

Outcomes in young adulthood: are we achieving community participation and inclusion?

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Abstract

Background Despite recognition of the importance of integrated community living and support, there is evidence that parents remain the primary caregivers of young adults with intellectual disability (ID). In addition, employment rates remain low in this population. This study aimed to investigate the changes in living arrangements and participation in daytime activities over time in a community population of young people with ID.

Method The sample consisted of 536 participants aged 4.0–18.9 years at Wave 1, followed up at Wave 5 when aged 20.5–37.6 years. Information was collected on their living arrangements and daytime activities at both time points, along with living skills and information on community social inclusion at Wave 5. For parents still caring for their adult child with ID, information was also collected on parental ratings of their own mental and

physical health, and their satisfaction with the long-term care arrangements for their adult child. **Results** A significant proportion of young people were still living with their parents at Wave 5. A greater proportion of those with a severe–profound degree of ID were living in residential care. Parents caring for their adult child reported high levels of mental health problems and dissatisfaction with the long-term care arrangements for their child. A small proportion of young people were in paid employment, and the majority was engaged in structured activities provided for those with an ID. Over one-third of the sample participated in a structured daytime activity for 10 or fewer hours per week, and 7% were not engaged in any structured daytime activity.

Conclusions These results suggest that adequate provision of accommodation and employment services for young adults with an ID is lacking. In many cases the responsibility of care continues to reside with parents as their children transition from childhood to adulthood. Greater attention is needed to address these issues and facilitate social inclusion and integration for young people with ID.

Keywords adult outcomes, inclusion, living arrangements, employment

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Introduction

Social inclusion and community participation are highlighted in the United Nations Convention on the Rights of Persons with Disabilities (United Nations 2006). In Australia, the Disability Services Act (Commonwealth of Australia 1986) and the more recent National Disability Plan (Commonwealth of Australia 2011) identify increased independence, increased access to employment opportunities and improved community participation as areas for action. Opportunities for independent living, daytime activities and employment are important aspects of social inclusion and participation in the community. The transition to adulthood often involves independent living and further education and training, or paid employment. These milestones and markers of adulthood are often more challenging to achieve for people with an intellectual disability (ID).

Living circumstances

In the majority of developed countries, there has been a move away from large, segregated residential institutions for young people and adults with ID, with a trend towards small residential houses in community settings (Braddock *et al.* 2001). Currently in Australia, accommodation types can include institutions/large residential care, group homes, at home with family care with or without outreach or 'in home' support, nursing homes (meant to accommodate the aged) and boarding houses.

Despite the shift away from segregated residential living for young people with ID, research over the past 10–14 years reveals that a significant number of young people with ID are not living independently in the community. In a cross-sectional study, Braddock *et al.* (2001) reported that in 1998, 72.7% of young people (15–24 years) with ID in Australia lived in their family home. For the 25- to 64-year-old age group, 29.3% lived in the family home. In terms of living independently, 19.7% of those aged 15–24 years lived in their own home, while 53.8% of the 25- to 64-year age group lived independently. In Canada, in 1999, 33.4% were reported to be living in family homes (natural or foster parents, age not specified), while in the USA in 1998, 60% were

reported as living with family caregivers (Braddock *et al.* 2001). No information was provided on age range or degree of ID for these data, so it is not clear whether these differences in percentage of people living in the family home are due to sample demographics differences or availability of accommodation options. Smaller community studies in other countries have reported similar rates, with 72.5% of young adults (aged 18–22 years) living in the family home (O'Brien 2006), 62% of adults with Williams syndrome (aged 19–56 years) (Howlin & Udwin 2006). It has also been estimated that 20% of residents living in aged care nursing homes are aged less than 60 years and have an ID (Braddock *et al.* 2001). Overall, research currently suggests that the family home is the predominant place of residence for many young adults with ID.

With a significant proportion of young people living with their parents, the impact of this ongoing living arrangement warrants attention. Although parents of young people with an ID report not feeling a burden of care, ageing parents caring for their adult children with an ID do feel socially isolated and experience persistently high rates of mental health problems (Burton-Smith *et al.* 2009; Llewellyn *et al.* 2010; Gray *et al.* 2011). Mothers of young adults with ID living at home who had made long-term plans for future living arrangements report the most positive well-being and lowest levels of worries about the future (Freedman *et al.* 1997). However, research indicates that the parents of young people with ID are generally reluctant to or tend not to make residential plans for their son or daughter (Bigby 1996; McConkey *et al.* 2006).

Daytime activities

In industrialised countries, high rates of unemployment (50–70%) have been reported among people with disabilities (Parmenter 2011). A review of 23 studies of community participation concluded that compared with their non-disabled peers, people with an ID are three to four times less likely to be in employment (Verdonschot *et al.* 2009). In a follow up study of 149 young adults (aged 18–22 years) who were identified in childhood with ID (IQ < 80), O'Brien (2006) reported that 13.4% were in full time sheltered employment, and 27.5% in independent employment, while noting that there

was a generally high level of employment in general in the region where this study was conducted. A significant association was found between degree of childhood ID and more independent type of daytime activity. Specifically, those adults with less severe childhood impairment were found to have more independent daytime occupations; all who were employed were in the mild-borderline range. No adults with moderate to severe ID were reported as being employed. Of 239 adults (mean age 30.6 years) with Williams syndrome, Howlin & Udwin (2006) reported that 3.1% (4) were in fulltime independent employment and 4.6% (11) in part time independent employment. Sixty-eight per cent were in some form of daytime activity or attended a day centre, 8.8% in unpaid voluntary positions and 6% in no form of structured daytime activity.

A small number of studies have reported higher employment rates. In a sample of 66 adults (aged 43 years) from the National Survey of Health and Development (UK), Hall and colleagues (2005) reported that 56.1% of the sample were employed, although the majority of this group had a mild degree of ID. Data from a nationwide study in the Netherlands reported that 47% of the sample (aged 15–65) were participating in paid work (Dusseljee *et al.* 2011). This rate was moderated by degree of ID, with a higher proportion (60%) of people with a mild degree of ID being in paid employment compared with people with a moderate degree of ID (30%).

Few studies have addressed inclusion in terms of community engagement or social networks for young people with ID. In their review of the literature, Verdonschot *et al.* (2009) looked at community participation in terms of ability to engage in domestic life, interpersonal relationships (including family, friends and intimate relationships), education, work and employment, and community, civic and social life (encompassing recreation and leisure activities). Verdonschot *et al.* noted that the focus of research was often on individuals with mild ID only, and found that living arrangements were linked to community participation. Specifically, those living in segregated settings experienced less community participation and the longer people with ID had lived in the community, the greater their community involvement. Dusseljee *et al.* (2011) highlighted that while most of their sample had some form of

daytime activity, this did not mean they were interacting with the wider community, instead finding that interaction with individuals without an ID was not common. Severity of ID and age were identified as risk factors for exclusion, specifically those with a more severe degree of ID and those who were older were less likely to be interacting with their wider communities (Dusseljee *et al.* 2011).

Current study

The present study aimed to describe community inclusion in terms of living circumstances, participation in daytime activities, community social involvement and social competence for a sample of young adults with ID over an 18-year period. The potential impact of behaviour and emotional problems these adult outcomes was also examined. In addition, this study looked at the mental health of parents caring for their adult children. These data were drawn from the Australian Child to Adult Development study (ACAD).

Method

Participants

The ACAD study is an epidemiological cohort of 578 children and adolescents aged 4–19.5 years at Wave 1 (1991–1992), who were recruited in 1991 from every health, education and family agency that provided services to children with ID of all levels and whose families lived in six census districts in the states of New South Wales and Victoria, Australia. This sample represents a population of approximately 179 000 children and adolescents and reflects the general Australian community in terms of mix of social class, ethnic diversity and rural–urban environment (Einfeld & Tonge 1996a). For children and adolescents with moderate and severe or profound ID, ascertainment was likely to be virtually complete (Einfeld & Tonge 1996a,b). However, as in other studies, some young people with the mildest forms of ID blend in to the population and may not have been identified because they may not have had impairments that required services. Those children and adolescents in the cohort with mild ID may therefore be biased towards higher levels of disturbance.

Ethics approval was obtained from the Monash University Standing Committee on Ethics in Research on Humans, Melbourne, Australia; South Eastern Sydney Area Health Service Research Ethics Committee—Eastern Section, Randwick, Australia; the University of New South Wales Committee on Experimental Procedures Involving Human Subjects, Kensington, Australia, and the University of Sydney Human Research Ethics Committee. All participants were provided with information and consent forms. When participants were capable of signing the consent form themselves, they signed it; however, when they were not capable of signing it, legal guardians consented on their behalf.

Measures

Outcomes

Parents or carers completed questions on living circumstances (e.g. at home with family, residential care/group home, independent), type of daytime activity (e.g. mainstream school, special school, paid job, day activity programme, no organised daytime activity), social inclusion, living skills, and behaviour and emotional problems.

Community inclusion. Information was gathered at each time point 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. For the purposes of this paper, ‘*independent living*’ means living outside of the family, for example in a house, unit or apartment, either alone or shared. While no full time, onsite living support is provided, some external support (with either support workers or family) may be provided. Information on living circumstances and daytime activities was collected at all five waves of data collection. At Time 5 information was also collected on community social involvement the participant had engaged in over the past 3 months. Taken from the Australian Bureau of Statistics General Social Survey (Woolf *et al.* 2010)

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. A sum of the total types of these activities was used in outcome analyses as a measure of social involvement in the community, with higher scores indicating a greater number of these activities.

Index of Social Competence. The Index of Social Competence (Parmenter & Knox 1991) was completed 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 inter-rater reliability and construct validity (Parmenter & Knox 1991; McEvoy & Dagnan 1993). It is completed by primary caregivers. Higher scores on this measure indicate less social competence (living skills).

Developmental Behaviour Checklist (DBC-P and DBC-A). The DBC-P (Einfeld & Tonge 1995, 2002) was used to measure behaviour and emotional problems. The DBC consists of 95 items and is completed by parents or other primary caregivers. It has been designed specifically for measuring behaviour and emotional problems in young people with ID. The DBC provides measures of overall behavioural/emotional disturbance, (the Total Behaviour Problems Score or TBPS) and five subscale scores derived from factor analysis (‘*Disruptive*’, ‘*Self-absorbed*’, ‘*Anxiety*’, ‘*Communication disturbance*’ and ‘*Social-relating problems*’). At Waves 4 and 5, the adult version of the DBC (DBC-A) (Mohr *et al.* 2005, 2012) was completed for those participants aged 19 years and above. The DBC-A consists of 106 items, sharing 94 items of the DBC-P (7 edited to be appropriate for adults), 1 inappropriate item of the DBC-P deleted, and 12 additional items. The DBC has been shown to be both a reliable and valid measure of behaviour and emotional problems in young people with ID

(Einfeld & Tonge 1995, 2002; Hastings *et al.* 2001; Dekker *et al.* 2002; Mohr *et al.* 2005).

Parental well-being. At Wave 5 the parents of young people living at home were asked to rate their own overall health on a scale of 1–5, with 1 = excellent health and 5 = poor health. Parents also rated their mental well-being using the General Health Questionnaire (GHQ-28) (Goldberg & Williams 1988). The GHQ-28 provides four subscale scores, namely *Somatic Symptoms* (e.g. Have you recently felt that you are ill?, Have you recently been feeling run down and out of sorts?), *Anxiety and Insomnia Symptoms* (e.g. Have you recently had difficulty staying asleep once you are off?, Have you recently been getting scared or panicky for no good reason?), *Social Dysfunction* (e.g. Have you recently felt on the whole that you were doing things well?, Have you recently been managing to keep yourself busy and occupied?), and *Severe Depression* (e.g. Have you recently felt that life is entirely hopeless?, Have you recently found yourself wishing you were dead and away from it all?). Likert scoring was used (0–1–2–3), with higher scores indicating greater difficulties. Australian GHQ-28 normative data ($n = 1216$, aged 18–65+ years) (Purcell *et al.* 2005) was available for comparison.

At Wave 5 parents caring for their adult children at home were also asked to rate their satisfaction with the long-term care arrangements in place for their son/daughter on a scale of 1–3: 1 = very satisfied and 3 = dissatisfied.

Degree of ID. Children were categorised as having a mild, moderate or severe/profound degree of ID. Assignment to categories was based on the results of existing cognitive assessments as provided by parents–carers, according to the ranges of ID specified by the *Diagnostic and Statistical Manual of Mental Disorders* (American Psychiatric Association 1994).

Procedure

The ACAD study gathers data on a broad range of potential biopsychosocial risk and protective variables (Einfeld & Tonge 1996a; Tonge & Einfeld 2003; Einfeld *et al.* 2006). Data collection has taken place at five time points: Wave 1 (1991–1992), Wave

2 (1995–1996), Wave 3 (1999), Wave 4 (2002–2003) and Wave 5 (2008–2009) through a mail survey of a questionnaire booklet to the parents and caregivers of the young people with ID.

Results

Participant characteristics

Participation was consistently high throughout the study. The response rate, excluding the 42 participants who had died since Wave 1, at Wave 2 was 82.5% ($n = 477$), 78.5% ($n = 448$) at Wave 3, 84.0% ($n = 438$) at Wave 4 and 72.7% ($n = 400$) at Wave 5. Analyses were limited to individuals who were aged 4–18 years at Wave 1. Thus, the total number of participants at Wave 1 was 536 with an age range of 4.0–18.98 years, with a mean (SD) age of 11.71 years (4.03). At Wave 5, the sample consisted of 354 participants, ranging in age from 20.5 to 37.6 years, with a mean (SD) age of 28.2 (4.2) years.

Descriptive statistics comparing key characteristics for Wave 5 participants and non-participants are presented in Table 1. There were no significant differences found between those who participated at Wave 5 and those who did not in terms of age [$t(534) = 0.58$, $P = 0.56$], proportion of females ($P = 0.27$, Fisher's exact), or behaviour and emotional problems [$t(532) = -0.10$, $P = 0.92$]. There was also no significant difference found between the proportion of those with a moderate to profound degree of ID in terms of Wave 5 participation ($P = 0.429$, Fisher's exact).

Table 1 Descriptive statistics for Time 5 participants and Time 5 non-participants

	Wave 5 participants	Wave 5 non-participants
TI age in years mean (SD)	11.64 (4.03)	11.85 (4.05)
DBC TBPS mean (SD)	0.45 (0.24)	0.45 (0.27)
Proportion of female	44%	39%
Proportion of participants with moderate to profound degree of ID	68.38%	64.74%

DBC, Developmental Behaviour Checklist; TBPS, Total Behaviour Problems Score; ID, intellectual disability.

At Wave 1, 58% ($n = 310$) of the sample were male, 32.1% ($n = 172$) were in the mild range of ID, 40.1% ($n = 215$) in the moderate range, 21.3% ($n = 114$) in the severe range, and 4.3% ($n = 23$) in the profound range. Information on degree of ID was unavailable for 12 participants.

Living circumstances

At Wave 1, 83.8% (357) of the sample were living at home with family (or foster carers), and 16.2% (69) were living in-care (i.e. group homes of six or fewer people, or large residential care). At Wave 5, 61.3% (217) were living at home with family, 29.7% (105) were living in care, while 9% (32) were living independently. Table 2 describes living circumstances by degree of ID.

For those young people living at home with their family at Wave 5, information was collected on parental ratings of their own physical and mental health. Seventy-three parents (33.80%) rated their physical health as *very good* to *excellent*, 90 (41.67%) as *good* and 53 (24.54%) as *fair* to *poor*. In rating their mental health on the GHQ-28, parents

reported a mean Total GHQ score of 21.04 (SD 10.45), mean *Somatic Symptoms* score of 5.76 (SD 3.87), mean *Anxiety and Insomnia* of 6.13 (SD 3.93), mean *Social Dysfunction* of 7.54 (SD 2.17) and mean *Severe Depression* of 1.16 (SD 2.97). Comparison with the GHQ-28 Australian normative data (Purcell *et al.* 2005) indicated significantly higher total and subscale scores for the parents of young people with an ID ($P < 0.001$).

Parents caring for their adult children at home were also asked about their satisfaction with the long-term care arrangements for their son/daughter. Twenty-three per cent reported they were *very satisfied*, 43% *somewhat satisfied* and 34% reported being *very dissatisfied*. Dissatisfaction with long-term care arrangements was associated with parental *Anxiety* ($r = 0.23$, $P = 0.01$), *Social Dysfunction* ($r = 0.31$, $P < 0.01$) and *Severe Depression* ($r = 0.28$, $P < 0.01$), as measured by the GHQ at Wave 5.

In terms of behaviour and emotional problems, at Wave 1 there was no significant difference between those who were living in care ($M = 41.03$, $SD = 23.20$) and those who were not ($M = 44.19$, $SD = 23.61$), $t(422) = -1.03$, $P = 0.302$. At Wave 5,

Living circumstances	Wave 1 <i>n</i>	Wave 5 <i>n</i>
Mild		
At home with family (or foster parents)	126 (94.7%)	85 (76.6%)
In care (group home or large residential)	7 (5.3%)	11 (9.9%)
Independent	0 (0%)	15 (13.5%)
	133	111
Moderate		
At home with family (or foster parents)	159 (90.3%)	109 (69.9%)
In care (group home or large residential)	17 (9.7%)	30 (19.2%)
Independent	0 (0%)	17 (10.9%)
	176	156
Severe		
At home with family (or foster parents)	62 (63.9%)	20 (26.7%)
In care (group home or large residential)	35 (36.1%)	55 (73.3%)
Independent	0 (0%)	0 (0%)
	97	75
Profound		
At home with family (or foster parents)	8 (47.1%)	1 (12.5%)
In care (group home or large residential)	9 (52.9%)	7 (87.5%)
Independent	0 (0%)	0 (0%)
	17	8

Table 2 Living circumstances by degree of intellectual disability from Wave 1 to Wave 5

n's do not match total sample because of missing IQ data for some subjects.

those living in care had a significantly higher mean DBC-A Total Behaviour Problem Score of 39.69 (SD 22.24) while those not living in care had a mean of 33.88 (SD 21.87), $t(320) = -2.22$, $P = 0.027$.

Participation in daytime activities

At Wave 1, 17.5% (72) of the sample were attending a mainstream daytime activity (e.g. mainstream school, technical and vocational training, or a paid job), while this figure dropped to 14.1% (50) of participants at Wave 5. At Wave 1, 82% (338) of the sample were attending activities specifically for people with an ID (e.g. special school, special unit in a mainstream school, day activity programme or sheltered workshop), while 79.1% (280) were attending such programmes at Wave 5. All young people participated in some form of organised daytime activity at Wave 1, while 6.8% (24) had no organised daytime activity at Wave 5. Forty-one (11.3%) young people were working in a paid job at Wave 5, all of whom were in the mild to moderate range of ID. Eighty-nine (22.3%) people were working in a sheltered workshop at Wave 5. The majority of people working in a sheltered workshop at Wave 5 were in the mild-moderate range of ID; there was one person with a severe degree of ID. Overall, 43% of young people with a mild degree of ID were in some form of employment (sheltered workshop or paid job) at Wave 5. Table 3 describes daytime activities by degree of ID.

At Wave 5, of those participants engaged in some form of daytime activity, 66.26% (216) attended for more than 20 h per week, 25.15% (82) attended between 10 and 20 h per week, and 8.59% (28) spent less than 10 h per week in a daytime activity. Table 4 describes activity hours by degree of ID.

At Wave 1 there was no significant difference in terms of behaviour and emotional problems between those attending mainstream daytime activities ($M = 38.89$, $SD = 22.11$), and those attending activities for young people with ID ($M = 41.69$, $SD = 23.45$), $t(409) = -0.931$, $P = 0.353$. At Wave 5, those attending mainstream daytime activities had a mean DBC-A Total Behaviour Score of 29.30 (SD 20.80), compared with a mean of 36.12 (SD 22.33) for those attending activities specifically for young adults with ID, $t(328) = -2.01$, $P = 0.045$.

Table 3 Daytime activities by degree of intellectual disability from Wave 1 to Wave 5

Daytime activities	Wave 1	Wave 5
Mild		
Mainstream	38 (29.5%)	24 (21.6%)
Non-mainstream	91 (70.5%)	73 (65.8%)
No organised activity	0 (0%)	14 (12.6%)
	129	111
Moderate		
Mainstream	30 (17.5%)	25 (16%)
Non-mainstream	140 (81.9%)	124 (79.5%)
No organised activity	1 (0.6%)	7 (4.5%)
	171	156
Severe		
Mainstream	4 (4.3%)	0 (0%)
Non-mainstream	90 (95.7%)	72 (96%)
No organised activity	0 (0%)	3 (4%)
	94	75
Profound		
Non-mainstream	17 (100%)	8 (100%)
Total	18	8

n's do not match total sample because of missing IQ data for some subjects.

Community inclusion and social competence

At Wave 5, participants attended a mean (SD) of 3.64 (1.79) different types of community activities. Table 5 describes community social inclusion and social competence scores by degree of ID.

Predictors of outcome

Outcomes in terms of living arrangements, daytime activity, community inclusion and social competence (living skills) were assessed for all participants at Wave 5. Predictors of outcome are presented in Table 6. Multinomial logistic regression using *living at home* as base value, found that age was a significant predictor of Wave 5 living arrangement being *in care* or *independent*. Wave 1 behaviour and emotional problems was also associated with living in care at Wave 5. Multinomial logistic regression using *non-mainstream programmes* as the base value, found that degree of ID was significantly associated with Wave 5 main daytime activity being a *mainstream* activity or having *no daytime activity*. Participants who had a moderate to profound ID were less likely to be in mainstream programmes or no daytime activity than

	Mild	Moderate	Severe	Profound
Less than 10 h	11 (11.6%)	11 (7.4%)	4 (5.6%)	2 (25%)
10–20 h	28 (29.5%)	33 (22.3%)	19 (26.8%)	0 (0%)
More than 20 h	56 (58.9%)	104 (70.3%)	48 (67.6%)	6 (75%)
Total	95	148	71	8

Table 4 Hours per week spent in organised daytime activity by degree of intellectual disability at Wave 5

n's do not match total sample because of missing IQ data for some subjects.

Table 5 Wave 5 social competence and community inclusion by degree of intellectual disability

	Index of Social Competence Mean (SD)			Community inclusion Mean (SD)
	Community skills	Self-care	Communication	
Mild	10.00 (4.73)	11.23 (4.32)	3.50 (1.39)	3.67 (1.81)
Moderate	13.25 (4.42)	13.16 (4.65)	4.26 (1.43)	3.85 (1.82)
Severe	19.10 (1.98)	22.24 (4.22)	6.76 (1.21)	3.13 (1.25)
Profound	20.00 (0.00)	25.38 (1.19)	7.88 (0.35)	3.64 (1.79)

in a non-mainstream activity at Wave 5. Females were also significantly less likely to be in mainstream programmes at Wave 5. Self-care, community and communication skills were associated with degree of ID in that those with moderate to profound ID had lower social competence (i.e. higher scores on this scale). However, age, gender, degree of ID, and behaviour and emotional problems at Wave 1 were not associated with Wave 5 community social inclusion score.

Discussion

This study found a high proportion of adults with ID were still being cared for in the family home (61%) and a very small number were living independently (9%). This is higher than previously reported rates of adults living in the family home in 1998 (Braddock *et al.* 2001), although that study covered a broader age range (25–64 years) than this study. While the proportion of participants living at home with parent(s) decreased over the duration of the study as they moved from childhood to adulthood, the proportion of those living in care increased to 30%, with the majority of people with severe–profound ID living in care. This is likely to be a reflection of the high physical and medical care

needs of this population. By Wave 5, 12% of adults in the mild-moderate range of ID were living independently, a rate significantly lower than that reported by Braddock *et al.* (2001). These high rates of adults being cared for in the family home, with low rates of independent living, also suggests that the current provision of out of home residential services is inadequate, a finding supported by previous research in Australia and internationally (Braddock *et al.* 2001). Additionally, adult living skills were associated with Wave 1 degree of ID, with young people with a more severe degree of ID having poorer living skills across all domains assessed. This factor is likely contributing to the low rates of independent living and employment observed in this study and in previous research (e.g. Woolf *et al.* 2010). This finding highlights the need for programmes to better enhance community living skills for young people with ID, or to better facilitate access to such programmes, for example during the transitional school years.

Consistent with previous reports, one quarter (25%) of the parents caring for their adult child in the home reported fair to poor physical health, and elevated mental health problems, including anxiety and depressive symptomatology. Although the causal nature of these mental health problems

Table 6 Associations between age, gender, degree of ID and Wave 1 DBC score with living arrangements, daytime activity and community social inclusion at Wave 5

	Living arrangements [†] RRR		Daytime activity [‡] RRR		Regression coefficient		Regression coefficient – living skills		
	In care	Independent	Mainstream	No activity	Community social inclusion	Self-care	Communication	Community skills	
Age	1.18 ^{**}	1.13 [*]	0.99	1.08	-0.05	-0.06	-0.02	-0.01	
Female	1.08	1.14	0.52 [*]	0.52	0.15	0.77	0.05	0.44	
Mod-profound ID	5.85 ^{**}	0.75	0.36 ^{**}	0.23 ^{**}	0.07	5.20 ^{**}	1.68 ^{**}	5.33 ^{**}	
W1 DBC total score	1.02 ^{**}	1.01	1.00	1.01	-0.01	0.01	0.00	0.02 [*]	

* $P < 0.05$, ** $P < 0.01$.[†] 'At home' as base value.[‡] 'Non-mainstream' as base value.

RRR, relative risk ratio; DBC, Developmental Behaviour Checklist; ID, intellectual disability.

remains unknown, service supports and treatment are required to address this need in ageing parents who are caring for their adult children. Over a third of these parents reported being very dissatisfied with the long-term care arrangements for the son/daughter living at home with them. This dissatisfaction was associated with parent self-reported anxiety and depression. It is possible that concern regarding their child's future care plays a contributing role in the development of anxiety and depression in parents still caring for their adult child with ID. Further exploration of this issue might seek to better understand what parents preferences are for satisfactory long-term plans for their adult children, and how their own health and well being impacts planning.

The rate of paid employment in this sample is very low (11%), although similar to that reported by Howlin & Udwin (2006) in a follow-up study of adults with Williams syndrome. If combined with the rate of employment in sheltered workshops, the total rate of employment was 33.8%, a rate still low, but closer to that of Dusseljee *et al.* (2011) and Hall *et al.* (2005). However the overall rate of employment for young people with a mild degree of ID (43%) is significantly lower than the rate of 60% reported by Dusseljee *et al.* (2011) in the Netherlands. This finding is likely a reflection of a declining trend in open employment opportunities for people with ID in Australia (Australian Institute of Health and Welfare (AIWH) 2008; Department of Education Employment and Workplace Relations 2011), despite a number of Australian federal policy initiatives and government funding initiatives over the past decade (Dempsey & Ford 2009).

In addition to low levels of employment, of concern is the number of young people (6%) who were in no form of organised daytime activity. Similarly, a significant proportion of those who were participating in some form of daytime activity, 34%, were engaged in this activity for 10 or fewer hours per week. These data highlight the need for improved employment opportunities, improved employment support services and better access to such support. Improvements are also needed in the area of participation in daytime activities for young adults with a severe to profound degree of ID.

This study supported previous findings that young people with ID are often excluded from

participation in mainstream daytime activities and employment (Verdonschot *et al.* 2009; Dusseljee *et al.* 2011), frequently only attending activities specifically for people with disabilities. Social involvement in the community at Wave 5 was not associated with Wave 1 gender, age, degree of ID or behaviour and emotional problems. While these childhood factors are not associated with community inclusion in adulthood, future research needs consider what factors (e.g. community attitudes, financial considerations, accessibility) may influence the social involvement of adults with ID in their communities. These results are also consistent with those of Dusseljee *et al.* (2011), highlighting that people with a more severe–profound degree of ID are at high risk of social exclusion and are more likely to attend daytime activities specifically for persons with an ID.

A recent working paper by the International Labour Organisation highlighted the need address barriers to inclusive employment (Parmenter 2011), including lack of information, training and transport, the provision of financial support to employers, and facilitating the transition from school to employment. The development of social skills is also recognised as an important element in acceptance within an employment setting (Riches & Green 2003). Successful inclusive employment is also reliant upon employer attitudes, sustainable programmes with stakeholder commitment, a person-centred approach which includes a comprehensive needs assessment, and communication with parents or caregivers (Parmenter 2011). Supported mainstream employment programmes have been found to be cost-effective (Tuckerman *et al.* 1999; Cimera 2009), beneficial to quality of life (Eggleton *et al.* 1999) and important in influencing the self-concept of people with disabilities (Knox *et al.* 2000). Employment has been identified by young people with ID as important in providing a social outlet outside the home (Parmenter & Knox 1991). It is concerning that only 11.3% of our study sample were in paid employment, with a further 22.5% working in sheltered workshops. Although Wehman *et al.* (2003) have argued that working 30 h or more a week is one indicator of quality of employment, participants in this study were frequently only engaged in activities on a part time basis, with many attending less than 20 h per week.

This study found higher levels of behaviour problems at Wave 5 in those young people living in care and in non-mainstream daytime activities. It is interesting to note that these differences were not apparent at Wave 1, but developed as the young people transitioned into adulthood where having early behaviour problems was found to be associated with living in care as an adult. Further research is needed to examine the potential role behaviour problems play in living arrangements and access to employment. It is possible that these emotional and behavioural difficulties restrict access to activities and opportunities for social inclusion and community participation, but it is also possible that the restricted opportunities for participation in mainstream life contribute to these mental health problems. The exact causal mechanisms of this process remain to be determined. With socioeconomic status and financial hardship identified as a predictors of behaviour and emotional problems in childhood (Emerson & Hatton 2007a,b,c; Emerson *et al.* 2009), the impact of this factor on opportunities and participation warrants exploration.

This study investigated living circumstances and participation in daytime activities in a community sample of young people with ID over time. Participants were from both rural and metropolitan regions in Victoria and New South Wales, Australia, and at Wave 1, representative of children and adolescents with ID (Einfeld & Tonge 1996a,b). A potential limitation of this study is the lack of information on type of employment and amount earned. Future research could also investigate perceived barriers to independent living and employment.

It may be argued that for adults with an ID, living at home with their parents and not having access to full time employment or full time daytime activities increases social isolation and impedes community participation and inclusion. This is likely to impact upon the quality of life and mental health of young people with ID. Additionally, the effect of the long-term caring role embarked upon by many parents cannot be overlooked. Although many parents do not see this role as a burden, there is a significant impact upon their well-being. Services and supports to address the needs of parents should be developed and their efficacy evaluated.

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