JIDR Journal of Intellectual Disability Research
Published on behalf of mencap and in association with IASSID

Journal of Intellectual Disability Research doi: 10.1111/jir.12953

VOLUME 66 PART 7 pp 655–666 JULY 2022

Social and community inclusion outcomes for adults with autism with and without intellectual disability in Australia

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Abstract

Background Research suggests that adults with autism tend to have *poor* outcomes. Outcomes have mostly been defined using summary outcome ratings, with less focus on specific outcomes such as employment, living situation, social satisfaction, loneliness, and friendships. This study aimed to explore social and community outcomes, including employment, education, living arrangements, friendships, and social satisfaction, for autistic adults with and without intellectual disability.

Method Eighty-four adults with autism (mean age 34.2 years, SD = 4.5; 67% with co-occurring intellectual disability), recruited as children and adolescents, participated in the current study. Adult social and community inclusion outcomes were explored through interview and questionnaire, both parent/carer-report and self-report.

Results Participants predominantly lived with family or in supported accommodation, did not pursue higher education, and mostly participated in day activity programmes. Most had limited friendships as reported by parents/carers; however, self-report data (n = 28) indicated that adults were largely satisfied with their social relationships. Overall outcome was *poor* for 57%, and *good/very good* for 34%. Adults with intellectual disability generally had poorer outcomes.

Conclusion Autistic adults encountered numerous difficulties in leading an independent life. Adults with co-occurring intellectual disability were most likely to experience difficulties; however, outcomes ranged from *poor* to *very good* for adults without intellectual disability. Discrepancies in parent/carer-report and self-reported experiences of friendships highlight the need to ensure individual experiences are captured in addition to parent/carer-report. Appropriate resources and programmes are crucial for adults with autism to support them to have the choice to live independently.

Keywords adult, autism, community inclusion, outcome, social inclusion

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Introduction

Research on outcomes in adulthood for individuals with Autism Spectrum Disorder[1] (hereafter referred to as autism) has predominantly used summary ratings (*good*, *fair*, *poor*), comprised of a range of variables, including independent living, employment, and friendships, to describe outcome in adulthood. Widely used criteria (Howlin *et al.* 2004) describe a *Very Good*/*Good* outcome as achieving a high level of independence, having some friends, and a job, and a *Poor*/*Very Poor* outcome requiring specialist accommodation and/or a high level of support, having little to no autonomy, and no friendships. Two systematic reviews (Mason *et al.* 2021; Steinhausen *et al.* 2016) concluded that autistic adults generally have *poor* outcomes. Both reviews found that nearly half (48–49%) achieved *poor*/*very poor* outcomes, 27–31% achieved a *fair* outcome, and only 20% achieved a *good* outcome.

There is, however, considerable variation in outcome research findings that cannot be explained simply in terms of cohort age or sample selection. In some studies, no participants achieved a *good* outcome (Billstedt *et al.* 2005; Cedurland *et al.* 2008); others reported over 40% achieving a *good* outcome (Pickles *et al.* 2020). The impact of co-occurring intellectual disability is important. The Billstedt and Cedurland studies included participants with co-occurring intellectual disability, while the Pickles study did not. In their meta-analysis, Mason *et al.* (2021) found that higher IQ in adulthood was positively correlated with *good* outcomes and negatively with *poor* outcomes; however, IQ only significantly predicted *poor* outcomes (it did not predict *good* or *fair* outcomes), and childhood IQ did not predict outcome when controlling for other variables. Despite evidence that degree of intellectual disability impacts outcomes in adulthood, it is clear this is not the sole factor, and the impact of other variables, such as age, sex, socioeconomic status, autism symptom severity, and mental health (Howlin and Magiati 2017), warrants further exploration.

Howlin and Magiati (2017) highlighted that while there is some disagreement between outcome studies, it is clear that outcomes for adults with autism, in terms of independent living, employment, and relationships, are poorer than those of same age typically developing peers as well as those with other developmental disabilities. Few adults live independently, with most continuing to live with family or in supported accommodation, regardless of intellectual level (Billstedt *et al.* 2005; Eaves and Ho 2008; Howlin *et al.* 2013; Gray *et al.* 2014), and unemployment, or underemployment, is high (Kamio *et al.* 2012; Howlin *et al.* 2013). These outcomes, as well as overall outcome ratings, are established for young adults in particular. However, outcomes in middle and later adulthood are less well understood, particularly for people with autism and co-occurring intellectual disability.

While current research is important for exploring outcomes, as well as being a useful way to compare various populations, measures of outcome often fail to capture the individual experiences of autistic adults and their wellbeing and social satisfaction. The literature suggests that autistic adults have limited friendships (Howlin *et al.* 2013) and social participation (Orsmond *et al.* 2013), and often experience greater loneliness than typically developing peers (Mazurek 2014). Despite this, some adults are satisfied with more limited social interaction or seeing friends only occasionally (Ee *et al.* 2019). Although friendship is a key variable used in calculating adult overall outcome ratings, it is most often rated by parents or caregivers, leaving a gap in our understanding of how autistic adults perceive their own friendships and their satisfaction with social participation.

The current study of a population of adults with autism in Australia aimed to (1) determine a summary rating of overall outcome as per criteria defined by Howlin *et al.* (2004); (2) explore community inclusion outcomes (living, education, and daytime activity) and determine whether these outcomes differ from the general Australian population; (3) explore social inclusion outcomes (friendships and social satisfaction); (4) compare overall, community, and social outcomes for those with and without intellectual disability.

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[1] Throughout this paper, we use a combination of ‘person-first’ (e.g. adult with autism) and ‘identity-first’ (e.g. autistic adult) language to reflect the differing views on terminology within the autism community (see, e.g. Kenny *et al.* 2015).

Method

Sample

Participants were recruited for the Australian Child to Adult Development (ACAD) Study from Victoria and New South Wales, Australia in 1991 through health and education agencies (Einfeld and Tonge 1996a; Einfeld and Tonge 1996b; Gray *et al.* 2012). Data were collected at six time points: Time 1 (1991–1993), Time 2 (1995–1996), Time 3 (1999), Time 4 (2002–2003), Time 5 (2007–2009), and Time 6 (2016–2019).

At entry to the study, participants were likely to be representative of all children in the community who had an autism diagnosis and were receiving services (Tonge and Einfeld 2003). All participants met criteria for DSM-III-R Autistic Disorder (American Psychiatric Association [APA] 1987) following assessment by a multidisciplinary team at study entry. Participants were reassessed at Time 2 to confirm diagnosis against DSM-IV criteria (APA 1994; Gray *et al.* 2012). At Time 6 the Autism Diagnostic Interview-Revised (ADI-R; Rutter *et al.* 2003) was completed, and current Autism Spectrum Disorder diagnoses were reviewed for all participants against the DSM-5 criteria (APA 2013). All participants met current DSM-5 criteria for Autism Spectrum Disorder.

Measures

Degree of intellectual disability

At Time 1 (age 2.8–19.8 years), participants were categorised into four groups according to their degree of intellectual disability: no intellectual disability, mild, moderate, or severe (see Gray *et al.* 2014). At Time 6, current degree of intellectual disability was reviewed and categorised following DSM-IV (APA 1994) and DSM-5 (APA 2013) criteria by consensus diagnosis between two authors (L.A.C and K.M.G). Time 6 categorisation was based on a range of assessments, including cognitive (Wechsler Abbreviated Scale of Intelligence, 2nd edition; Wechsler 2011), adaptive functioning (Adaptive Behaviour Assessment System-3; Harrison P and Oakland 2015), and daily living skills (Index of Social Competence; McConkey and Walsh 1982).

Overall outcome rating

An overall adult outcome rating was calculated for each participant based on the criteria of Howlin *et al.* (2004) in which scores are assigned to current living status, employment, and friendships. Information collected via interviews (including the ADI-R) and all study questionnaires was used to inform ratings across each of these three areas. Ratings were determined by consensus discussion between two authors (L.A.C and K.M.G). Scores for living, employment, and friendships were summed to calculate an overall outcome score. The total score provides an overall outcome rating (*Very Good*, *Good*, *Fair*, *Poor* or *Very Poor*).

Community inclusion

Information on current living arrangements, highest level of educational attainment, and current daytime activities was collected using a parent/carer and/or self-report questionnaire. Living arrangements were grouped into three categories: *independent* (living alone, with a partner, or with friends), *with family* (parents, sibling, or other family member), and *supported accommodation* (group disability accommodation). Educational attainment was categorised according to the Australian Standard Classification of Education (ASCED; Australian Bureau of Statistics 2001); Year 10 or below, Year 11, Year 12, Certificate, Diploma, Bachelor, Postgraduate. Attendance at mainstream or special schools was noted. Current daytime activities included volunteer work, organised day activity programme, paid employment with/without additional support, sheltered workshop/disability enterprise, education course, and no organised daytime activity. Total number of hours engaged in daytime activities per week was also recorded.

Social inclusion

Friendship was assessed using the current rating of a single item (number 65) from the ADI-R (Rutter *et al.* 2003), completed with a parent/caregiver. The item on friendships assesses the quality and quantity of the participants friendships, providing a score from 0 (one or more appropriate relationships) to 3 (no peer relationships).

Loneliness and social dissatisfaction were assessed using the Modified Worker Loneliness Questionnaire (Chadsey-Rusch *et al.* 1992), a self-report measure designed to assess aloneness and social dissatisfaction in individuals with intellectual disability. It is a 12-item questionnaire with a 3-point response scale. It consists of two domains: Aloneness and Social Dissatisfaction. Scores for each domain range from 0 to 12, with higher scores indicating higher levels of loneliness or social dissatisfaction.

Australian population community inclusion

Community inclusion data for the Australian general population was obtained from the 2016 Australian Census (Australian Bureau of Statistics 2016). TableBuilder software within the ABS system was used to extract relevant data for the population aged 25–44 years – the group closest in age to the study sample. Current living arrangement data were divided into *independent* (those who indicated they lived alone, with a partner, or in a group household), and *with family* (those who indicated they were the non-dependent child of the household reference person). Highest level of educational attainment was categorised following ASCED (Australian Bureau of Statistics 2001). Current employment was divided into *working in the labour force* or *not in the labour force*.

Procedure

All participants were invited to participate at each time point and were sent a questionnaire to be completed by a parent or carer, and, at Time 6, the adult themselves where possible. At Time 6, interviews were also conducted with parents/carers. Ethics approval was obtained from Monash University Human Research Ethics Committee (CF15/1045-2015000486). Informed consent was provided by parents/carers, and where possible, the adult themselves.

Statistical analyses

Descriptive data (M, SD) and frequencies (n, %) were calculated for each variable. Fisher's exact tests and t-tests were used to evaluate differences in outcome based on presence or absence of intellectual disability. Significance was set at $P < 0.05$.

Results

At Time 6, 84 participants completed the questionnaire (response rate of 75% excluding the seven participants who have died since Time 1). Participants were aged between 26.8 and 44.2 years (M = 34.2, SD = 4.5), and 81% (n = 68) were male. (See Table 1 for participant demographic details at Times 1 and 6.). There was no significant difference between those who participated at Time 6 and those who did not in terms of Time 1 degree of intellectual disability, $\chi^2(4, n = 119) = .05$, $P = 0.97$.

Overall outcome rating in adulthood (Time 6)

Overall outcome scores (Howlin *et al.* 2004) were calculated for all participants except one (this individual was in prison at the time of data collection, and comparative scores for living status and employment could not be determined). Table 2 shows frequencies for each outcome category for the sample overall, as well as the breakdown for those with and without intellectual disability. The majority of the sample achieved a *Poor* or *Very Poor* outcome (58% n = 48), with less than 20% (n = 16) achieving a *Very Good* outcome. There was a significant difference between participants with and without an intellectual disability (Fisher's exact test, $P < 0.001$); individuals without intellectual disability were more likely to have a *Very Good* or *Good* outcome (74%, n = 20) and those with intellectual disability were more likely to have a *Poor* or *Very Poor* outcome (80%, n = 45).

Table 1 Sample demographics

	Time 1 ***n* = 119**	**Time 6** ***n* = 84**
Male	98 (82%)	68 (81%)
Mean age (SD)	8.7 (4.3)	34.2 (4.5)
Age range (years)	2.8–19.8	26.8–44.2
Degree of intellectual disability		
Average	11 (9%)	14 (17%)
Borderline	16 (13%)	13 (15%)
Mild	29 (24%)	13 (15%)
Moderate	46 (39%)	21 (25%)
Severe/profound	17 (14%)	23 (27%)

Table 2 Overall outcome rating Time 6

	Total sample (*n* = 83) *n* (%)	Intellectual disability			
		Average/borderline(*n* = 27) *n* (%)	Mild (*n* = 12) *n* (%)	Moderate (*n* = 21) *n* (%)	Severe/profound (*n* = 23) *n* (%)
Very Good	16 (19%)	13 (48%)	3 (25%)	0 (0%)	0 (0%)
Good	12 (15%)	7 (26%)	4 (33%)	1 (5%)	0 (0%)
Fair	7 (8%)	4 (15%)	3 (25%)	0 (0%)	0 (0%)
Poor	47 (57%)	3 (11%)	2 (17%)	20 (95%)	22 (96%)
Very Poor	1 (1%)	0 (0%)	0 (0%)	0 (0%)	1 (4%)

Note: Overall outcome rating not calculated for *n* = 1 participant.

Community inclusion in adulthood (Time 6)

Frequencies of current living arrangements, highest level of education, and employment are presented in Table 3.

Current living arrangements

Most participants continued to live with family (42%, *n* = 35) or in supported group accommodation (39%, *n* = 33), with only 19% (*n* = 16) living independently. Two participants who lived with family were living relatively independently in a separate unit on their parent's property and many had a high degree of autonomy. Additional paid support in the home was limited for participants living independently; only three participants received additional support, from 3 to 12 h per week. Five participants living with family received between 1 and 20 h per week of support. Most participants living in supported accommodation received full time care; however, two participants were living in more independent supported housing and received support for self-care activities for 3–4 h per day. The majority of those living in supported accommodation had moderate to severe/profound intellectual disability (88%, *n* = 29), while those living independently were predominantly without intellectual disability (81%, *n* = 13) (Figure 1a).

Table 3 Community inclusion outcomes (total *n* = 84)

	Time 6 *n* (%)
Living arrangements	
Supported group accommodation	33 (39%)
With family	35 (41%)
Independently	16 (19%)
Highest level of education	
Secondary school	
Special school	55 (65%)
Mainstream school (Year 10 or below)	4 (5%)
Mainstream school (Year 11 or 12)	8 (10%)
Certificate/Diploma	11[†] (13%)
Bachelor's degree	5[‡] (6%)
Postgraduate degree	1 (1%)
Current daytime activity[§]	
Organised day activity (day programme)	47 (56%)
Employed in paid job *without support*	20 (24%)
Employed in paid job *with support*	2 (2%)
Sheltered workshop or disability enterprise	4 (5%)
Volunteer work	2 (2%)
Education course	4 (5%)
No activity	9 (11%)

[†] *n* = 3 currently enrolled.

[‡] *n* = 1 currently enrolled.

[§] Total greater than 100% as some participants involved in more than one daytime activity.

Highest level of education

Most participants' highest level of education was secondary school (80%, *n* = 67), with 82% (*n* = 55) of these in a special school. Some participants (13%, *n* = 11) had pursued further education post-secondary school, completing training certificates and diplomas. Four participants (5%) were still enrolled in their course at the time of data collection. Two of these

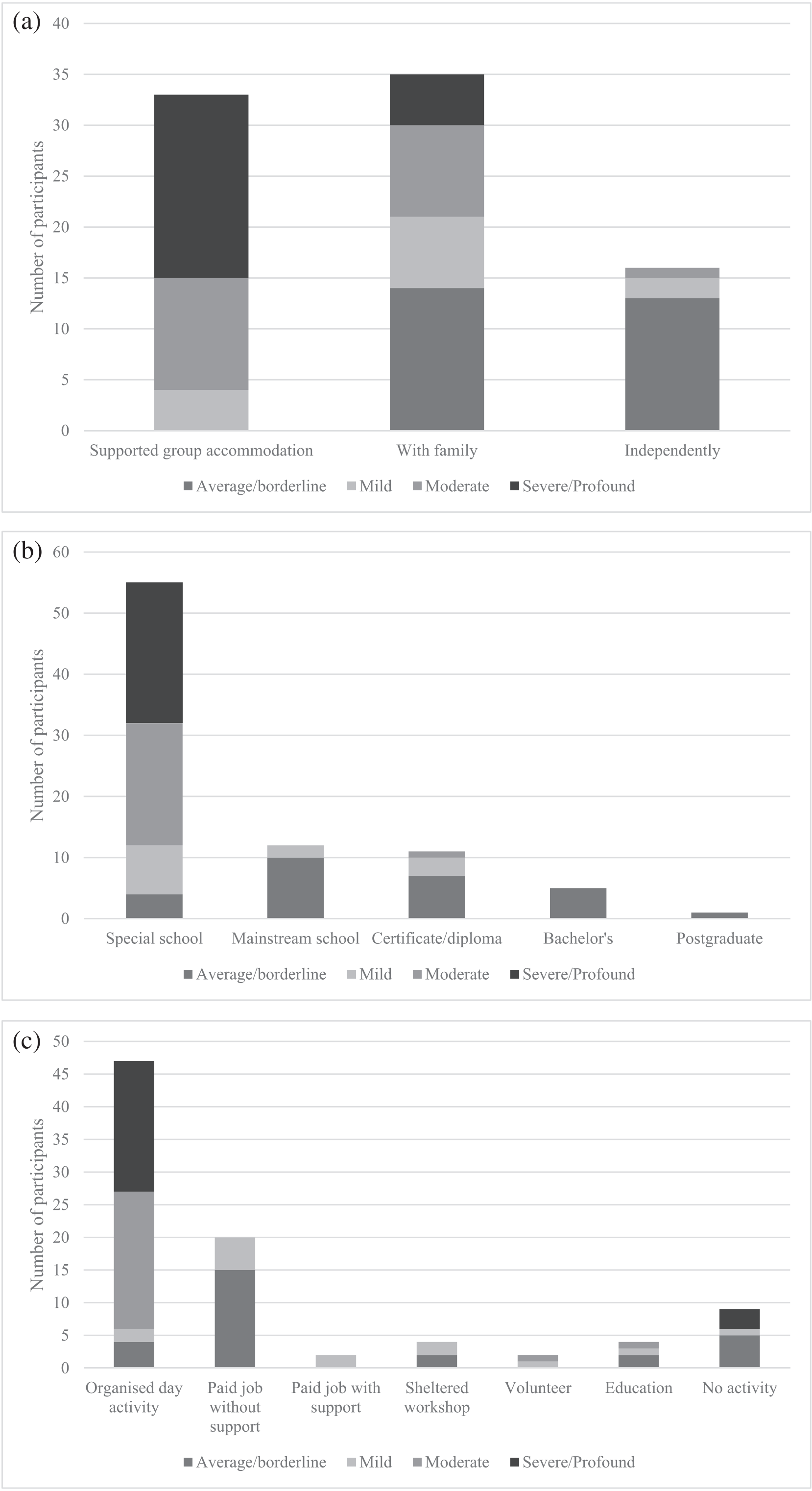

Figure 1. (a) Current living arrangements by degree of intellectual disability. (b) Highest level of education by degree of intellectual disability. (c) Current daytime activity by degree of intellectual disability.

courses were designed for adults with intellectual and other disabilities, focussing on workplace and independent living skills. Six participants (7%) had completed university degrees (*n* = 5 bachelor's degrees, *n* = 1 master's degree), including one participant currently completing a bachelor's degree. Only one participant with moderate intellectual disability completed post-secondary education; no participants who completed university degrees had intellectual disability (Figure 1b).

Current daytime activity

Most participants (56%, *n* = 47) were attending organised day programmes for people with disability. Day programmes involved activities such as group outings to local cafes and activity centres, craft, and gardening activities, with support from paid professional support workers. While most participants (83%, *n* = 39) attended day programmes for 20 h or more per week, 13% (*n* = 6) attended 10–19 h, and 2 participants (4%) attended for fewer than 10 h. One participant attended a day programme in addition to undertaking an education course. Four participants (5%) were employed in sheltered workshops or disability enterprises. Participation in these programmes ranged from 14 to 26 h per week. Participants attending organised day programmes mostly had moderate to severe/profound intellectual disabilities (72%, *n* = 41). Some (*n* = 10) participants with no or mild intellectual disability were also attending disability-specific activities (Figure 1c).

Twenty-two participants (26%) were employed in the mainstream workforce. Two participants worked in permanent positions and received additional support in the workplace. A further 20 participants (24%) were employed in the mainstream workforce without any additional support. Hours of work varied from 2 to 42 h per week. Of the 20 participants employed without support, nine (45%) worked full time hours (38–42 h per week), four (20%) worked 20–30 h per week, two (10%) worked 10–19 h per week, and five (25%) worked fewer than 10 h per week. All of those in paid work were participants with mild or no intellectual disability (Figure 1c).

Two participants volunteered for a few hours per week in addition to their organised day programme. Twelve participants (14%) were unemployed. Three of these participants were, however, undertaking education courses, with the remaining nine participants (11%) not involved in any daytime activity. Five participants (55%) who had no daytime activity did not have intellectual disability (Figure 1c). Of those who had no regular daytime activity, time was spent mostly online (*n* = 2), working on projects (*n* = 1), searching for work (*n* = 1), and caring for elderly relatives (*n* = 1). Four participants had no daily activities.

Comparison with Australian population

Data on current living arrangements and current employment status were extracted for a total of 6 513 390 people aged between 25 and 44 years living in Australia. Figure 2a–c shows comparisons between the data from the current study and the Australian general population. When comparing living arrangements (Figure 2a), a minority of adults in the Australian population continued to live with their families, compared with nearly half of the autistic sample. Conversely, most of the Australian population lived independently, compared with less than a quarter of the current sample. There were no general Australian population comparison data available for living in supported accommodation. Adults with autism participated in the labour force at a considerably lower rate than adults in the general Australian population (Figure 2b). Few adults with autism participated in post-secondary education (certificates, diplomas, or university degrees), compared with nearly two-thirds of the general Australian population who had completed post-secondary education (Figure 2c).

Social inclusion in adulthood (Time 6)

Current friendship information was available from the ADI-R for 75 participants. Twelve participants (16%) had one or more friendships with peers involving sharing of personal interests and activities that include reciprocity and mutual responsiveness. Eight participants (11%) had one or more relationships with peers, although limited in terms of shared interests or reciprocity. Fifteen (20%) had some limited relationships with others, and over half (53%, *n* = 40) had no peer relationships.

The Modified Worker Loneliness Questionnaire was completed as a self-report measure by 28 participants (33% of the sample). Most participants

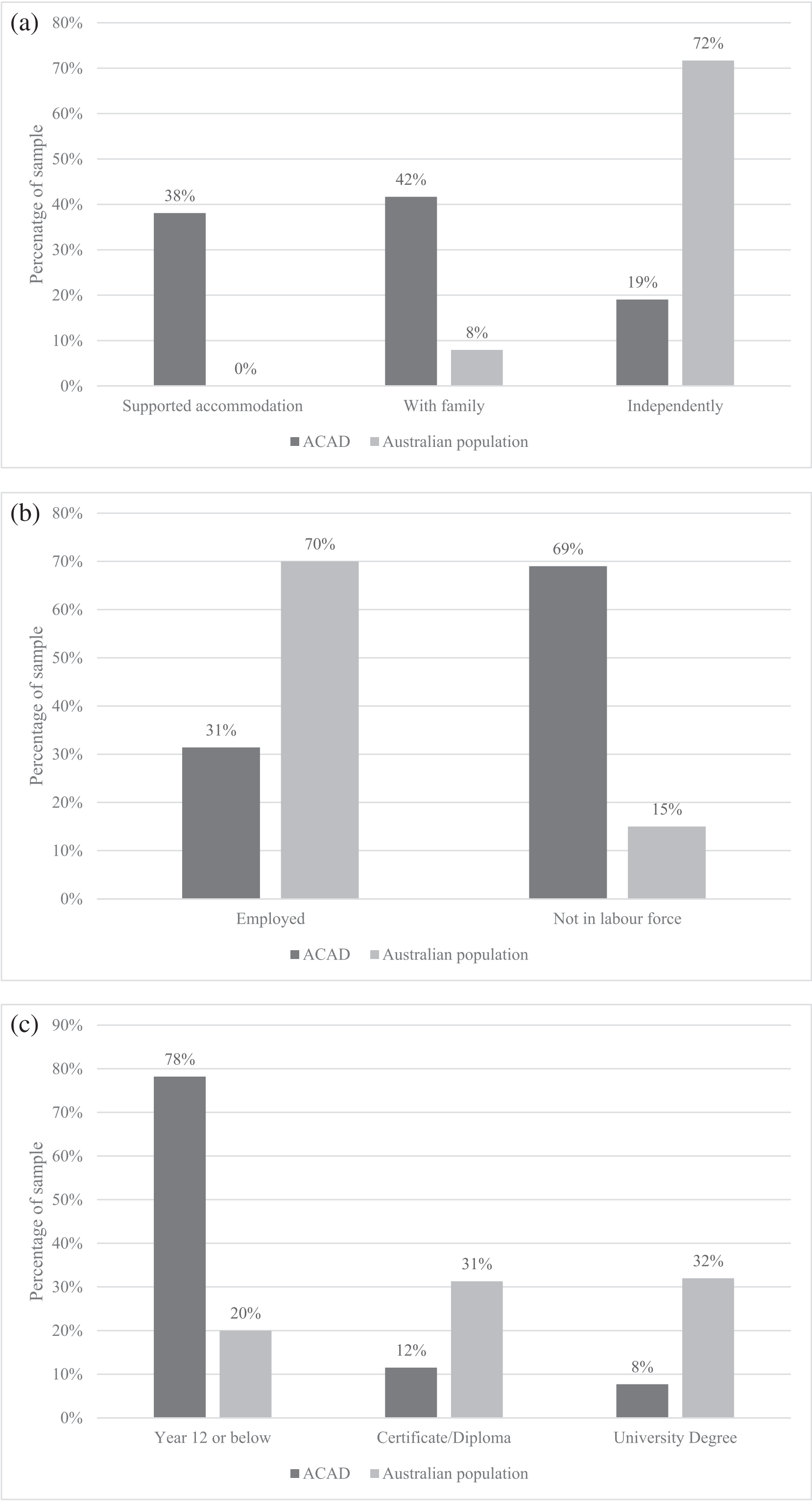

Figure 2. (a) Comparison of living arrangements between ACAD autism sample and Australian general population. (b) Comparison of engagement in the labour force between ACAD autism sample and Australian general population. (c) Comparison of highest educational attainment between ACAD autism sample and Australian general population.

(71%, *n* = 20) who completed this questionnaire did not have an intellectual disability. Scores for the Aloneness subscale ranged from 0 to 12 (M = 4.0, SD = 3.0), and for the Social Dissatisfaction subscale from 0 to 7 (M = 2.6, SD = 2.3). Nearly all participants (86%, *n* = 24) responded 'yes' to 'I have friends', with 54% (*n* = 15) responding 'yes' to 'I have lots of friends'.

Discussion

This study considers a range of important outcomes for autistic adults in Australia. Findings suggest that adults with autism experience a number of difficulties with both community and social inclusion.

Overall outcomes

The overall social functioning outcomes of this Australian sample were comparable to those of Howlin *et al.* (2004) (United Kingdom) and Farley *et al.* (2017) (USA). Similar rates of *Poor/Very Poor* outcomes were seen across all three samples (46–58%). Slightly more participants in the Australian sample were considered to have achieved a *Good/Very Good* outcome (33.8%) when compared with the Howlin and Farley samples (22% and 20%, respectively), with far fewer participants in the Australian sample achieving a *Fair* outcome (8.4%). This could be due to scores particularly in the employment variable, being more likely to be at the extreme ends of the scoring metric described by Howlin *et al.* (2004). Most Australian participants were either employed without support (24%) or involved in an organised day programme/no activity (67%), scoring *0* or *3* on this factor, respectively. Few (2%) were involved in any kind of supported employment (i.e. a score of *1* or *2*).

Overall outcome scores have been widely used throughout the autism adult outcome literature to date, providing a summary description of what adulthood looks like for people with autism. However, overall scores allow little room for nuance, potentially providing an overly simplistic view of adult outcomes and little information to inform support needs. For example, an individual may achieve an employment score of *0*, indicating that they are currently engaged in regular employment, but this score may not reflect the fact that the individual is only working for 1 or 2 h per week. Further, scores related to independent living may be biased; while some individuals who are living with family may be capable of living independently, financial, or other stressors may prevent them from doing so. These are important areas for further exploration in order to identify the barriers and therefore supports needed, to allow individuals to have a choice in how they live.

Community inclusion

Adults with autism in Australia continue to be disadvantaged in terms of key aspects of independent living (Gray *et al.* 2014), particularly when compared with the general Australian population. They were more likely to be living at home with family, not pursue post-secondary education, and be unemployed than the general population. The impact of co-occurring intellectual disability on community inclusion outcomes was clear; adults with moderate to severe/profound intellectual disability were over-represented in supported living, participation in unpaid daytime activities, such as day activity programmes, and lower levels of education achieved.

Higher rates of independent living, and lower rates of living in supported group accommodation, were reported in this Australian sample compared with others in the USA, UK, and Sweden (Billstedt *et al.* 2005; Eaves and Ho 2008; Howlin *et al.* 2013; Farley *et al.* 2017). The influence of intellectual disability on living situation was comparable to that reported by Lord *et al.* (2020); participants without intellectual disability were more likely to be living independently or with family, and those with intellectual disability predominantly living in supported group homes or with family. For adults living independently or with family, few were in receipt of additional paid support.

Participation in the labour force was limited, particularly when compared with the general Australian population. Although a quarter of participants (26%), were involved in the mainstream workforce, hours of work per week were limited. Similar rates of employment are reported in other studies (Howlin *et al.* 2013; Farley *et al.* 2017). Further, while the majority (56%) of the current sample was involved in organised day programmes, a disturbing number of participants (11%, *n* = 9) had no regular daytime activity at all. This figure was, however, considerably lower than the rates of unemployment/no activity reported in other studies, with as many as 20–55% of adults unemployed (Howlin *et al.* 2013; Farley *et al.* 2017). Of particular concern is the fact that most (55%) participants without a daytime activity did not have an intellectual disability, highlighting the lack of availability of suitable resources, supports and activities for autistic adults, including those without intellectual disability.

It is encouraging to see that there were a number of adults who were living and working independently. Future research should continue to explore the factors that support adults to live and work more independently and examine how these elements can be incorporated into interventions and programmes to assist all individuals to achieve their goals. Facilitation of community engagement and participation in recreational activities should also be considered in future research.

Social inclusion

When considering parent/carer-report, three-quarters of participants were considered to have either no peer relationships or limited peer relationships, and 16% reported having close friendships. Similar rates were identified by Howlin *et al.* (2013), also using parent-report, in a population of adults with autism without intellectual disability. However, among individuals who were able to self-report on the loneliness questionnaire in the current study, nearly all (86%) reported having friends. These higher rates of friendships compared with parent/carer report are similar to those in other self-report studies. For example, Mazurek (2014) noted that 60% of participants reported having a close or best friend, although they do not indicate whether any participants had intellectual disability. Similar discrepancies in proxy- and self-report information on friendships have been reported for children and adolescents with autism, with some studies indicating a greater number of friendships reported by the child themselves when compared with parent reports (Petrina *et al.* 2014), highlighting the importance of gathering information from multiple sources to understand how adults experience friendships and how their views may differ from those of their parents/carers. Future research should further explore the experiences of friendships for autistic adults and the impact on their quality of life and mental health.

The self-report questionnaires provided some important insights into the experiences of a subset of individuals ($n = 28$, 33%). Respondents reported being largely satisfied with their social environment and friendships. While the loneliness data is limited, further investigation of feelings of social satisfaction and loneliness for autistic adults is warranted given the disparity between parent/carer reported friendships and self-reported friendships and social satisfaction. Future research also needs to explore how adults experience loneliness and how social satisfaction can be improved, ensuring information is gained directly from autistic adults themselves. There is a need for further development and evaluation of self-report measures of social satisfaction and loneliness, particularly for people intellectual disability, so that they can report directly on their experiences.

Limitations

The cohort effect in this population is important to consider. As participants were recruited in the early 1990's when they were children and adolescents, the results reported are likely to reflect identification and diagnostic practices at that time. There have also been considerable changes in supports and services provided for individuals with autism, impacting on each individual's experience and outcome. The results therefore may not be generalisable to children diagnosed since this study began. However, this study does point to a number of areas where adults with autism may experience additional challenges and barriers compared with the general Australian population, irrespective of when they received an autism diagnosis. Further, while there was a decline in sample size from Time 1 ($n = 119$) to Time 6 ($n = 84$), there was no significant difference in degree of intellectual disability between Time 6 participants and non-participants.

Clinical assessment measures, such as the ADI-R (Rutter *et al.* 2003) and ADOS (Lord *et al.* 2012), were not available when the study commenced. However, autism diagnoses were made based on clinical best practice at the time, using the current DSM diagnostic criteria. Diagnoses were reviewed and confirmed for all participants according to the

DSM-IV and DSM-5 diagnostic criteria during the course of the study.

The number of participants who were able to self-report was limited. Although the self-report questionnaires, particularly in relation to friendships and loneliness, provided important findings, future research would benefit from exploring the experience of adults with autism in a larger sample. This will require the adaptation or development of measures to support participation of more people with autism.

Conclusion

Adults with autism and co-occurring moderate to severe/profound intellectual disability are at greater risk for poor outcomes in adulthood, characterised by ongoing requirement of care and support, limited engagement in employment, and restricted friendships. However, participants with no or mild intellectual disability also experienced outcomes ranging from *poor* to *very good*, indicating that intellectual ability is not the sole factor determining outcome in adulthood. Further exploration of other factors impacting outcome should be a focus of future research. Modifiable factors, such as functional skills, are of particular importance as these can be targeted in interventions aimed at improving skills to further support adults. The higher rates of *good* outcomes, including independent living, seen in the current study compared with previous studies is encouraging. Nevertheless, the majority of participants still experience considerable difficulties, highlighting the need for more appropriate and effective resources to support autistic adults to live more independently and participate in their community as they desire.

Acknowledgements

This study was supported by the Australian Research Council, grant DP150104369 awarded to Kylie M. Gray, Bruce J. Tonge, Stewart L. Einfeld, Patricia Howlin, and Roger J. Stancliffe. Lauren A. Cameron was supported by an Australian Government Research Training Program (RTP) Scholarship. The authors would like to thank the families who have granted us the privilege of being part of their lives.

Open access publishing facilitated by Monash University, as part of the Wiley - Monash University agreement via the Council of Australian University Librarians.

Source of funding

This study was supported by the Australian Research Council, grant DP150104369 awarded to Kylie M. Gray, Bruce J. Tonge, Stewart L. Einfeld, Patricia Howlin, and Roger J. Stancliffe. Lauren A. Cameron was supported by an Australian Government Research Training Program (RTP) Scholarship.

Conflict of interest

The authors have no conflict of interests to declare.

Data availability statement

The data that support the findings of this study are available on reasonable request from the corresponding author. The data are not publicly available due to privacy and ethical restrictions.

References

American Psychiatric Association (1987) *Diagnostic and Statistical Manual for Mental Disorders*. American Psychiatric Association, Washington, DC.

American Psychiatric Association (1994) *Diagnostic and Statistical Manual for Mental Disorders*. American Psychiatric Association, Washington, DC.

American Psychiatric Association (2013) *Diagnostic and Statistical Manual for Mental Disorders*. American Psychiatric Association, Washington, DC.

Australian Bureau of Statistics (2001) *Australian Standard Classification of Education (ASCED)* [Online]. Australian Bureau of Statistics. Available at: https://www.abs.gov.au/ausstats/abs@.nsf/0/F501C031BD9AC9C5CA256AAF001FCA33?opendocument (retrieved 23 September 2020).

Australian Bureau of Statistics (2016) *Census of Population and Housing* [Online]. Available at: https://www.abs.gov.au/websitedbs/censushome.nsf/home/2016 (retrieved 23 September 2020).

Billstedt E., Gillberg C. & Gillberg C. (2005) Autism after adolescence: Population-based 13- to 22-year follow-up study of 120 individuals with autism diagnosed in childhood. *Journal of Autism and Developmental Disorders* **35**, 351–60.

Cedurland M., Hagberg B., Billstedt E., Gillberg I. C. & Gillberg C. (2008) Asperger syndrome and autism: A comparative longitudinal follow-up study more than

5 years after original diagnosis. *Journal of Autism and Developmental Disorders* **38**, 72–85.

Chadsey-Rusch J., DeStefano L., O'Reilly M., Gonzalez P. & Collet-Klingenberg L. (1992) Assessing the loneliness of workers with mental retardation. *Mental Retardation* **30**, 85–92.

Eaves C. & Ho H. H. (2008) Young adult outcome of autism spectrum disorders. *Journal of Autism and Developmental Disorders* **38**, 739–47.

Ee D., Hwang Y. I., Reppermund S., Srasuebkul P., Troller J. N., Foley K. *et al.* (2019) Loneliness in adults on the autism spectrum. *Autism in Adulthood* **1**, 182–93.

Einfeld S. & Tonge B. J. (1996a) Population prevalence of psychopathology in children and adolescents with intellectual disability: I rationale and methods. *Journal of Intellectual Disability Research* **40**, 91–8.

Einfeld S. & Tonge B. J. (1996b) Population prevalence of psychopathology in children and adolescents with intellectual disability: II epidemiological findings. *Journal of Intellectual Disability Research* **40**, 99–109.

Farley A., Cottle K. J., Bilder D., Viskochil J., Coon H. & McMahon W. M. (2017) Mid-life social outcomes for a population-based sample of adults with ASD. *Autism Research* **11**, 142–52.

Gray M., Keating C. M., Taffe J., Brereton A. V., Einfeld S. & Tonge B. J. (2012) Trajectory of behavior and emotional problems in autism. *American Journal of Intellectual and Developmental Disabilities* **117**, 121–33.

Gray M., Keating C. M., Taffe J. R., Brereton A. V., Einfeld S. L., Reardon T. C. *et al.* (2014) Adult outcomes in autism: Community inclusion and living skills. *Journal of Autism and Developmental Disorders* **44**, 3006–15.

Harrison P L. & Oakland T. (2015) *Adaptive Behavior Assessment System*. Western Psychological Services, Torrance, CA.

Howlin P. & Magiati I. (2017) Autism spectrum disorder: Outcomes in adulthood. *Current Opinion in Psychiatry* **30**, 69–76.

Howlin P., Goode S., Hutton J. & Rutter M. (2004) Adult outcome for children with autism. *Journal of Child Psychology and Psychiatry* **45**, 212–29.

Howlin P., Moss P., Savage S. & Rutter M. (2013) Social outcomes in mid- to later adulthood among individuals diagnosed with autism and average nonverbal IQ as children. *Journal of the American Academy of Child and Adolescent Psychiatry* **52**, 572–81.

Kamio Y., Inada N. & Koyama T. (2012) A nationwide survey on quality of life and associated factors of adults with high-functioning autism spectrum disorders. *Autism* **17**, 15–26.

Kenny L., Hattersley C., Molins B., Buckley C., Povey C. & Pellicano E. (2015) Which terms should be used to describe autism? Perspectives from the UK community. *Autism: The International Journal of Research and Practice* **20**, 442–62.

Lord C., McCauley J. B., Pepa L. A., Huerta M. & Pickles A. (2020) Work, living, and the pursuit of happiness: Vocational and psychosocial outcomes for young adults with autism. *Autism* **24**, 1691–703.

Lord C., Rutter M., DiLavore P. C., Risi S., Gotham K. & Bishop S. (2012) *Autism Diagnostic Observation Schedule*. Western Psychological Services, Torrance, CA.

Mason D., Capp S. J., Stewart G. R., Kempton M. J., Glaser K., Howlin P. *et al.* (2021) A meta-analysis of outcomes studies of autistic adults: Quantifying effect size, quality, and meta-regression. *Journal of Autism and Developmental Disorders*, **51**, 3165–79.

Mazurek O. (2014) Loneliness, friendship, and well-being in adults with autism spectrum disorder. *Autism* **18**, 223–32.

McConkey R. & Walsh J. (1982) An index of social competence for use in determining the service needs of mentally handicapped adults. *Journal of Mental Deficiency Research* **26**, 47–61.

Orsmond I., Shattuck P. T., Cooper B. P., Sterzing P. R. & Anderson K. A. (2013) Social participation among young adults with an autism spectrum disorder. *Journal of Autism and Developmental Disorders* **43**, 2710–9.

Petrina N., Carter M. & Stephenson J. (2014) The nature of friendship in children with autism spectrum disorders: A systematic review. *Research in Autism Spectrum Disorders* **8**, 111–26.

Pickles A., McCauley J. B., Pepa L. A., Huerta M. & Lord C. (2020) The adult outcome of children referred for autism: Typology and prediction from childhood. *The Journal of Child Psychology and Psychiatry*, **61**, 760–7.

Rutter M., Le Couteur A. & Lord C. (2003) *Autism Diagnostic Interview-Revised*. Western Psychological Services, Los Angeles, CA.

Steinhausen H.-C., Mohr Jensen C. & Lauritsen M. B. (2016) A systematic review and meta-analysis of the long-term overall outcome of autism spectrum disorders in adolescence and adulthood. *Acta Psychiatrica Scandinavica* **133**, 445–52.

Tonge B J. & Einfeld S. (2003) Psychopathology and intellectual disability: the Australian Child to Adult longitudinal study. In: *International Review of Research in Mental Retardation* (ed. L. M. Glidden), pp. 61–91. Academic Press, San Diego, CA.

Wechsler D. (2011) *Manual for the Wechsler Abbreviated Scale of Intelligence-Second Edition*. Pearson, Bloomington, MN.

Accepted 17 May 2022