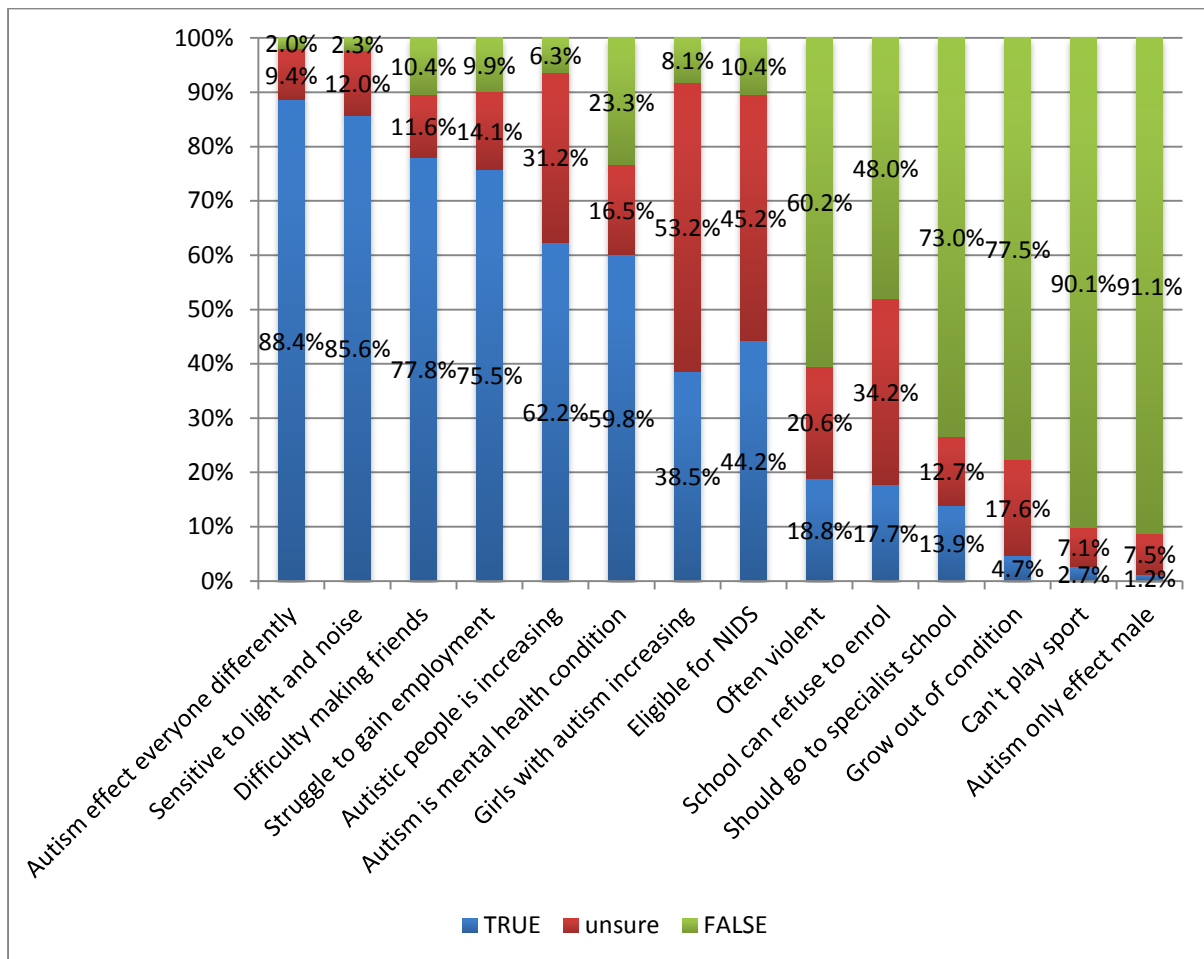


Figure 1: What do they 'know' about autism?

Younger respondents were more likely to believe that autism affects everyone differently ($p < 0.05$) and that people with autism are eligible for the NDIS ($p = 0.001$); and less likely to believe that people with autism are often violent ($p = 0.001$) or should go to a specialist school ($p = 0.002$). Respondents with a lower level of educational attainment were more likely to believe people with autism are often violent ($p = 0.02$).

Do they think autism can be cured?

Only slightly more than half (54.5%) of respondents were aware that autism cannot be cured; 11.1% ($n = 268$) thought that it can and 34.3% ($n = 832$) were unsure. Female respondents were more likely than males to be aware that autism cannot be cured (62.7% vs 45.1%; $p = 0.03$) (Figure 2).

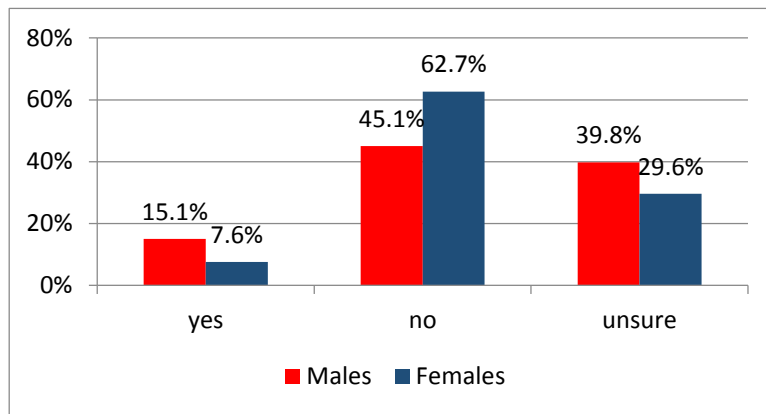


Figure 2: Do they think autism can be cured?

Do they think autistic people are discriminated against?

In response to the question, "To what extent do you think autistic people are discriminated against?" a large portion (84.1%) of respondents reported they perceived discrimination against autistic people to occur to 'some extent' or to 'a great extent'; only a very small portion of the sample (4.1%) reported 'not at all', while 11.4% were 'unsure' of the extent of discrimination towards people with autism.

Do they think they can support autistic people¹?:

In response to the question, "I personally have a good understanding of how to support people with autism?" 29% of respondents reported they agreed to some extent, where as 46% disagreed. A quarter (25%) reported they didn't know.

¹ Essential Poll 19 July 2016

Do they think schools and employers should make adjustments for autistic people?

Nearly three-quarters of the respondents 'agree' or 'strongly agree' that schools (74.1%) and employers (70.3%) should make adjustments for autistic people; with only a small proportion (6.6% and 5.7% respectively) disagreeing or strongly disagreeing with this statement. Less than one-quarter of respondents were 'unsure' or 'neither agree nor disagree' for both the school and work policy questions (Figure 3).

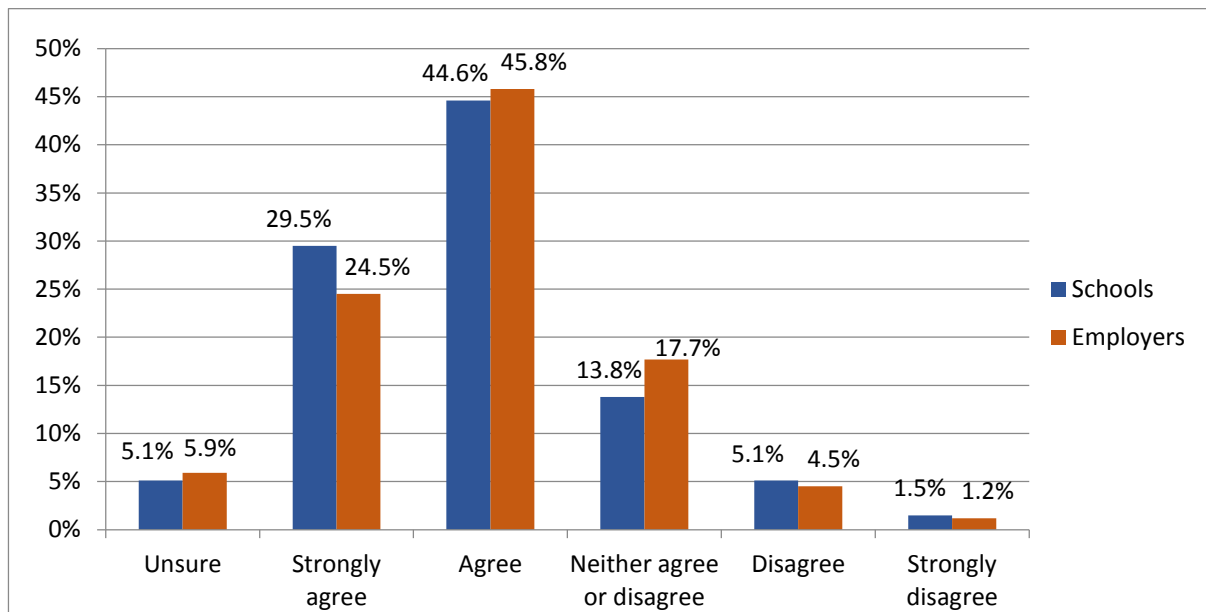


Figure 3. Should schools and employers make adjustments for autistic people?

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 - General awareness, knowledge and understanding of autism and social isolation

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).

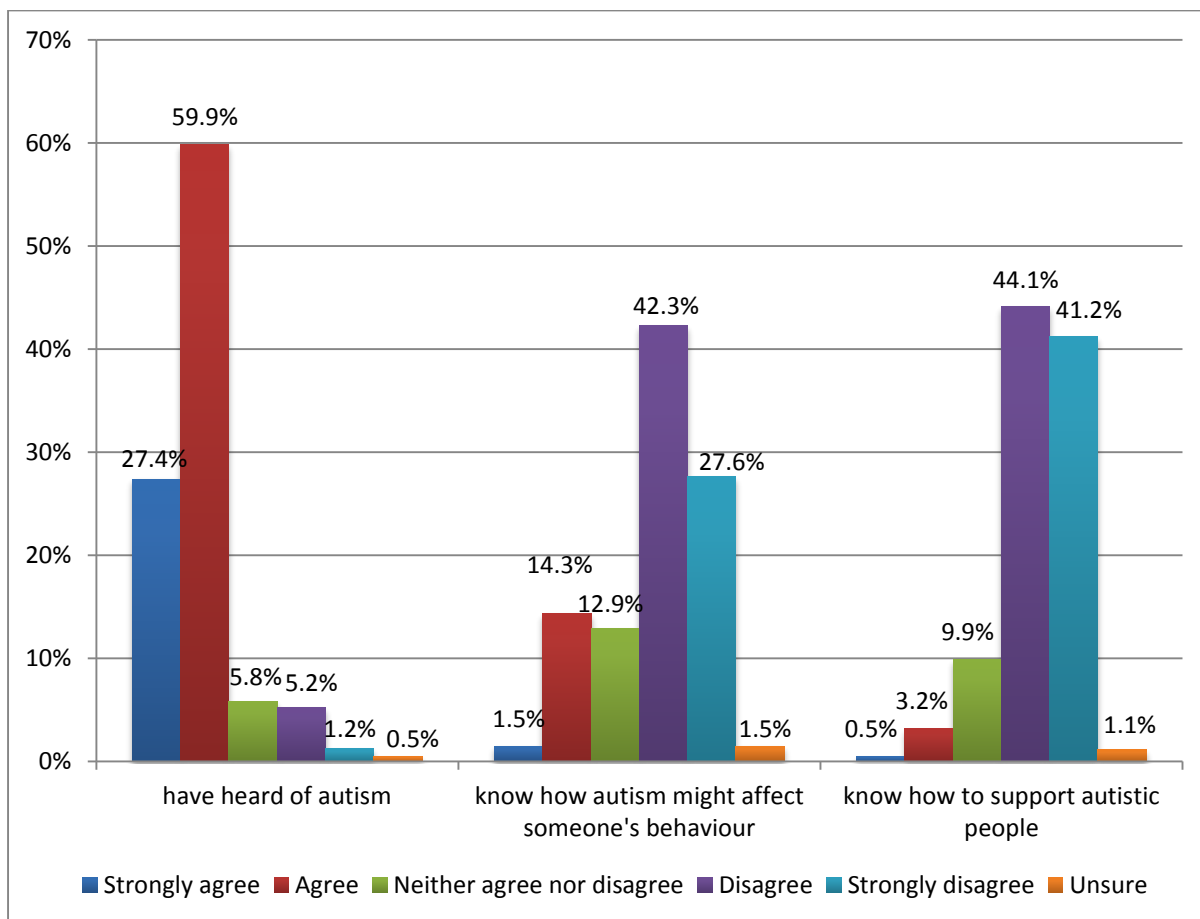


Figure 3: To what extent do you agree or disagree that... Most people I come across

Responses from autistic people

Forty-nine of the 57 respondents who identified as autistic and responded in relation to their own experiences agreed or strongly agreed that most people have heard of autism. However, only eight agreed that most people know how autism might affect someone's behaviour and only one that most people know how to support autistic people.

Community Attitudes and Social Isolation

In relation to their personal experiences, 51.6% agreed or strongly agreed that they feel socially isolated; 40.6% that they have lost friends because of the way those friends have responded to their or their family member's autism; 39.3% that they sometimes feel unable to leave the house because they are worried about people behaving negatively towards them because of their or their family member's autism. Demonstrating the devastating impact of other people's negative attitudes on key aspects of autistic people's personal lives, 20.1% reported that they have lost a job due to their or their family member's autism, and 26.5% that there are members of their family who they no longer speak to because of the way they have responded to their or their family member's autism (see Figure 4).

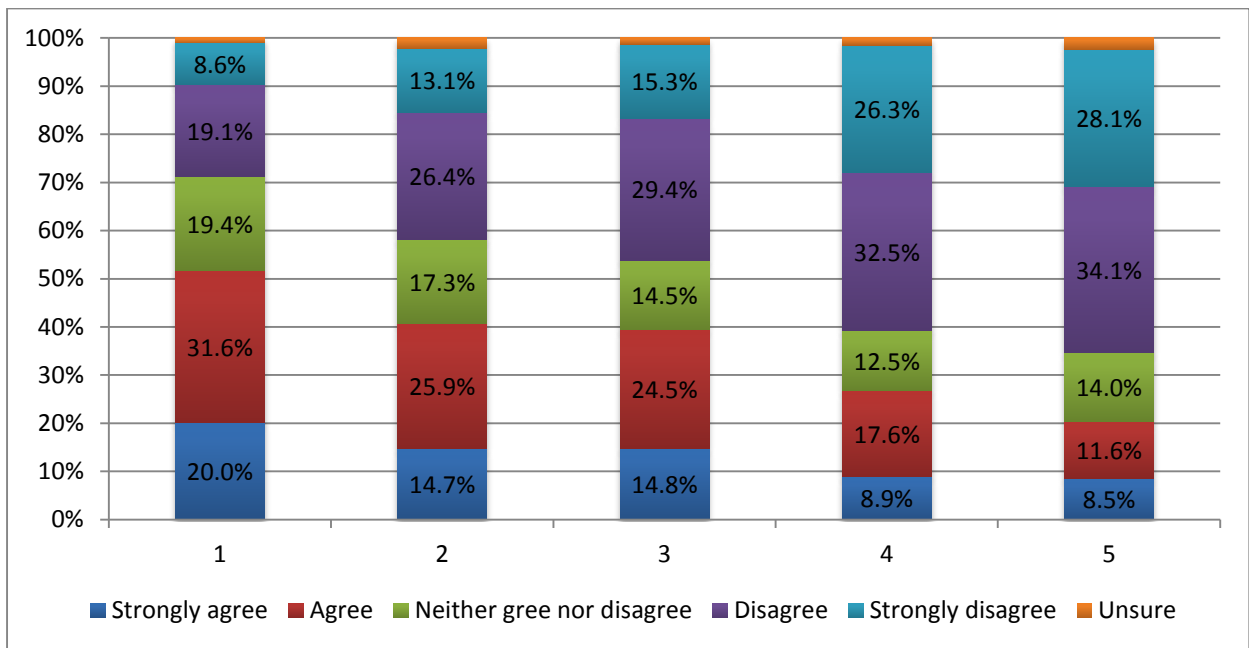


Figure 4: Problems with social interactions

1. I feel socially isolated
2. I have lost friends because of the way those friends have responded to my autism/my family member/person that I care for on the autism spectrum
3. I sometimes feel unable to leave the house because I am worried about people behaving negatively towards me because of my autism / my family member/person that I care for on the autism spectrum
4. There are members of my own family who I no longer speak to because of the way they have responded to my autism / my family member/person that I care for on the autism spectrum
5. I have lost a job due to my autism / my family member/person that I care for on the autism spectrum

Respondents also reported experiencing negative reactions when out in the community. More than half reported that often or sometimes people stare at them (81.4%), tut or shake their head (61.3%), or actively avoid them (63.6%) (see Figure 5).

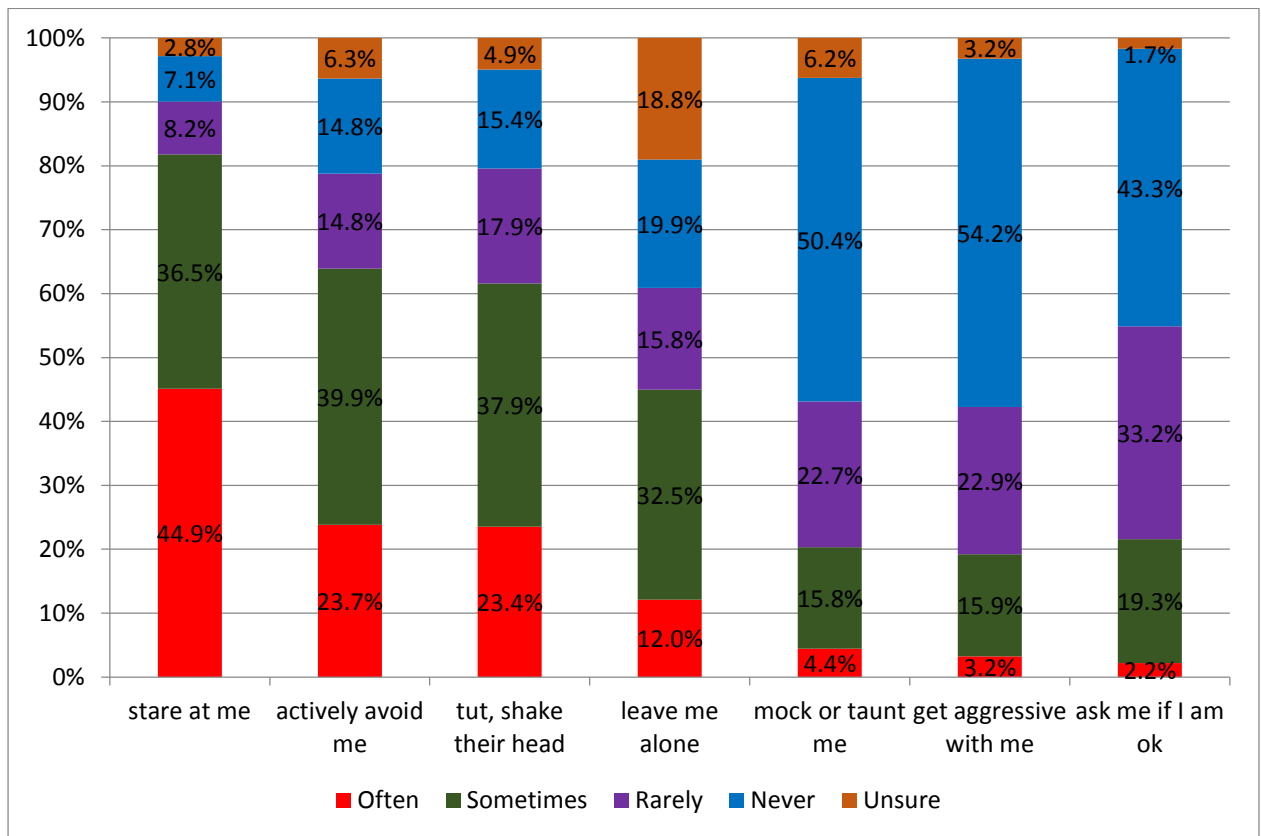


Figure 5: Problems with community interactions

More than half of the respondents reported that they had avoided going to a restaurant or café (51.3%); and more than a third avoided going to a concert (48.2%), sporting events (44.3%), the shops (44.3%), the cinema (39.6%), or the theatre (38.6%) (see Figure 6).

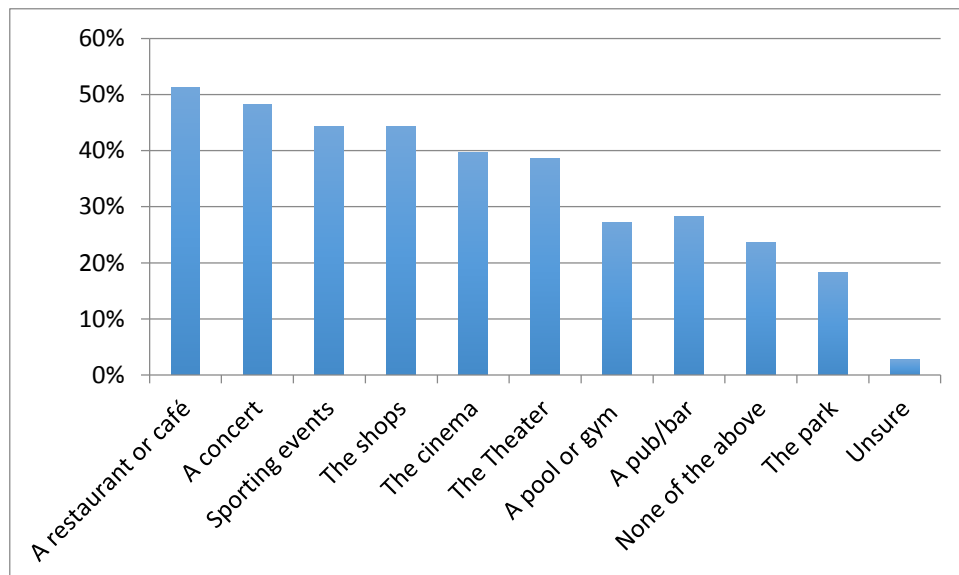


Figure 6: Avoiding community spaces

The main reasons given for this avoidance related to physical aspects of the environment, such as the number of people (80.4%) and the level of light or noise (67.8%); suggesting a need for advocacy to increase the range of sensory friendly experiences. However, respondents also reported social barriers, such as being worried about how people will respond to them (40.5%) and needing support to go to these places (35.8%) (see Figure 7).

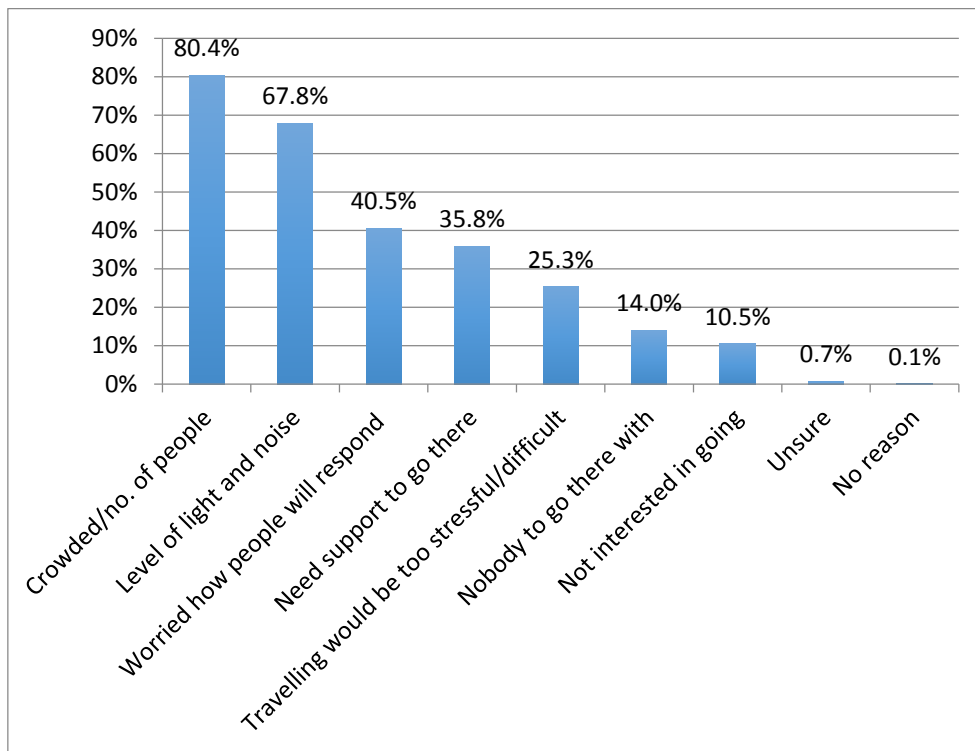


Figure 7: Reasons for avoiding community spaces

Responses from autistic people

As with the broader sample, when those responding on behalf of themselves were asked how often they are described in various ways by others, there was a mix of positive and negative descriptions. More than half of the 57 respondents who identified as autistic and responded in relation to their own experiences reported that they are often or sometimes described as anxious (77%), shy (70%) or weird (68%). However, 84% reported that they are often or sometimes described as clever, 82% as friendly and 79% as focused.

Among this group of respondents, 70% (n=40) reported that they feel socially isolated, 47% that they have lost friends because of the way those friends have responded to their autism, 42% that they sometimes feel unable to leave the house because they are worried about people behaving negatively towards them because of their autism, 37% that they have lost a job due to their autism, and 26% that there are members of their own family who they no longer speak to because of the way they have responded to their autism.

A substantial proportion of this group reported that people often or sometimes stare at them (61%), actively avoid them or get out of their way (49%), tut, shake their heads or make disapproving noises (37%), get aggressive with them (26%), and mock or taunt them (25%). On a more positive note, 49% reported that people often or sometimes leave them alone to clear their head and 37% that people often or sometimes ask them if they are ok or if they can help.

While statistical comparisons between this group and the remainder of the sample must be interpreted with caution due to the small cell sizes, it is interesting to note that those who responded in relation to their own experiences were more likely to state that they were described as focused, shy, or weird; and less likely to state that they were described as aggressive. They were also more likely than carers to report feeling socially isolated and to have lost both friends and jobs due to (the way others respond to) their autism. They were less likely than carers to report that people stare at them, actively avoid them or get out of their way, tut, shake their heads or make disapproving noises. They were more likely to report that people ask them if they are ok or if they can help, but also that people get aggressive with them.

There were a number of differences between autistic people and carers of autistic people in their experiences of both positive and negative interactions with other people. It is likely that many of these differences are age-related (i.e., all autistic respondents were adults but the majority of carers were caring for a child or adolescent); such as autistic people being less likely to report descriptors such as aggressive and naughty and less likely to report people staring at them or showing other signs of disapproval. However, other differences likely reflect the very real differences between being an autistic person and being a carer or family member, such as feeling socially isolated and losing friends.

There were few differences between autistic people and carers of autistic people in reporting that they avoided going to places in the community and the reasons for this avoidance. Those responding on behalf of themselves were more likely to report avoiding going to a pub/bar (61%) and less likely to report avoiding going to a cinema (23%); and those who avoided such experiences were more likely than carers to report that their reasons for avoidance were nobody to go with (54%) and not interested in going (30%). Again, this is likely to be a combination of the age-related differences and the difference between being an autistic person and being a carer or family member.

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.²

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

² 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