

Adult Outcomes in Autism: Community Inclusion and Living Skills

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Abstract Longitudinal research has demonstrated that social outcomes for adults with autism are restricted, particularly in terms of employment and living arrangements. However, understanding of individual and environmental factors that influence these outcomes is far from complete. This longitudinal study followed a community sample of children and adolescents with autism into adulthood. Social outcomes in relation to community inclusion and living skills were examined, including the predictive role of a range of individual factors and the environment (socio-economic disadvantage). Overall, the degree of community inclusion and living skills was restricted for the majority, and while childhood IQ was an important determinant of these outcomes, it was not the sole predictor. The implications of these findings in relation to interventions are discussed.

Keywords Autism · Community inclusion · Living skills · Adult outcomes

Introduction

Studies of adult outcomes in autism have focused on broad constructs of outcome, typically including evaluations of social functioning in terms of independence, social relationships, employment status, and living arrangements. The overwhelming majority of these studies indicate that adults with autism remain largely dependent upon others for support in day to day activities. If we adopt a five point scale ranging from *very poor* to *very good* outcomes, results indicate that the outcomes are *poor–very poor* for 50–60 % of adults (Beadle-Brown et al. 2005; Eaves and Ho 2008; Gillberg and Steffenburg 1987; Howlin et al. 2004, 2013; Rutter and Lockyer 1967). Rates of *good–very good* outcomes vary more widely across studies, ranging from as low as 3–16 % (Beadle-Brown et al. 2005; Gillberg and Steffenburg 1987; Mawhood and Howlin 1999; Rutter et al. 1967), to better rates of 22–33 % (Howlin et al. 2004, 2013; Larsen and Mouridsen 1997), and even relatively high rate of 48 % (Farley et al. 2009). A number of these studies have focused solely on individuals with high functioning autism (Farley et al. 2009; Larsen and Mouridsen 1997; Mawhood and Howlin 1999; Rumsey et al. 1985; Szatmari et al. 1989; Howlin et al. 2013) which may account for some of the variation in outcomes. The varying criteria used to define outcome categories, the era of the study, the geographical location and provision of support and services is also likely to have influenced results. For example, the high rate of positive outcomes reported by Farley et al. (2009) has in part been attributed to the highly supportive and inclusive religious community in Utah, USA.

Outcome research evaluating social functioning has often included specific measures of social inclusion, primarily reporting where people live and whether they are

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employed. Again, overall the primary finding is of a high degree of dependence, either upon families or support services. Even among higher functioning adults, rates of independent or semi independent living range from 16 to 36 % (Farley et al. 2009; Howlin et al. 2013; Lord and Venter 1992; Mawhood and Howlin 1999; Rumsey et al. 1985; Szatmari et al. 1989) with only one study reporting a rate of 50 % in a sample of 18 adults with high functioning autism and Asperger's Disorder (Larsen and Mouridsen 1997). In samples including adults with intellectual disability (ID), much lower rates of independent living are reported, ranging from as low as 0.11 % (1 person) (Beadle-Brown et al. 2006) to 15.7 % (Howlin et al. 2000), however a number of the studies report rates below 5 % (Ballaban-Gil et al. 1996; Billstedt et al. 2005). The majority of adults either continue to live with family or live in some form of residential accommodation.

In terms of employment, research indicates a relatively small number of adults with autism are in paid work. In higher functioning samples, in which the majority of participants did not have ID, rates of paid employment range from 20 to 55 %, although the majority of adults worked in sheltered workshop programmes and participated in day programmes (Farley et al. 2009; Larsen and Mouridsen 1997; Lord and Venter 1992; Rumsey et al. 1985; Szatmari et al. 1989). In adults with a broader range of cognitive impairment, varying employment rates of 5–33 % have been reported (Ballaban-Gil et al. 1996; Howlin et al. 2000, 2004; Taylor and Seltzer 2011). A significant proportion of adults (16–63 %) worked in sheltered workshops, participated in supported day programmes, or did volunteer work (Ballaban-Gil et al. 1996; Howlin et al. 2000, 2004; Taylor and Seltzer 2011). In a recent follow-up study, Howlin et al. (2013) reported a high proportion of adults (55 %) who had never worked or were long term unemployed, compared to only 10 % reported by Farley et al. (2009).

As concern surrounding adult outcomes in autism has grown, studies have begun to examine the relationship between childhood factors and adult social functioning. Age, cognitive ability, early language development and severity of autism symptoms have all been implicated as important determinants of adult outcome (Eaves and Ho 2008; Gillberg and Steffenburg 1987; Howlin and Moss 2012; Smith et al. 2012). Smith et al. (2012), for example, reported individuals with autism and ID were more likely to have lower levels of childhood daily living skills, and reduced rates of overall improvement in daily living skills during adolescence and young adulthood than individuals with autism without ID. Nevertheless, the role of IQ appears to be complex. While findings suggest the absence of ID seems to improve the chance of a young adult with autism securing competitive employment (Chiang et al. 2012; Taylor and Seltzer 2011), those young adults with

autism but without ID are reported to be at greater risk of having no daytime activities at all compared to their peers with comorbid autism and ID (Taylor and Seltzer 2011). Similarly, there is a lack of clarity surrounding the role of early autism symptoms and the impact of specific skill deficits (Howlin and Moss 2012). Howlin et al. (2013), for example, reported that early deficits in reciprocal social interaction skills (as measured by the ADI-R; Rutter et al. 2003) were associated with poorer adult social outcomes, but Gillespie-Lynch et al. (2012) found that while early response to joint attention was predictive of adult social functioning, initiation of joint attention was not; and interestingly neither was IQ.

Very few studies have examined the role of additional factors in relation to outcomes in adults with autism. Little is known about the association between socio-economic status and adult outcomes. Whilst Gillberg and Steffenburg (1987) reported no association between socio-economic status assessed in childhood and adult outcomes in terms of social adjustment, in contrast Chiang et al. (2012) found current participation in employment among school leavers was significantly higher among those from high income families.

This study aimed to describe outcomes in a community sample of adults with autism in relation to community inclusion (living arrangements, daytime activities, employment) and living skills. Predictors of these outcomes, including the role of individual factors (age, gender, IQ, behaviour and emotional problems) and the environment (socio-economic disadvantage) were also examined.

Method

Sample

Participants were recruited in 1991 from metropolitan and nonmetropolitan regions and in New South Wales and Victoria, Australia. Health and education agencies providing autism services in the regions were contacted, including two community autism assessment services and a specialist school for children with autism. Upon entry into the study, participants represented a range of children and adolescents with autism in the community who were accessing a variety of support services. Retention rates were high throughout the study. Of 119 participants recruited at Time 1, 89 participated at Time 5. No significant difference was found between those who participated at Time 5 and those who did not in terms of Time 1 behaviour and emotional problems (DBC Mean Item Score), $t(117) = 1.62$, $p = .11$, or degree of ID, $\chi^2(4, n = 119) = 7.32$, $p = .12$.

Participants were initially assessed using a multidisciplinary assessment and all met DSM-III-R (American Psychiatric Association 1987) criteria for Autistic Disorder. In order to confirm diagnosis using DSM-IV criteria (American Psychiatric Association 1994), participants were reassessed at Time 2 using a structured psychiatric interview (based on Rutter and Graham 1968). Interviews consisted of a detailed family and developmental history, a mental state examination of the child (Einfeld 1992; Tonge et al. 1994) and completion of current measures (Autism Behavior Checklist; Krug et al. 1980 and the Childhood Autism Rating Scale; Schopler and Dalldorf 1980). Blind independent assessments (using direct observation by one way screen or video recording) of a random selection of 25 % of cases of Autistic Disorder were conducted by a second clinician (AB or BT). Interrater reliability between these clinicians was high (Cohen's kappa = 0.98).

Measures

Developmental Behaviour Checklist

DBC-P (Parent/carer version; Einfeld and Tonge 1995, 2002) and *DBC-A* (Adult version; Mohr et al. 2005, 2011) were completed by parents or carers. Both versions of the DBC have been specifically developed to measure a broad range of behaviour and emotional problems in individuals with ID. The DBC provides a *Total Behaviour Problem Score*, as well as a measure of disturbance across five dimensions: Disruptive/Antisocial Behaviour (e.g. *Abusive. Swears at others; Stubborn, disobedient or unco-operative*), Self-Absorbed (e.g. *Hits self or bites self; Chews or mouths objects, or body parts*), Communication Disturbance (e.g. *Repeats back what others say like an echo; Talks to self or imaginary people or objects*), Anxiety (e.g. *Distressed about being alone; Cries easily for no reason, or over small upsets*) and Social Relating (e.g. *Aloof, in his/her own world; Doesn't show affection*). The DBC-P consists of 95 items and is completed by parents or other primary caregivers of children and adolescents aged 4–18 years. The DBC-A is also carer-completed but is used with individuals aged 19 years and over and consists of 106 items. Both measures have well established psychometric properties, including high internal consistency and test-retest reliability (Dekker et al. 2002; Einfeld and Tonge 1995; Einfeld and Tonge 2002; Hastings et al. 2001). Rather than relying on the *Total Behaviour Problem Score* or TBPS, analyses were based on the following scores derived from the item scores on the DBC: Mean Item Score (MIS—total score divided by the number of items), Proportion of Items Checked (PIC—proportion of items positively checked), and Intensity Index (II—proportion of positively checked items which are scored 2 on the 0–2

scale) (see Taffe et al. 2008 for a detailed description of the advantages of this scoring system).

Index of Relative Socio-economic Disadvantage (IRSD)

Socio-Economic Indices for Areas (SEIFA) (Australian Bureau of Statistics 2006) were used in this study to provide a measure of social disadvantage. These indices summarise socio-economic disadvantage for communities in relation to their access to material and social resources and their ability to participate in society. These indices are calculated by combining information about individuals and households living in an area. One of these indices [Index of Relative Socio-economic Disadvantage (IRSD)], was determined for each participant in this study using data collected on where families were living at Time 1. The IRSD is a standardised score, with a mean value of 1,000 and standard deviation of 100. This score provided a community-level summary measure of relative disadvantage, with low scores indicating greater relative disadvantage.

Community Inclusion

Information was gathered at each time point from parents or carers on where participants lived (at home with parent(s), independently, group home, or supported accommodation), daytime activities (day programme or sheltered workshop, paid employment, study), and whether they were in paid employment, including details on support received at work (support from a fellow worker, case-worker/professional support, volunteer support, family or friend support, or no support). At Time 5 information was also collected from parents or carers on community social involvement the participant had engaged in over the past 3 months. Taken from the Australian Bureau of Statistics General Social Survey (Australian Bureau of Statistics 2002) activities surveyed include recreational or community groups, religious activities, visiting a cafe, bar or restaurant, participating in or attending sporting events, visiting a library, museum or gallery, attending movies, theatre or concerts, and visiting a park or garden. The number of different types of activities an individual participated in over the past 3 months (from 0 to 9) was used in outcome analyses as a measure of social involvement in the community.

Index of Social Competence

The Index of Social Competence (McConkey and Walsh 1982) was completed by parents or carers at Time 5 to provide a measure of skills needed to function in everyday life (living skills). It consists of 12 items, measuring

competency across three factor analytically derived subscales—Communication skills, Self-care skills, and Community skills. The Index of Social Competence has been shown to have high internal consistency, good interrater reliability, and construct validity (McConkey and Walsh 1982; McEvoy and Dagnan 1993). It is completed by primary caregivers. Higher scores on this measure indicate impaired social competence (living skills).

Degree of Intellectual Disability (ID)

As described previously (Gray et al. 2012), participants were categorised into four groups according to their degree of ID at Time 1: no ID (average or above IQ), a mild, moderate, or severe degree of ID. These groups were defined by specified range of ID according to the DSM-IV (American Psychiatric Association 1994). Categorisation was based upon the results of cognitive assessments—usually a Wechsler measure (Wechsler 1974, 1991) as determined by the child's chronological age, or the Stanford-Binet (Thorndike et al. 1986). When available, current cognitive assessment results provided by parents/carers were used. In the absence of current cognitive assessment results, assessments were administered by one of the psychologists in the project team at Time 1.

Procedure

Data collection has taken place at five time points: Time 1 (1991–1992), Time 2 (1995–1996), Time 3 (1999), Time 4 (2002–2003), and Time 5 (2007–2009). On each occasion a mail survey of a questionnaire booklet was sent to the parents and caregivers. At Time 5 the questionnaire booklet included the DBC, Community inclusion measures and the Index of Social Competence. Ethics approval for the study was obtained from the ethics committees of Monash University, University of NSW, University of Sydney, and South Eastern Sydney Area Health Service. Informed consent was provided by caregivers/guardians, and where possible, the young people themselves.

Statistical Analyses

Standard regression was used to model Time 5 outcomes of behaviour and emotional problems, employment, living arrangements, daytime activities, community social inclusion and living skills, as functions of Time 1 measures of behaviour and emotional problems, age at study entry, gender, degree of ID, and socio-economic disadvantage. All predictor variables were entered in the regression analyses in one step. Regression and correlational analyses were also used to examine the relationship between different Time 5 outcome measures.

Results

At entry into the study (Time 1) participants were aged 2.8–19.8 years with a mean age of 8.7 years (SD 4.3). The mean age of the sample at Time 2 was 12.8 (SD 4.4), at Time 3 15.7 (SD 4.5), at Time 4 19.2 (SD 4.5), and at Time 5 24.8 (SD 4.7). Details of age, gender, and degree of ID at Times 1 and 5, and socio-economic disadvantage at Time 1 are provided in Table 1.

Table 2 provides frequencies of type of living arrangement, daytime activities, and time spent in organised daytime activities, in addition to means and standard deviations for living skills and community social involvement. A large proportion (61 %) of participants remained living in the family home at Time 5 and few (9 %) were living independently. Only one participant had no organised daytime activity, but 27 % of the sample was engaged in activities for fewer than 20 h per week. Daytime activities most commonly involved participation in day programmes or sheltered workshops (67 %), with a much smaller proportion in paid employment (18 %) or studying (14 %). Among those who were in a paid employment at Time 5 ($n = 14$), 5 had mild ID, 6 had average IQ/borderline ID, 2 had moderate ID, and 1 had severe ID. Of those attending a day programme or sheltered workshop ($n = 52$), 7 had average IQ/borderline ID, 5 had a mild degree of ID, 27 moderate, and 13 severe.

For comparison purposes, the mean living skills scores and mean community involvement score were examined in relation to corresponding scores in ID samples. The mean scores across the three areas of living skills [11.17 (*Community skills*); 12.84 (*Self care*); and 4.54 (*Communication*)] were not significantly different from scores previously reported on the same measure in a sample of 376 adults with ID (10.92, 12.84 and 4.44 respectively; McConkey and Walsh 1982). The community social involvement mean score of 4.25 however was significantly greater than the corresponding score of 3.64 [$t(441) = 2.75, p < .01$] found in a community sample of 354 young adults with mild-profound ID (Gray et al. 2013). This community social involvement score reflects the number of different types of social activities individuals had participated in during the previous 3 months (from 0 to 9). Table 3 provides the frequencies for each activity, in addition to corresponding frequencies reported in a Social Survey of the general Australian population (Australian Bureau of Statistics 2002). The proportion of individuals participating in recreational or cultural group activities (47 %) and community or special interest group activities (38 %) was significantly higher in this sample than reported in the general population [16 and 13 % respectively; $\chi^2(1, n = 4,901) = 63.09, p < .001, \chi^2(1, n = 4,901) = 50.38, p < .001$]. However, in relation to participation rates

in other social activities the differences between this sample and the general population was smaller. It is interesting to note however that a slightly smaller proportion of this sample attended movies, theatres or concerts (64 % compared to 74 %) and this difference was significant $\chi^2(1, n = 4,901) = 4.59, p < .05$. Similarly, a marginally smaller percentage of this sample attended church or religious activities or went to a café, restaurant or bar than was reported for the general population (14 and 81 % compared to 20 and 86 % respectively), however, these differences were not significant.

Time 1 Predictors of Community Inclusion in Adulthood (Time 5)

Outcomes in terms of community inclusion were assessed for all participants at Time 5. Community inclusion encompassed information on living arrangements, daytime activities, and community social involvement.

Multinomial logistic regression using 'living at home with parents' as base value, found that degree of ID was the only significant predictor of Time 5 living arrangement being 'in care' or 'independent'. When compared to those with moderate ID, participants with severe ID were significantly more likely to be in care, and those with average IQ more likely to be independent. Two participants who were living in supported mainstream accommodation at university were not included in this analysis. Time 1 behaviour and emotional problems (DBC-P) was not associated with Time 5 living arrangements. Table 4 presents relative risk ratios for Time 5 living arrangements.

Multinomial logistic regression using 'day programme or sheltered workshop' as the base value, found that degree of ID was the only significant predictor of Time 5 main daytime activity being 'study' or 'paid employment'. When compared to individuals with moderate ID participants in the mild, borderline or average groups were significantly more likely to be working in paid employment, and individuals with mild and borderline ID were also significantly more likely to be studying than those with moderate ID. Time 1 behaviour and emotional problems (DBC-P) were not associated with Time 5 daytime activities. Table 4 presents relative risk ratios for Time 5 main daytime activities.

Table 4 also provides odds ratios for participants spending fewer than 20 h per week in an organised daytime activity. Individuals with mild and borderline ID were significantly more likely than those with moderate ID to be engaged in organised daytime activities for fewer than 20 h per week. Higher rates of behaviour and emotional problems (DBC-P) at Time 1 also indicated a higher likelihood of being engaged in activities for fewer than 20 h per week.

Table 1 Sample demographics

	Time 1 N = 119	Time 5 N = 89
Gender (% male)	82.4	80.9
Age range (years)	2.8–19.8	17.1–35.2
Mean age (SD)	8.7 (4.3)	24.8 (4.7)
IQ range		
Average (%)	11 (9.2 %)	6 (6.7 %)
Borderline (%)	16 (13.4 %)	15 (16.9 %)
Mild ID (%)	29 (24.4 %)	19 (21.3 %)
Moderate ID (%)	46 (38.7 %)	35 (39.3 %)
Severe ID (%)	17 (14.3 %)	14 (15.7 %)
Mean index of socio-economic disadvantage (SD)	1,025 (58.9)	
Range	902–1,179	

Table 2 Time 5 community inclusion and living skills

	Time 5 N (%)	
Living arrangements		
At home	54 (61 %)	
In care	25 (28 %)	
Independent	8 (9 %)	
Mainstream supported university accommodation	2 (2 %)	
Daytime activity		
Day programme or sheltered workshop	52 (67 %)	
Post secondary school study	11 (14 %)	
Paid employment	14 (18 %)	
No organised daytime activity	1 (1 %)	
Time in organised activities per week		
Fewer than 10 h	4 (5 %)	
10–20 h	17 (22 %)	
More than 20 h	58 (73 %)	
	Range	M (SD)
Community social involvement	1–9	4.25 (2.17)
Social competence (living skills)		
Community skills	4–20	11.17 (6.18)
Self care	6–27	12.84 (5.75)
Communication	2–8	4.54 (1.95)

Regression analysis on Time 5 community social involvement found no significant associations with Time 1 age, gender, degree of ID, socio-economic disadvantage or behaviour and emotional problems (see Table 4).

Predictors of Living Skills in Adulthood (Time 5)

Predictors of living skills as measured by the Index of Social Competence (McConkey and Walsh 1982) are presented in Table 5. All subscales were associated with degree of ID, in that those with mild, borderline, and average IQs had greater living skills (i.e. lower scores on this scale). Self care and communication scores were also associated with Time 1 socio-economic disadvantage, whereby living in a more advantaged area was associated with greater impairment in these skills. Time 1 behaviour and emotional problems (DBC) were not associated with Time 5 living skills.

The relationships between Time 5 living skills and other outcome measures were also examined. The relationship between Time 5 behaviour and emotional problems and Time 5 living skills was found to be significant across the three domains of community skills ($r = .33, p = .001$), self care skills ($r = .35, p < .001$), and communication skills ($r = .30, p = .004$). However, Time 5 community social involvement was not associated with Time 5 living skills across any of the three domains of community skills ($r = -.06, p = .60$), self care skills ($r = -.19, p = .07$) or communication skills ($r = -.10, p = .36$).

Logistic regression analyses were used to examine the relationship between participation in different daytime activities at Time 5 and Time 5 living skills. Odds ratios for participants being in paid employment or studying compared to participating in a day activity programme or sheltered workshop were calculated, controlling for age, gender and degree of ID. Results indicated that those with more impaired living skills (higher scores) were significantly less likely to be in paid employment or studying and this was true across each of the three domains (community skills OR = 0.66, $p = .001$; self care OR = 0.81, $p = .02$; communication skills OR = 0.58, $p = .02$). Similar analyses were conducted to examine the relationship between Time 5 living arrangement and Time 5 living skills. Odds ratios for participants living independently compared to living at home or in care were calculated, again controlling for age, gender and degree of ID. No significant association was found between self care and living independently (OR = 0.67, $p = .08$) or communication skills and independent living (OR = 0.39, $p = .08$). However, those with more impaired community skills (higher scores) were less likely to be living independently (OR = 0.51, $p = .05$).

Discussion

This study aimed to examine adult community inclusion (living arrangements, daytime activities, community social

Table 3 Time 5 participation in social activities in the past 3 months

Activity	Time 5 N (%)	ABS General Social Survey 2002 N (%) respondents aged 18–34 ^a
Recreation or cultural group activities	42 (47 %) [†]	759 (16 %)
Community or special interest group activities	34 (38 %) [†]	607 (13 %)
Church or religious activities	12 (14 %)	939 (20 %)
Went out to a café, restaurant or bar	72 (81 %)	4,153 (86 %)
Took part in sport or physical activities	48 (54 %)	–
Attended sporting event as spectator	23 (26 %)	–
Visited library, museum or art gallery	38 (43 %)	2,083 (43 %)
Attended movies, theatres or concert	57 (64 %)**	3,566 (74 %)
Visited park, botanic gardens, zoo or theme park	52 (58 %)	2,813 (58 %)
None of the above	3 (3 %)	203 (4 %)

[†] $p < .001$; ** $p < .05$

^a Based on sum of published figures relating to two age groups: 18–24 years ($n = 1,905$) and 25–34 years ($n = 2,907$) (Australian Bureau of Statistics 2002)

involvement) and living skills (community, self care, and communication skills) outcomes in a community sample of children and adolescents with autism.

Community Inclusion

Consistent with previous research (for example Ballaban-Gil et al. 1996; Billstedt et al. 2005; Howlin 2000; Howlin et al. 2004, 2013), the majority of individuals with autism were either living with their parents or were in care. Importantly, more than half (61 %) of the individuals were living with their families at Time 5, with only eight adults living independently (9 %). This suggests that parents are bearing much of the burden of caring for their adult children. Whilst virtually all (99 %) of the sample were engaged in some form of daytime activity, for the majority this consisted of a day programme or sheltered workshop. Fourteen adults (18 %) were in paid employment; a number which is considerably lower than previously reported in high functioning adults with autism (Farley et al. 2009; Szatmari et al. 1989; Howlin et al. 2013) although higher than that reported in a previous study by Howlin et al. (2000). Although only one person was not engaged in some form of organised daytime activity, a significant number were still engaged fewer than 20 h per week.

Table 4 Associations between Time 5 community inclusion and Time 1 behaviour and emotional problems, controlling for age, gender and socio-economic disadvantage

	RRR—living arrangements ^b		RRR—daytime activity ^c		OR—hours in daytime activity ^d	Regression coefficient
	In care	Independent	Study	Paid job	<20 h	Community social involvement
Age	1.13	1.17	0.62*	0.97	0.94	0.05
Female	1.93	8.93	0.45	0.90	1.82	−0.03
Degree of ID ^a						
Severe	10.47*	0.00	0.00	1.36	2.62	−0.48
Mild	0.12	2.31	91.01**	12.80*	16.12**	−0.56
Borderline	0.89	13.77	16.24*	8.67*	16.46**	−0.85
Average	0.00	112.58**	6.26	21.91*	3.7	1.57
Socio-economic disadv.	1.00	0.98	0.98	1.00	1.00	−0.01
T1 DBC MIS	10.33	26.57	11.62	0.58	51.33**	−1.74

DBC MIS Developmental Behaviour Checklist Mean Item Score, *Socio-economic disadv* socio-economic disadvantage, *RRR* relative risk ratio, *OR* odds ratio

* $p < .05$; ** $p < .01$

^a Reference category is moderate ID

^b 'at home' as base value

^c 'day activity or sheltered workshop' as base value

^d 'engaged more than 20 h' as comparison

Interestingly, level of social activity in this sample appeared to be higher than that found in a corresponding sample of adults with ID who did not have autism, and in relation to certain types of activities, higher than has been reported in the general Australian population of equivalent chronological age. It is possible that the young adults with autism are more likely to engage in activities that are organised and structured by others, rather than initiating their own activities. Although not asked in this study, it would be useful in future studies to ascertain whether adults with autism initiated their own leisure activities or whether they were organised by others.

Time 1 IQ was the only significant predictor of living arrangements and daytime activities at Time 5. As expected, those with a more severe degree of ID were more likely to be living in care, and those with an average IQ were more likely to be living independently. The same pattern was true of daytime activities; individuals with either a mild degree of ID, or a borderline-average IQ were more likely to be in paid employment or undertaking post secondary school study. These findings replicate previous studies that have shown adults with autism without ID are more likely to be living independently and to be in paid employment, than their peers with an ID (for example Szatmari et al. 1989; Larsen and Mouridsen 1997; Taylor and Seltzer 2011; Chiang et al. 2012). This study however did not measure language at Time 1, and given that previous work has highlighted the importance of early language skills (for example Gillespie-Lynch et al. 2012), this

Table 5 Association between Time 5 living skills and Time 1 age, gender, degree of ID, and socio-economic disadvantage

	Living skills (Index of Social Competence)		
	Community	Self care	Communication
Age	0.19	0.06	0.05
Female	0.59	0.71	0.33
Degree of ID ^a			
Severe	4.67**	3.03	0.97*
Mild	−6.04 [†]	−5.64 [†]	−2.02 [†]
Borderline	−6.60 [†]	−6.17 [†]	−2.30 [†]
Average	−7.26 [†]	−5.62**	−1.90**
Socio-economic disadv.	0.02	0.02*	0.01*
T1 DBC MIS	0.17	−0.86	−0.25
<i>F</i>	13.70	7.49	10.63
<i>R</i> ²	0.58	0.43	0.52

Socio-economic disadv socio-economic disadvantage, *DBC MIS* Developmental Behaviour Checklist Mean Item Score

* $p < .05$; ** $p < .01$; [†] $p < .001$

^a Reference category is moderate ID

warrants attention in future research. Although child and adolescent behaviour and emotional problems did not contribute to adult outcomes in terms of living arrangements and activities, it was associated with a reduced number of hours per week engaged in these activities. This finding highlights the need to not only look at type of activity, but also to look at number of hours spent in the

activity in order to obtain a more complete picture of employment and daytime activities.

Living Skills

Living skills are an important aspect of community inclusion, particularly in terms of living independently, working, and social engagement within the community. In line with Smith et al.'s (2012) reported association between living skills and IQ, in this study it was found that at Time 5, living skills (as measured by the Index of Social Competence; McConkey and Walsh 1982) were influenced by Time 1 IQ. That is, children and adolescents with mild-borderline ID or average IQ at Time 1 had better outcomes in terms of living skills at Time 5. Neither gender nor Time 1 behaviour and emotional problems were associated with adult Time 5 living skills.

Early socio-economic disadvantage was associated with Time 5 self-care and communication skills, in that living in a more socio-economically advantaged area was associated with poorer skills. Although this somewhat counterintuitive result was significant, it was only at the level of .05, with very small regression coefficients, and therefore requires further investigation.

Furthermore, there was a relationship between Time 5 living skills and Time 5 behaviour and emotional problems. Higher rates of behaviour and emotional problems at Time 5 were associated with more impaired living skills. Similarly, although there was no relationship observed between Time 5 living skills and Time 5 community social involvement, these living skills were found to be associated with day time activity. Both paid employment and post-secondary education were associated with better living skills and there was at least some indication that community skills may be related to living independently.

Summary

Children and adolescents with comorbid autism and severe ID seem to be at particular risk for poor community inclusion and living skills as adults. However, IQ alone does not seem to determine social outcomes. Many children with average and above average intelligence also continue to live with their families and remain unemployed as adults (Howlin et al. 2005, 2013).

Compared to earlier research (Gillberg and Steffenburg 1987; Ballaban-Gil et al. 1996; Howlin et al. 2000, 2004), we found fewer adults with autism now living in care and more engaged in activities during the day. Despite this improvement, a significant number continue to live at home with their families and the number in employment is still low. As Howlin et al. (2013) have noted, the reliance on aging parents as the primary caregivers for adults with

autism is particularly concerning and efforts to enhance accommodation provision is required.

Determinants of adult outcomes in autism are clearly multi-faceted and complex. Whilst this study makes a significant contribution to the scarce literature on predictors of adult outcomes in autism, limitations do need to be acknowledged, including the wide age range of the sample at study commencement, and the reliance on parent/carer report. Although examining the role of childhood and adolescent intervention was beyond the scope of this study, this is a critical question to which we do yet have an answer. With a focus rightly on childhood intervention, especially early childhood, it is essential to investigate the long term outcomes of these interventions. Are we correct in assuming that early intervention changes outcomes for adults with autism? In what way? In addition, closer examination of the role of socio-economic background certainly appears warranted, particularly focussing on individual and family socio-economic stress or adversity. Further longitudinal work is undeniably needed to help identify additional individual and environmental factors that can help promote independence and social inclusion during adulthood.

Research needs to address the best way to improve the poor living skills that are associated with these poor social outcomes and help to facilitate and support community inclusion. Indeed, authors have previously identified the need for interventions to target behaviours that may be more responsive to change, such as living skills (Henninger and Taylor 2013; Smith et al. 2012). Furthermore, innovative employment support programmes have been shown to be both possible and successful (Howlin et al. 2005; Shattuck et al. 2012; Wareham and Sonne 2008), justifying the need to direct resources toward implementing and supporting such initiatives. There is an undeniable need for research and support to facilitate the development of interventions to build skills throughout childhood and adolescence, along with better supports and programmes in adulthood, in order to shift the outcomes observed to date in longitudinal studies.

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Conflict of interest The authors declare that they have no conflict of interest.

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