

DEINSTITUTIONALISATION IN AUSTRALIA PART II: RESULTS FROM A LONG-TERM STUDY

Louise Young and Adrian F. Ashman

Introduction

Early longitudinal studies of deinstitutionalised populations reported successful community placement for younger people with less severe intellectual disability and higher levels of adaptive behaviour while unsuccessful relocations were due to inappropriate social behaviour, inadequate nutrition, and poor home maintenance (e.g. Schalock *et al.*, 1981a: 1981b). Hence, it was believed that community relocation was not an option for older residents and those with more severe levels of intellectual disability and/or challenging behaviour. The beneficial effects of relocation for aging residents with severe and profound intellectual disability have only recently been highlighted (see e.g. Heller *et al.*, 1998a,b; Stancliffe and Lakin, 1998) and this paper provides further evidence for the benefits of deinstitutionalisation for those who are ageing, have severe levels of intellectual disability and have been institutionalised for most of their life.

The study reported here was undertaken for three reasons. First, the intent was to follow residents over a number of years to provide insights into the merits of living in a community setting rather than an institution as suggested by Cullen *et al.* (1995). To judge the effectiveness of the deinstitutionalisation process, data were collected over a 2.5 year period (from 6 months before the relocation to 2 years post-relocation in the community). Data collection required selection and development of instruments suitable for determining adaptive and maladaptive behaviour, choice-making, and objective quality of life.

Second, the effectiveness and/or value of deinstitutionalisation for people with severe and profound disabilities has not been definitely established (Erb, 1995). Previous research has shown that relocation, especially in older adults with intellectual disability can result in increased mortality, adverse physical effects, and emotional, behavioural and mental health

***Louise Young, Ph.D.**

Lecturer in Medical Education, School of Medicine, The University of Queensland, Brisbane, Qld 4072, Australia.

Tel: 0061 7 3365 5082 Fax: 0061 7 3365 5522 E-mail: l.young@uq.edu.au

Adrian Ashman, Ph.D.

Professor, Schonell Special Education Research Centre, School of Education, The University of Queensland.

* For Correspondence

difficulties (Heller *et al.*, 1998a; Heller, 1988). There may be beneficial transition effects for older and younger people (Heller *et al.*, 1998a) but there may also be complications because many of those relocated had severe levels of intellectual disability, cerebral palsy and/or epilepsy and health problems.

Third, it is clear that adaptive behaviour typically increases in community settings but this depends upon the nature of opportunities and services provided. The frequency and severity of maladaptive behaviour, such as aggression and self-injury, may not necessarily decrease as a result of moving into the community even though community residences provide more favourable staffing ratio and are said to provide better outcomes when compared with institutions (Stancliffe and Lakin, 1998). However, positive outcomes for community living are not always favourable in terms of adaptive behaviour and residents who remain in institutions may be no worse off than those who are relocated in terms of some objective benefits (see e.g. Stancliffe and Lakin, 1999; Cullen *et al.*, 1995). Choice-making was also selected as a dependent variable as the availability of choice is considered integral to quality of life (Kearney *et al.*, 1998). To evaluate the overall effectiveness of deinstitutionalisation it seems important to monitor these changes over time.

In this project the intention was to monitor changes in skills and life circumstances of adults with intellectual disability as they were relocated from an institution to community homes and to record any changes in quality of life issues that might be considered equivalent to the experiences of others in the community without intellectual disability. Other studies (e.g. Cullen *et al.*, 1995; Cummins and Dunt, 1990; Heller *et al.*, 1998b) have incorporated this type of longitudinal approach

using one baseline measure and repeated measures so there are established precedents for the current design. Internal validity was established as each individual acted as his/her own control so that changes in, for example, adaptive behaviour or community access were due to changes in the provision of residential services for a specified individual.

The research took place in Queensland, Australia, between 1995 and 2001. In 1993 the government of the day decided to close the government-run institution, Challinor Centre, and relocate its residents to community based housing. The study involved the long-term follow-up of the population of residents who once lived in the centre and who were relocated into community homes located in outer suburban areas of Brisbane and provincial areas along the east coast. Descriptions of the relocation process and details about the new residential arrangements have been described elsewhere (see e.g. Young *et al.*, 2001, 2000) for descriptions of the institution and community service provisions.

Method

Participants

The 57 males and 47 females in this study were relocated from the institution to community accommodation for at least 24 months. At the time of their initial assessment in the institution, the residents ranged from 21 to 84 years of age (mean = 47 years, SD = 15 years) and had spent from 2 to 70 years (mean = 26 years, SD = 16 years) living in institutional care and from 2 to 70 years at Challinor (mean = 19 years, SD = 13 years). All had a primary diagnosis of intellectual disability. Based on a review of facility files, 15 individuals

were classified as having mild intellectual disability, 26 had moderate intellectual disability, and 63 had severe or profound intellectual disability. Fifty residents also had additional disabilities, involving vision, hearing, or mobility impairments. Over half the group had one or more socially unacceptable challenging behaviours and most had little or no experience in community living arrangements. This was a population requiring high support because 74% of the group had severe intellectual disability, challenging behaviours, specific health needs and/or had been institutionalised long-term. The research was designed to evaluate changes in adaptive and maladaptive behaviour, choice-making, and objective life quality for a population that was considered problematic for community living.

Assessment materials

Data collection required selection and/or development of instruments to assess changes in: (a) adaptive and maladaptive behaviour, (b) choice-making, and (c) objective life quality. Felce's (1997) theory of quality of life provided the theoretical basis and rationale for selection and use of the Adaptive Behaviour Scale (Nihira *et al.*, 1993), Resident Choice Assessment Scale (Kearney *et al.*, 1995), and the Life Circumstances Questionnaire. Only objective aspects of life quality were evaluated and an indication of life quality is also reflected through assessments of adaptive behaviour and choice-making (Emerson, 1985). The assessment materials are described below.

Adaptive Behaviour Scale

The AAMR Adaptive Behaviour Scale - Residential and Community 2nd Edition (ABS) (Nihira *et al.*, 1993) provided an assessment of adaptive (Part I) and maladaptive behaviour (Part II). Ratings of adaptive behaviour are made in a number of domains including independent functioning, physical development, economic activity, domestic activity, self-direction, responsibility and socialisation. The Adaptive Behaviour Scale Part II has ratings of maladaptive behaviour in domains that include social behaviour, conformity, stereotyped and hyperactive behaviour, self-abusive behaviour, and disturbing interpersonal behaviour. The scores recorded for the study were domain scores and total scores for ABS Parts I and II.

This assessment was chosen because it has established reliability and validity in determining the behaviour of adults with intellectual disability, alpha coefficients ranging from .82 to .98 (Part I) and .81 to .94 (Part II), and it was the most suitable tool to use because of the age range and level of intellectual disability of the participants. In the present study, the overall inter-rater reliability coefficient for 10% of the sample established at each data collection point was .94 (Part I), ranging from .59 (Self direction) to .94 (Independent functioning) on each of the domains, and .67 (Part II), ranging from .36 (Social engagement) to .81 (Social behaviour).

Resident Choice Assessment Scale

Opportunities to exercise personal preferences and freedom of choice are implicit in the principle of normalisation (Nirje, 1985). So, a measure of the degree to which individuals were involved in making choices was necessary to indicate

changes in lifestyle from institution to community. As the model under which participants were relocated paid greater attention to individual needs, choice-making was a way of recording whether this was occurring. Size of residence is not the only factor that influences choice availability but it is also the provision of opportunities for self-determination (Vandergriffe and Chubon, 1994). A model of service that encourages opportunities for self-determination will be reflected in increased choice-making. The opposite is environmental restrictiveness (Kearney *et al.*, 1998) and if levels of choice-making decrease after relocation, then only the place of residence and not the lifestyle has changed.

Choice-making was assessed using the psychometrically validated 25-item Resident Choice Assessment Scale (RCAS) described by Kearney *et al.* (1995). Example questions include "Does the client choose the time that he/she gets out of bed in the morning?" and "Does the client choose his/her own recreation activities?" Questions are rated on a 1 (Never) to 7 (Always) Likert scale (Likert, 1932) and mean scores (range 0-7) were calculated. The RCAS was selected because of its demonstrated test-retest (.91) and interrater (.84) reliability and construct validity (Kearney *et al.*, 1995) and it is valid for use by direct-care staff in rating the extent of choice available to adults with developmental disabilities. In the present study inter-rater reliability was .73.

Life Circumstances Questionnaire

Information on various aspects of a person's lifestyle would indicate whether life conditions have changed over time in the community. As most participants have severe and profound intellectual disability, a limited behavioural repertoire, and/or

limited communication skills it was deemed inappropriate to use validated quality of life assessments such as QOL-Q (Schalock and Keith, 1993) or Com QOL-ID (Cummins, 1993) that require participation by individuals with intellectual disability or multiple staff participation in individual assessments over repeated assessment sessions. Only objective information was evaluated owing to difficulties with the use of subjective evaluation in people with intellectual disabilities such as stability of their objective perceptions over time, unreliability of longitudinal subjective perceptions and the difficulties associated with collecting reliable subjective evaluations from this population.

Lifestyle was assessed using the Life Circumstances Questionnaire (LCQ) developed by the authors as a semi-structured interview and based on an interview questionnaire developed and used by Ashman *et al.* (1991) in a study of older people with intellectual disability living in the community. It is not a standardised instrument and, after trialing, modifications were made based on feedback from professionals working in the field of intellectual disability. Scoring, reflecting improvements in life circumstances, was based on the expectations or experiences of adults without intellectual disability and the scoring procedure was checked with professionals and adults ranging in age from 20 to 70 years for consistent, accurate responses, and modified where necessary. Improved or increasing conditions or experiences were reflected by increasing scores.

The LCQ is an 11 page document that seeks information about objective aspects of life quality. A description has been reported elsewhere (Young *et al.*, 2001, 2000). Data were collected during a conversational interview of approximately one hour that provided a flexible format for

gathering information about aspects of people's lives.

Inter-rater reliability in the present study was .88, with averages for separate domains ranging between .52 (Social/emotional well-being) and .97 (Material well-being). The low correlation for Social/emotional well-being may have been caused by variations in respondents' (staff) judgements about social contacts and friendships. Respondents were asked to rate how many friends an individual had and there may have been discrepancies caused by staff who named all social contacts as friends even though they were instructed to only count a friend in the same context as they would consider a person a friend.

Proxy Respondents

In the present study, staff involved in direct care were respondents for objective information and completion of standardised assessments. The use of proxy respondents has been shown to have both satisfactory reliability (Schalock and Keith, 1993; Stancliffe, 1999) and questionable reliability (Rapley *et al.*, 1998; Reiter and Bendov, 1996). Proxies are not a substitute for first-hand subjective information, but in the present study, it was deemed appropriate to have proxy respondents rather than no respondents (Stancliffe, 1999) and they are accurate for objective issues related to quality of life (Cummins, 1998).

Reliability was established for each instrument. Two staff persons served as informants for all assessments to obtain inter-informant agreement data for approximately 10% of residents. Proxy respondents required specific criteria including fluent English and literacy skills and must have been employed in direct care activities with the resident for at least

six months. Instruments were administered identically on every occasion. The commercial version of the ABS and printed copies of the RCAS and LCQ were administered according to specified criteria.

Procedure

The research involved an assessment of adaptive and maladaptive behaviour, choice-making, and life circumstances that occurred approximately 6 months prior to leaving the institution and then again at 1-, 6-, 12-, 18- and 24 months of community living. All assessments were conducted by the authors who administered assessment forms and interviewed direct care staff. Apart from the initial institutional assessment, the same member of staff was used at each time interval in the community provided they were still involved in direct-care activities. Whenever the designated member of staff was no longer working at the house, another person was selected in consultation with the service management, but this person must have worked with the resident in direct care activities for at least six months.

Assessments and interviews were completed in a two-hour visit to the residence to collect the information. For a small number of residents located in regional Queensland, direct-care staff completed the assessments independently after verbal instruction and direction over the telephone. The Life Circumstances Questionnaire was administered via telephone and one assessment visit was made to each regional residence at either 6 or 12 months. Ethical clearance was obtained from appropriate bodies within the University of Queensland and Disability Services Queensland to undertake the project and agreement to the family member's

participation in the study was obtained from families or legal guardians when required.

Results

Data were analysed using Statistical Package for Social Sciences Version 6.1 (SPSS, 1995). All quantitative data were checked for assumptions of normality, homogeneity of variance, and sphericity. The relatively large sample size ($N = 104$) compensated for the non-normal distribution of some results. Where assumptions of sphericity have been violated the Greenhouse-Geisser correction was applied to produce a more conservative estimate of effect. Mixed measures MANOVA results report Greenhouse-Geisser values. As the primary research question focuses on change over time, a planned comparison was used, namely, trend analysis. A relationship among means is described as a linear trend when the relationship can be represented as a straight line and as higher order trends, such as quadratic with one change of direction, or cubic with consistent increases and decreases in direction (Howell, 1997; May *et al.*, 1990). The overwhelming majority of results exceeded .80 of Cohen's criteria for power which indicates a large effect and all were above .50 (Cohen, 1988).

Adaptive Behaviour

A mixed measures MANOVA with repeated measures was performed on the mean scores for ABS Part I for the total population. Trend analysis allowed for a comparison of patterns in skill level and lifestyle of the institution population over time. Results showing changes over time are presented in TABLE I.

There was a statistically significant difference in the total mean scores for adaptive behaviour over time, $F(1, 92) = 5.5$, $p < .001$. Trend analysis revealed a significant positive linear trend in adaptive behaviour scores over time, $F(1, 92) = 10.8$, $p < .001$, and a significant quadratic trend, $F(1, 92) = 4.5$, $p < .05$. A linear trend is reflected by increased adaptive behaviour scores over time, however, by 24 months it was beginning to plateau which explains the quadratic component. Analysis of the separate domains of the ABS revealed significant improvements over time in Economic Activity, Language Development, Numbers and Time, Domestic Activity, Pre-vocational/Vocational Activity, Responsibility, and Socialisation.

Planned comparisons revealed a significant positive linear trend for Language Development, $F(1, 92) = 6.46$, $p < .05$; Numbers and Time, $F(1, 92) = 4.6$, $p < .05$; Prevocational/Vocational Activity, $F(1, 92) = 7.3$, $p < .01$; and Socialisation, $F(1, 92) = 25.5$, $p < .001$. Adaptive behaviours in these domains increased in a positive direction over the two years of community living and at this time there was no indication of a plateauing of skills.

Significant linear and quadratic trends were recorded for Economic Activity, $F(1, 92) = 8.7$, $p < .01$ and 9.67 , $p < .01$; Domestic Activity, $F(1, 92) = 13.94$, $p < .001$ and 11.64 , $p < .001$; and Responsibility, $F(1, 92) = 12.2$, $p < .001$ and 10.2 , $p < .01$. While the linear trend provided evidence for the acquisition of adaptive skills, the quadratic trend indicated that such increases were beginning to plateau as time progressed.

The areas showing no significant change over 24 months in the community were Independent Functioning, Physical Development, and Self-Direction. These have remained stable. With the exception of Physical Development, there has been no increase in adaptive skills that encour-

TABLE I
Adaptive Behaviour Scale Part I Mean Scores Over Time for the Group (n = 104)

ABS Part I Domains (maximum score)	Assessment Time							F (df = 1,92)
	Institution	1 month	6 months	12 months	18 months	24 months		
Independent Functioning (119)	M	44.7	46.1	47.5	46.5	45.2	45.1	1.15
	SD	28.8	26.9	27.8	27.1	27.4	27.5	
Physical Development (24)	M	15.1	15.0	15.2	15.4	15.2	15.0	.65
	SD	5.6	4.9	5.1	5.3	5.2	5.3	
Economic Activity (25)	M	2.4	3.1	3.5	3.5	4.5	3.5	2.58*
	SD	3.2	3.3	3.6	3.7	9.5	3.2	
Language Development (43)	M	14.1	14.4	14.8	15.2	14.8	15.4	2.52*
	SD	10.3	9.6	9.8	9.4	9.6	9.8	
Numbers/ Time (14)	M	2.1	1.9	2.4	2.3	2.5	2.5	2.32*
	SD	3.4	3.2	3.6	3.5	3.6	3.4	
Domestic Activity (23)	M	4.3	5.1	5.7	6.3	6.1	6.0	7.97**
	SD	5.6	6.4	6.5	6.3	6.4	6.3	
Prevocational/ Vocational (11)	M	2.0	2.5	2.5	2.7	3.1	3.0	2.85**
	SD	3.2	3.7	3.6	3.7	3.7	3.7	
Self-direction (23)	M	8.3	9.2	9.5	8.8	9.6	9.8	1.92
	SD	6.6	6.6	6.4	5.8	5.4	5.9	
Responsibility (10)	M	2.8	3.8	3.7	3.9	4.0	3.8	7.26**
	SD	2.9	3.1	3.3	2.9	2.8	2.9	
Socialisation (26)	M	11.6	12.2	13.3	12.7	14.2	14.2	8.34**
	SD	6.2	6.0	5.6	5.6	3.9	4.1	
Total (318)	M	107.4	114.1	118.0	117.2	119.5	118.9	5.46***
	SD	66.3	64.0	65.0	61.8	60.3	60.2	

* $p < .05$

** $p < .01$

*** $p < .001$

age independence and self-reliance which suggests that staff are still over-controlling residents.

Maladaptive Behaviour

A mixed measures MANOVA with repeated measures was performed on the total mean scores for the group. Scores over time are shown in TABLE II. Analysis revealed there was a significant change in the overall level of maladaptive behaviour after 24 months of community living, $F(1, 92) = 3.55, p < .01$, but post hoc tests revealed no linear or quadratic trends indicating the changes were not in any consistent or favourable direction. Scores on the ABS Part II showed a significant decrease in the amount and severity of challenging behaviour after one month, $t(96) = 3.36, p < .001$, compared to the rates before leaving the institution but after this initial decrease scores began to increase and by the two year follow-up were nearly back at the institution levels.

Analysis of the individual domains of ABS Part II showed significant negative linear and quadratic trends for Trustworthiness, $F(1, 92) = 6.03, p < .05$ and $6.75, p < .05$, and a quadratic trend for Sexual Behaviour, $F(1, 92) = 4.4, p < .05$. Over 24 months of community living residents had become more trustworthy and were exhibiting less inappropriate sexual behaviour, however, the quadratic trend suggested these results were beginning to plateau.

Trend analysis of the individual ABS Part II domains with significant changes over time revealed no linear or quadratic trend for the domains of Social Behaviour, Sexual Behaviour, Social Engagement and Disturbing Interpersonal Behaviour indicating that while scores had changed at some time during the relocation (usually in the early weeks following transfer from

the institution to the community residence and in the honeymoon period when both residents and staff were testing each other), by 24 months they were not significantly different from the Challinor levels. One reason for fluctuating scores may be that staff notice behaviours more frequently in the smaller, more confined suburban houses and are less tolerant or accepting of annoying behaviours indicating higher expectations of normality. At Challinor there was always much background noise that may have masked bizarre behaviours, staff could isolate themselves from residents in locked staffrooms and they may have been more accepting of maladaptive behaviour over time.

Choice-making

A mixed measures ANOVA was performed on the mean RCAS scores for the total group and scores over time are presented in TABLE III. Results indicated statistically significant changes over time with residents in the community having increased choice-making opportunities from a mean of 3.0 everyday choices to 4.3 after 24 months, $F(1, 92) = 57.96, p < .001$.

Trend analysis revealed a significant positive linear trend, $F(1, 92) = 156.05, p < .001$ and a significant quadratic trend, $F(1, 92) = 31.85, p < .001$. After an initial positive increase, the amount of choice-making plateaued. However, as residents are making just over 60% of every day decisions for themselves at 24 months it would be desirable for the linear trend to continue to a score of seven for choices involving everyday decisions. Whilst the results from the RCAS indicated that opportunities for choice-making have increased consistently over time, with individuals now making more than half of

TABLE II
Adaptive Behaviour Scale Part II Mean Scores Over Time for the Group (n = 104)

ABS Part II Domains	Assessment Time							F (df = 1,92)
	Institution	1 month	6 months	12 months	18 months	24 months		
Social Behaviour	M	13.6	10.6	11.6	14.3	13.1	13.5	3.42*
	SD	13.5	11.1	10.8	13.5	11.6	12.4	
Conformity	M	8.2	6.0	7.0	7.7	6.9	7.4	2.13
	SD	8.0	6.3	7.3	7.8	6.4	7.1	
Trustworthiness	M	7.7	4.6	5.0	5.6	4.7	4.9	6.17***
	SD	8.7	6.1	6.2	7.6	5.5	5.5	
Stereotyped/ Hyperactive Behaviour	M	10.4	10.0	11.7	12.2	10.6	11.8	1.90
	SD	8.5	7.4	8.2	8.6	7.7	9.3	
Sexual Behaviour	M	4.0	2.2	3.0	3.0	2.9	2.9	4.79*
	SD	5.4	4.1	5.1	5.6	4.8	5.1	
Self-abusive Behaviour	M	5.4	4.1	5.1	5.6	4.8	5.1	2.15
	SD	5.1	4.3	5.1	5.2	4.5	4.4	
Social Engagement	M	8.2	7.8	8.6	8.3	6.5	7.2	3.15*
	SD	5.7	5.2	5.7	5.9	5.2	5.3	
Disturbing Interpersonal Behaviour	M	7.4	6.0	7.4	8.0	7.3	8.2	2.29*
	SD	7.6	6.7	7.0	8.4	6.9	8.3	
Total (318)	M	65.9	51.7	59.0	64.6	57.3	61.5	3.55***
	SD	45.0	35.9	38.1	44.6	36.0	41.2	

* $p < .05$ ** $p < .01$ *** $p < .001$

TABLE III
Resident Choice Assessment Scale Mean Scores Over Time for the Group (n = 104)

	Assessment Time							F* (df = 1,92) ^a ($p < .001$)
	Institution	1 month	6 months	12 months	18 months	24 months		
Resident Choice Assessment Scale	M	3.0	3.8	4.0	4.1	4.3	4.3	57.96***
	SD	1.34	1.45	1.32	1.24	1.21	1.21	

their own everyday decisions but there is still the challenge for services and support staff to find ways of facilitating opportunities for choice-making all of the time.

Objective Life Quality

Mixed measures MANOVA was performed on the total result and individual domains of the LCQ to determine changes in objective life quality. Results are presented in TABLE IV. Trend analysis of the overall result revealed a significant positive linear trend increase, $F(1, 92) = 166.42$, $p < .001$, indicating aspects of their life changed over time and a significant quad-

ratric trend, $F(1, 92) = 28.07$, $p < .001$, indicating these positive changes were beginning to plateau. Significant positive linear and quadratic trends were reported for the domains of Material Well-being, $F(1, 87) = 1016.9$, $p < .001$ and 24.2 , $p < .001$; Community Access, $F(1, 92) = 410.2$, $p < .001$ and 154.9 , $p < .001$; Routines, $F(1, 92) = 60.5$, $p < .001$ and 116.4 , $p < .001$; Self-determination, $F(1, 92) = 142.5$, $p < .001$ and 45.9 , $p < .001$; Social/Emotional Well-being, $F(1, 92) = 131.7$, $p < .001$ and 27.2 , $p < .001$; Residential Well-Being, $F(1, 92) = 907.4$, $p < .001$ and 624.4 , $p < .001$ and General factors, $F(1, 92) = 75.2$, $p < .001$ and 333.6 , $p < .001$. Residents had more personal possessions; increased variety, fre-

TABLE IV
Life Circumstances Questionnaire Mean Scores Over Time for the Group (n = 104)

Domains		Assessment Time						F* (df = 1,92) ^a (p < .001)
		Institution	1 month	6 months	12 months	18 months	24 months	
Material Well-being	M	9.8	18.4	24.4	30.3	35.9	40.6	655.2***
	SD	3.21	3.93	5.28	6.52	7.44	8.61	
Physical Well-being	M	17.1	12.9	14.6	15.2	15.1	15.6	16.9***
	SD	3.67	3.37	3.71	3.94	4.20	3.62	
Community Access	M	30.4	52.7	65.8	70.4	68.3	70.6	161.3***
	SD	12.46	19.11	20.37	18.76	17.65	15.95	
Routines	M	23.3	47.5	48.2	48.3	47.6	48.9	60.5***
	SD	16.26	17.72	14.28	15.05	16.65	15.39	
Self-determination	M	21.5	31.2	36.7	36.6	38.3	39.8	65.2***
	SD	16.60	14.63	14.24	14.05	13.53	15.72	
Social Emotional Well-being	M	21.8	28.6	34.5	34.3	36.3	37.2	42.4***
	SD	14.61	15.29	15.21	14.13	14.19	12.59	
Residential Well-being	M	14.3	30.7	30.9	31.5	32.4	32.4	552.7***
	SD	3.76	3.30	3.86	3.62	3.28	3.15	
General	M	4.6	11.4	13.1	11.6	11.3	10.2	110.2***
	SD	2.22	3.15	2.99	3.13	3.54	3.39	
Total	M	133.1	225.0	258.4	270.3	276.9	289.5	352.4***
	SD	54.92	58.67	59.78	51.02	49.99	48.04	

quency and opportunity for accessing the community; increased self-determination; increased contact with family and friends; and improved residential circumstances.

Physical well-being showed significant negative linear and quadratic trends $F(1, 92) = 23.38, p < .001$; and $8.55, p < .01$, indicating that in terms of medical visits residents were making fewer trips to the doctor whereas, in the institutions, every person had three monthly medical appointments whether they were required or not. Reduced medical appointments and medication, and fewer accidents could also be an indicator of improved health but this would require further investigation. Even a reduction in medical visits is evidence of a more normalised lifestyle in the community as citizens without intellectual disability do not visit the doctor on a regular three monthly schedule unless they are ill or require regular review for a health condition.

Discussion

Adults from 21 to 84 years, with intellectual disability were each followed over a two year period as the institution in which they had lived for many years was progressively closed. All residents were relocated into homes in the community and the changes in their lives were monitored in a repeated measures study. The study focused on four aspects of change - adaptive behaviour, maladaptive behaviour, choice-making and objective life quality - to determine if relocation from an institution affected their lifestyle in the community.

The repeated measures analyses of adaptive and maladaptive behaviour, choice-making, and objective life quality provided evidence that residents were

more active and participated more in the community than when they lived in the institution. Residents now lead lives that are more similar to those of people without intellectual disability. The most significant finding from this study was the increased levels of adaptive behaviour, choice-making, and objective life quality, and stable levels of maladaptive behaviour over 24 months of community living for the 104 residents. However, all areas assessed showed individual outcome variability over time. Implications of the findings are discussed below.

Adaptive Behaviour

The outcome of this research shows initial increases which, after two years, are beginning to plateau in some areas. This suggests that a lifestyle in the community based on the principle of normalisation requires more than just relocation to maintain and enhance adaptive behaviour. The plateauing of skills after 24 months might be indicative of a prolonged honeymoon period where there is a loss of interest by both residents and staff in joint participation in activities of daily living such as meal preparation or housekeeping. As well as an increased recognition of individual rights experienced in the community and because staff allow residents to make most daily choices from a known set of limited options, there is often no concomitant increase in an individual's responsibility to perform tasks or for staff to encourage or facilitate participation in activities. Staff seem to find it easier and quicker to do things for the residents without expecting them to participate.

While adaptive behaviour increased for most participants the results were by no means uniform. Some adults with mild/moderate levels of intellectual disability

showed few gains in adaptive skills while skills in the oldest age group may have levelled off due to the increasing presence of physical disability or loss of skills in a naturally age-related deterioration. Lack of adaptive skill acquisition may have been due to expectation from staff members that relocation into a community lifestyle would be all that was required to foster resident development. Staff were neither aware of the need for, nor did they have the skills, to teach new skills related to independent functioning and domestic activities. It appeared that it was often the unwitting modelling of social skills that made the most significant impact on residents. More complex skills (such as dressing) required a more advanced level of teaching expertise and did not change.

Increases in adaptive behaviour occurred in houses where staff were actively involved in teaching, facilitating acquisition of skills, providing opportunities for participants, and behaved pro-actively in fostering learning and individual development. Many staff did not often demonstrate skills or knowledge of explicit teaching (Westwood, 1997), or operated their house under a hotel model that meant no responsibility or obligation was placed on some residents to assist in daily chores. Staff may advocate residents' rights to make choices (reflected by increased scores on RCAS) but there was no indication of concurrent increase in resident responsibility to perform certain adaptive behaviours (reflected by a decrease in ABS Part I scores). It appears that a need exists for direct care staff to learn and use explicit teaching techniques such as active support (Jones *et al.*, 1999) and to foster responsible choice-making.

Maladaptive Behaviour

Residents' maladaptive behaviour remained at a relatively stable level as measured by the ABS, however, there was a change in the nature of problem behaviours. Most residents had little experience with community living and lacked the opportunity to make choices and decisions or act independently. Many showed extreme dependence on carers, and displayed a range of socially unacceptable behaviours. The separate domains of the ABS Part II show reduction over time (physical and verbal aggression) while other maladaptive behaviours increased (lack of conformity). These outcomes could be interpreted as residents making their own choices and decisions, albeit inappropriate ones. Stereotypic and self-abusive behaviours did not change so it does not appear to be the actual residential location and reduced resident numbers that are influential. That the group total score remained at the institutional level may be a function of changes in the nature and degree of maladaptive behaviour. However, the fact that maladaptive behaviour declined significantly at the first assessment and then returned to the institution levels suggests that it is possible to decrease the occurrence of these behaviours and further examination is required to determine why improvements were not maintained.

In the smaller, usually quieter community homes maladaptive behaviours are more audible or readily observable. Most community staff had expectations of residents' behaviour based on societal standards that are set at a higher level than institutional levels. It was acknowledged that in the institutional setting many residents acted in ways that were not acceptable by community standards and, hence, were rated as maladaptive even though the institution staff accepted them as com-

monplace (perhaps even normal for that group of people).

Another explanation for the lack of substantial improvement in maladaptive behaviour levels were the characteristics of the relocated individuals. All had experienced long-term institutionalisation so it is perhaps encouraging that the levels of maladaptive behaviour did not increase in the community. Other researchers have reported no change in maladaptive behaviour (Emerson and Hatton, 1996; Larson and Lakin, 1989) and it has been argued that maladaptive or challenging behaviour is not caused solely by institutional environments (Cullen *et al.*, 1995; Felce *et al.*, 1995). However, behaviour problems do not occur in a vacuum, are responsive to the environment, and often result from a shortfall in services rather than institutionalisation or deinstitutionalisation alone (Jacobson and Schwartz, 1983). The maintenance of uniform levels of maladaptive behaviour reinforces the need for specific behavioural programmes to modify maladaptive behaviour such as those based on positive behavioural support (Koegel *et al.*, 1996).

Choice-making

Independent choice-making was a relatively common experience for those living in the community with residents making over 60% of everyday choices (e.g. when to get out of bed, when to take a shower). However, there were differences associated with the level of intellectual disability. As might be expected adults with mild/moderate levels of intellectual disability recorded significantly more everyday choices whilst those with severe/profound disability, especially the younger members of the group, although these

individuals were still making choices 50% of the time. Choice-making behaviour was also beginning to plateau toward the end of the study. This could have been due to either staff familiarity with residents or inability by staff to facilitate greater choice-making due to their own modest developmental training skills or the nature of staffed community houses. For example, there are restrictions in terms of individual preferences about meals, household routines, recreation, and leisure pursuits that cannot always be accommodated because of the needs of the group or household (Rawlings *et al.*, 1995; Stancliffe, 1991). Conflicts can also occur as people with intellectual disability may not be aware of the consequences of their choices, and trial-and-error learning may be unsafe or inappropriate.

The slowing of choice-making frequency and opportunity may reflect the establishment of routines in the house and staff knowledge of residents and so they anticipate or predict choice rather than allowing the person to be active in choice situations. However, it is important for people to have their changing needs and preferences accepted through availability of a high level of choice-making, a point also made by Janicki (1990). It is not always appropriate for staff to anticipate a person's choices as they need to be actively involved in the process and interaction. Similarly, it is inappropriate for staff to allow residents to "do their own thing" as inappropriate choices restrict habilitation (Bannerman *et al.*, 1990; Crichton, 1998). However, many staff accept resident non-participation in self-care or domestic chores because they fail to understand that the resident is being denied the opportunity to become more autonomous through the acquisition of independent living skills. Choice-making should be related to the capabilities of individuals,

with staff direction and teaching occurring where inappropriate choices are being made rather than absolute acceptance of resident choice. This involves the reconciliation of individual rights versus responsibility issues which need to be addressed by both direct care staff and service providers

In Australia, community support staff seem overly conservative about their responsibilities vis-a-vis resident choice (Parmenter, 1994) and the plateauing of choice opportunities might reflect this conservatism. Hence, direct care staff need guidelines about when it is legitimate to stand back so that the resident learns from risk-taking activities and their consequences and when they should intervene to maintain duty of care.

Objective Life Quality

Objective life quality (living conditions, routines, possessions, social networks and community access) improved for all participants regardless of location, service provider, age or level of intellectual disability. The residents live in modern, brick, freestanding public housing, typical of the surrounding neighbourhood in outer suburban areas, and with more favourable staff:resident ratios than in the institution. Meal times are flexible and where possible times for rising or going to bed are determined by residents. Each household is responsible for house management. There are 15 hours of funded individual day activities per week for each person although there is variability in the degree of structure and all involve access to the local community, age-appropriate activities, and recreation. Despite these improvements in objective quality of life (mean score increased from 133 in the institution to 289 after 24 months), there is still much that

can be done given the maximum score is 530+. While it is encouraging that life circumstances improved most notably in standard of residential accommodation, increased opportunities for life routines and community access, and the development of wider social networks, discrepancies occur across services and even for individuals within the same service. These generally relate to the quality of staff interactions and their facilitation of leisure and recreation activities.

There was a great variety and number of home-based leisure activities in the early months of relocation but, by 24 months, these were declining, except in houses where residents were kept actively involved in leisure pursuits such as painting, puzzles, gardening, knitting, cooking and care for a pet. Lack of maintained leisure activity has been reported by other researchers (Dagnan *et al.*, 1998). No one in the present study attended full-time day services and community activities were only attended for several hours on a weekly basis (e.g. social groups, craft, pottery, swimming). This indicates a need for direct care staff to devise innovative ways for enabling residents to enjoy opportunities that lead to personal competence, development and autonomy. Other researchers undertaking longitudinal follow-up of community relocation have also found no evidence of people who were undertaking new or ordinary day time activities (Donnelly, *et al.*, 1997). With the exception of community access activity many houses have little structure and direction from staff in terms of individual programming and so are no improvement on life in the institution where residents also spent much of the time in undirected activity.

Summing up it can be said that adults with severe intellectual disability and who are aging have living conditions which are

more similar to people in the community without intellectual disability and are certainly more favourable than when they were living in the institution. Notwithstanding this, there are substantial individual differences in the quality and quantity of changes that suggest that community based services may not yet be addressing the needs of all residents and attention must be given to individual development and especially to the quality and training needs of staff support.

The research outcomes vindicate the government decision to close the institution and relocate residents into the community to provide choice-making and life quality that is similar to lifestyles experienced by people without intellectual disability. Variability in individual outcomes suggests there is not a single recipe for successful community living but services must be responsive to individual needs and there appears to be some benefit in the longitudinal monitoring of residential lifestyles, adaptive skills, choice-making and also the involvement of direct care staff in residents' lives.

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Summary

As part of an institutional closure programme in Queensland, Australia, 104 individuals most with moderate and severe levels of intellectual disability, who had been institutionalised long-term, were relocated to community-based group homes. Each individual was assessed 6 months prior to the relocation and then again after 1, 6, 12, 18 and 24 months of community living. Assessments involved ratings of adaptive and maladaptive behaviour, choice-making and objective life quality. The group means comparing institution to community ratings showed improvements in adaptive functioning but no significant change in maladaptive behaviour. There were also improvements in objective life quality and increased opportunities for choice-making following relocation to the community. These outcomes suggest that relocation to the community was associated with a more active and normalised lifestyle.

References

- Ashman, A. F., Hulme, P. and Suttie, J. N. (1991). The life circumstances of aged people with intellectual disability. *Australia and New Zealand Journal of Developmental Disabilities*, 16, 335-348.
- Bannerman, D. J., Sheldon, J. B., Sharman, J. A. and Harchik, A. E. (1990). Balancing the right to habilitation with the right to personal liberties: The rights of people with developmental disabilities to eat too many doughnuts and take a nap. *Journal of Applied Behaviour Analysis*, 23, 79-89.
- Cohen, J. (1988). *Statistical power analysis for the behavioural sciences*. New York: Academic Press.

- Crichton, J.** (1998). Balancing restriction and freedom in the care of people with intellectual disability. *Journal of Intellectual Disability Research*, 42, 189-195.
- Cullen, C., Whoriskey, M., Mackenzie, K., Mitchell, W., Ralston, K., Shreeve, S. and Stanley, A.** (1995). The effects of deinstitutionalisation on adults with learning disabilities. *Journal of Intellectual Disability Research*, 39, 484-494.
- Cummins, R. A.** (1993). *The Comprehensive Quality of Life Scale - Intellectual Disability* (4th ed.). Melbourne: Deakin University, School of Psychology.
- Cummins, R. A.** (1998). The second approximation to an international standard for life satisfaction. *Social Indicators Research*, 43, 307-334.
- Cummins, R. A. and Dunt, D.** (1990). The deinstitutionalisation of St. Nicholas Hospital: II. Lifestyle, community contact and family attitudes. *Australia and New Zealand Journal of Developmental Disabilities*, 16, 19-32.
- Dagnan, D., Ruddick, L. and Jones, J.** (1998). A longitudinal study of the quality of life of older people with intellectual disability after leaving hospital. *Journal of Intellectual Disability Research*, 42, 112-121.
- Donnelly, M., McGilloway, S., Mays, N., Perry, S. and Lavery, C.** (1997). A three to six year follow-up of former long-stay residents of mental hospitals in Northern Ireland. *British Journal of Clinical Psychology*, 36, 585-600.
- Emerson, E.** (1985). Evaluating the impact of deinstitutionalisation on the lives of mentally retarded people. *American Journal of Mental Deficiency*, 90, 277-288.
- Emerson, E. and Hatton, C.** (1996). Deinstitutionalisation in the UK and Ireland: Outcomes for service users. *Journal of Intellectual and Developmental Disability*, 21, 17-37.
- Erb, R. G.** (1995). Where, oh where, has common sense gone? (Or if the shoe don't fit why wear it?) *Mental Retardation*, 33, 197-199.
- Felce, D.** (1997). Defining and applying the concept of quality of life. *Journal of Intellectual Disability Research*, 41, 126-135.
- Felce, D., Lowe, K. and Blackman, D.** (1995). Resident behaviour and staff interaction with people with intellectual disabilities and seriously challenging behaviour in residential services. *Mental Handicap Research*, 8, 272-295.
- Heller, T.** (1988). Transitions: Coming in and out of community residences. In: M. Janicki, M., Krauss and M. M. Seltzer (Eds.). *Community residences for persons with developmental disabilities: Here to stay* (pp. 149-158). Baltimore: Paul H. Brookes.
- Heller, T., Factor, A., Hsieh, K. and Hahn, J. E.** (1998a). Impact of age and transitions out of nursing homes for adults with developmental disabilities. *American Journal on Mental Retardation*, 103, 236-248.
- Heller, T., Miller, A. B. and Factor, A.** (1998b). Environmental characteristics of nursing homes and community based settings, and the well-being of adults with intellectual disability. *Journal of Intellectual Disability Research*, 42, 418-428.
- Howell, D. C.** (1997). *Statistical methods for psychology*. Belmont, CA: Duxbury Press.
- Jacobson, J. W. and Schwartz, A. A.** (1983). Personal and service characteristics affecting group home placement success: A prospective analysis. *Mental Retardation*, 21, 1-7.
- Janicki, M. P.** (1990). Growing old with dignity: On quality of life for older persons with a life-long disability. In: R. L. Schalock (Ed.). *Quality of life: Perspectives and issues* (pp. 115-125). Washington, DC: American Association on Mental Retardation.
- Jones, E., Perry, J., Lowe, K., Felce, D., Toogood, S., Dunstan, F., Allen, D. and Pagler, J.** (1999). Opportunity and the promotion of activity among adults with severe intellectual disability living in community residences: The impact of training staff in active support. *Journal of Intellectual Disability Research*, 43, 164-178.
- Kearney, C. A., Bergan, K. P. and McKnight, T. J.** (1998). Choice availability and persons with intellectual disability: A longitudinal and regression analysis. *Journal of Developmental and Physical Disabilities*, 10, 291-305.
- Kearney, C. A., Durand, V. M. and Mindell, J. A.** (1995). Choice assessment in residential settings. *Journal of Developmental and Physical Disabilities*, 7, 203-213.

- Koegel, L. K., Koegel, R. L. and Dunlap, G.** (1996). *Positive behavioural support: Including people with difficult behaviour in the community*. Baltimore: Paul H. Brookes.
- Larson, S. and Lakin, K. C.** (1989). Deinstitutionalization of persons with mental retardation: Behavioural outcomes. *Journal of the Association for Persons with Severe Handicaps*, 14, 324-332.
- Likert, R.** (1932). A technique for the measurement of attitudes. *Archives in Psychology*, 140, 1-55.
- May, R. B., Masson, M. E. J. and Hunter, M. A.** (1990). *Application of statistics in behavioural research*. New York: Harper & Row.
- Nihira, K., Leland, H. and Lambert, N.** (1993). *Adaptive Behaviour Scale - Residential and Community* (2nd ed.). Washington, DC: American Association on Mental Retardation.
- Nirje, B.** (1985). The basis and logic of the normalisation principle. *Australia and New Zealand Journal of Developmental Disabilities*, 11, 65-68.
- Parmenter, T. R.** (1994). Quality of life as a concept and a measurable entity. *Social Indicators Research*, 33, 9-46.
- Rapley, M., Ridgeway, J. and Beyer, S.** (1998). Staff:staff and staff:client reliability of the Schalock and Keith (1993) Quality of Life Questionnaire. *Journal of Intellectual Disability Research*, 42, 37-42.
- Rawlings, M., Dowse, L. and Shaddock, A.** (1995). Increasing the involvement of people with an intellectual disability in choice making situations: A practical approach. *International Journal of Disability, Development and Education*, 42, 137-153.
- Reiter, S. and Bendov, D.** (1996). The self concept and quality of life of two groups of learning disabled adults living at home and in group homes. *The British Journal of Developmental Disabilities*, 42, 97-111.
- Schalock, R. L., Harper, R. S. and Carver, G.** (1981a). Independent living placement: Five years later. *American Journal of Mental Deficiency*, 86, 170-177.
- Schalock, R. L., Harper, R. S. and Genung, T.** (1981b). Community integration of mentally retarded adults: Community placement and program success. *American Journal of Mental Deficiency*, 85, 478-488.
- Schalock, R. L. and Keith, K. D.** (1993). *Quality of Life Questionnaire*. Worthington, OH: IDS Publication Company.
- SPSS.** (1995). *Statistical Package for Social Sciences* (Version 6.1). Chicago: SPSS Inc.
- Stancliffe, R. J.** (1991). Choice-making by adults in supported community accommodation: Hobson's choice. *Interaction*, 5, 23-33.
- Stancliffe, R.** (1999). Proxy respondents and the reliability of the Quality of Life Questionnaire empowerment factor. *Journal of Intellectual Disability Research*, 43, 185-193.
- Stancliffe, R. and Lakin, K. C.** (1998). Analysis of expenditures and outcomes of residential alternatives for persons with developmental disabilities. *American Journal on Mental Retardation*, 102, 552-568.
- Stancliffe, R. J. and Lakin, K. C.** (1999). A longitudinal comparison of day program services and outcomes of people who left institutions and those who stayed. *Journal of the Association for Persons with Severe Handicaps*, 24, 44-57.
- Vandergriff, D. V. and Chubon, R. A.** (1994). Quality of life experienced by persons with intellectual disability in various residential settings. *Journal of Rehabilitation*, 60, 30-37.
- Westwood, P.** (1997). *Commonsense methods for children with special needs* (3rd ed.). London: Routledge.
- Young, L., Ashman, A., Sigafos, J. and Grevell, P.** (2000). A preliminary report on the closure of Challinor Centre. *Journal of Intellectual and Developmental Disability*, 25, 119-126.
- Young, L., Ashman, A., Sigafos, J. and Grevell, P.** (2001). Closure of Challinor Centre: II. An extended report on 95 individuals after 12 months of community living. *Journal of Intellectual and Developmental Disability*, 26, 51-66.