

Transition to retirement and participation in mainstream community groups using active mentoring: a feasibility and outcomes evaluation with a matched comparison group

R. J. Stancliffe,¹ C. Bigby,² S. Balandin,³ N. J. Wilson⁴ & D. Craig²

¹ Centre for Disability Research and Policy, University of Sydney, Lidcombe, New South Wales, Australia

² School of Social Work and Social Policy, La Trobe University, Bundoora, Victoria, Australia

³ School of Health & Social Development, Faculty of Health, Deakin University, Burwood, Victoria, Australia

⁴ School of Nursing and Midwifery, University of Western Sydney, Richmond, New South Wales, Australia

Abstract

Background This paper reports on the feasibility and outcomes of a transition to retirement programme for older adults with disability. Without activities and social inclusion, retirees with disability are likely to face inactivity, isolation and loneliness.

Methods Matched intervention and comparison groups each consisted of 29 older individuals with disability. There were 42 men and 16 women with a mean age of 55.6 years. While attending their individual mainstream community group 1 day per week, intervention group participants received support from community group members trained as mentors. We assessed participants' loneliness, social satisfaction, depression, life events, quality of life, community participation, social contacts, and work hours before and 6 months after joining a community group.

Results Twenty-five (86%) of the intervention group attended their community group weekly for

at least 6 months. They increased their community participation, made an average of four new social contacts and decreased their work hours. Intervention participants were more socially satisfied post-intervention than comparison group members.

Conclusions The results demonstrate that participation in mainstream community groups with support from trained mentors is a viable option for developing a retirement lifestyle for older individuals with disability.

Keywords active support, community groups, inclusion, intellectual disability, outcomes, retirement

Introduction

Ageing and retirement

In Australia, the average age of retirement from the mainstream labour force for people aged 45 years and over in 2010–2011 was 53.3 years (57.9 years for men and 49.6 years for women) (Australian Bureau of Statistics 2011). Likewise, after age 45, the

Correspondence: Prof Roger J. Stancliffe, University of Sydney, Centre for Disability Research and Policy, Lidcombe, NSW, Australia (e-mail: roger.stancliffe@sydney.edu.au).

participation of service users with long-term disability in disability employment and day programmes declines (Australian Institute of Health and Welfare 2007; Dusseljee *et al.* 2011). With around 25% of clients aged over 45, Australian disability employment and day programme services face an ageing clientele (Australian Institute of Health and Welfare 2007). Consequently, there is a growing need to consider retirement and post-retirement lifestyles.

Frequently on retirement, adults with long-term disability lose contact with staff and peers from disability employment or day programme services (Judge *et al.* 2010; McDermott & Edwards 2012), but fail to develop new avenues for social connection and community participation, so risking social isolation (McCarron *et al.* 2011; McDermott & Edwards 2012). Furthermore, adults with long-term disability are at high risk of loneliness (Balandin *et al.* 2006a; Stancliffe *et al.* 2007). This is because they have few significant relationships (Balandin *et al.* 2006a) and have small social networks dominated by family, disability service staff and other service users (Bigby 2008; McCarron *et al.* 2011).

Social inclusion

Older people with intellectual disability (ID) rarely belong to mainstream community groups (Bigby & Balandin 2005; Verdonschot *et al.* 2009; McDermott & Edwards 2012) or experience social contact with community members without disability (Ashman & Suttie 1996; Dusseljee *et al.* 2011; McCarron *et al.* 2011). In their review of community participation, Verdonschot *et al.* (2009) noted most community participation by adults with ID involved co-residents with ID and disability staff. Such lack of social inclusion is even more pronounced in older age (Dusseljee *et al.* 2011). Thus, retirees with disability are likely to face isolation and loneliness in retirement which may result in depression and other health problems (Esbensen & Benson 2006).

One response to loneliness, depression, community participation and social inclusion is to support older individuals with disability to begin to develop a retirement lifestyle by accessing mainstream volunteering opportunities and community groups (Wilson *et al.* 2010). Such groups are available throughout Australia and are commonly used by

Australian retirees without disability. Currently, older people with ID rarely take part in these groups, which suggests that (1) barriers to such participation exist, and (2) there is no robust individualised approach to support significant numbers of older people with disability to attend mainstream community groups (Ingvaldsen & Balandin 2011).

Barriers to community participation and social inclusion

Older people with disability wish to continue participating in society (Judge *et al.* 2010; McDermott & Edwards 2012), yet researchers have identified two significant barriers to participation in activities such as community groups and volunteering. Firstly, older people with disability require additional support to participate effectively (Harlan-Simmons *et al.* 2001; Balandin *et al.* 2006c). Secondly, those in mainstream community settings are apprehensive about accepting people with disability because of a lack of training and support to help them meet the needs of disabled people (Bigby & Balandin 2005; Balandin *et al.* 2006b; Ingvaldsen & Balandin 2011). Additionally, stakeholders, including family members and disability staff, state a consistent preference for disability-specific retirement activity groups and doubt the viability of a socially inclusive transition-to-retirement approach. (Bigby *et al.* 2011).

Active mentoring

We developed an approach to supporting participation in mainstream community groups that we called 'active mentoring' (Wilson *et al.* 2010; Chng *et al.* 2013) intended to enable significant numbers of people with disability to be supported to join such groups, on the basis of one person with a disability per group. Active mentoring was one aspect of the full transition to retirement (TTR) programme, set out in more detail in a companion paper and manual (Stancliffe *et al.* 2013; Bigby *et al.* 2014). In these publications, we proposed that, with the right support, older people with disability can participate successfully in mainstream community groups or a volunteering activity as they transition to retirement.

Having a disability staff member provide support at the community group is costly and may interfere with social interactions between the person with disability and other group members. Leaving the person without specific support may undermine his/her ability to participate in the group. Therefore, we drew on the co-worker training approach to providing on-the-job support to people with disability in competitive employment (Farris & Stancliffe 2001; Storey 2003). We invited existing members of community groups to be trained to act as mentors to the person with disability and to use active mentoring to provide both social support and support for participation in activities at the group.

This project's focus was not on full retirement but on gradual transition to retirement by supporting participants to begin to develop a retirement lifestyle. The retirement focus was evident in multiple features of the intervention including (1) only selecting community groups that met during the day on weekdays so the participant would attend the group instead of working on that day; (2) choosing age-appropriate groups that served older Australians and retirees; (3) involving participants from the typical age range (45+) for Australians moving toward retirement; (4) conducting person-centred individual planning with an explicit focus on retirement.

This paper will examine (1) the feasibility of supporting older adults with disability to attend a mainstream community group; (2) the types of mainstream community groups or volunteering groups that participants joined; (3) the duration of participants' weekly attendance at their group; and (4) changes in outcomes experienced by participants that included loneliness, social satisfaction, depression, life events, quality of life, community participation, social contacts and work hours.

Method

Ethics approval and consent

The project was approved by the Human Research Ethics Committees at the University of Sydney and La Trobe University. Informed written consent was obtained from all participants. Consent was given by a family member or guardian for the small

number of participants with ID who were unable to consent for themselves.

Participants

Intervention participants were invited to join the project if they were aged 45 years or older and their work/day programme circumstances (e.g. part-time attendance, frequent absences, lack of engagement with work, age-related health problems or acquired disabilities) suggested that they might benefit from reduced work/day programme attendance. Participants were recruited on a rolling basis throughout the project, with the last participant starting at his community group more than 18 months after the first participant.

A total of 29 adults with long-term, often lifelong disability attended a community group at least once. Joining a group typically meant reducing attendance at work or day programme by 1 day per week. As each intervention participant joined the project, an individual with similar characteristics was recruited to serve in a comparison group whose work hours remained unchanged and who did not attend a community group. Each intervention-comparison pair was matched as closely as possible on work/day programme placement, full-time or part-time work status or day programme attendance, living arrangements, gender and age group. The 58 participants' age averaged 55.6 years ($SD = 6.6$, range 44.1 to 72.2 years). Sydney-based participants ($n = 52$) lived in widely dispersed parts of the metropolitan area. Melbourne-based participants ($n = 6$) lived in that city's northern suburbs. The characteristics of the intervention and comparison group participants are shown in Table 1.

Among the 40 participants with a primary diagnosis of ID, almost all were reported to have mild or moderate ID. All but four participants (two interventions, two comparisons) could speak and answer simple questions.

Mentors

Mentors were existing members of the community groups who volunteered to receive training and to support the participant when he/she was attending their group. There were 73 mentors (38 women, 35 men) for 26 intervention group participants. The

Table 1 Characteristics of intervention and comparison group participants ($N = 58$)

Variable	Group		Statistic
	Intervention $n = 29$	Comparison $n = 29$	
Disability programme attendance			
F/T work	9 (31%)	7 (24%)	$\chi^2 (2, N = 58) = 0.42, P = .81$
P/T work	17 (59%)	18 (62%)	
Day programme only	3 (10%)	4 (14%)	
Primary disability diagnosis			
Intellectual	20 (69%)	20 (69%)	$\chi^2 (5, N = 58) = 1.11, P = .95$
Mental health	1 (3%)	1 (3%)	
Physical	4 (14%)	5 (17%)	
Vision	1 (3%)	1 (3%)	
Hearing	1 (3%)	0 (0%)	
Acquired brain injury	2 (7%)	2 (7%)	
Living arrangements			
Independent	4 (14%)	1 (3%)	$\chi^2 (3, N = 58) = 3.89, P = .27$
Group home	12 (41%)	14 (48%)	
Hostel	9 (31%)	6 (21%)	
Family	4 (14%)	8 (28%)	
Gender			
Male	18 (62%)	24 (83%)	$\chi^2 (1, N = 58) = 3.11, P = .08$
Female	11 (38%)	5 (17%)	
Age (years)			
Mean	57.4	53.8	$t (56) = 2.16, P = .035$
Range	46.0–72.2	44.1–67.7	

27th participant had informal mentors and the remaining two participants withdrew before mentors could be appointed. Each participant had from 1 to 6 mentors (mean = 2.81). Mentors' age ranged from 23 to 87 years (mean = 64.1) and most were the same gender as the participant they supported (men 71%, women 77%). A detailed account of the mentors and their experiences is presented in a companion paper (Wilson *et al.* 2013).

Instruments

We planned to measure loneliness, depression, quality of life and life events. Because these variables (except life events) are somewhat subjective, we sought participant self-reports wherever possible. All self-report instruments were designed solely for first-person responses so no proxies were allowed. Some participants' communication skills made self-report difficult, despite our use of scales designed for people with ID. This situation resulted in some

missing data on self-report instruments. Therefore, we included separate proxy-report instruments where appropriate so that we would have some data for all participants. To enhance comparability with other older Australians, we selected several instruments that had been designed for use with the general population, but had previously been used successfully with people with disability. All proxy-report instruments were designed specifically for proxies. No self-reporting was permitted even if no suitable proxy was available.

Self-report instruments

Instruments used with the general population

Health-related quality of life. Health-related quality of life (HRQOL) was assessed using the SF-36 (Ware *et al.* 1993), a widely used self-report instrument. It contains 36 questions in eight subscales providing measures of perceived physical and mental health,

for which Australian norms have been published. This instrument has been used previously with people with ID (Llewellyn *et al.* 2003).

Loneliness. The 20-item self-report UCLA Loneliness Scale (Version 3) is the most frequently used measurement of loneliness (Russell 1996). It has sound test-retest reliability ($r = 0.73$) and internal consistency ($\alpha = 0.89$ – 0.94 ; Russell 1996) and was used effectively with older adults with cerebral palsy (Balandin *et al.* 2006a).

Instruments designed for people with intellectual disability

Loneliness. The Worker Loneliness Questionnaire (Chadsey-Rusch *et al.* 1992) assesses adults with ID on self-reported loneliness (aleness) and social dissatisfaction at work. Chadsey-Rusch *et al.* reported sound test-retest (0.76, 0.89) and inter-rater (0.85, 0.91) reliability for adults with mild and moderate ID, respectively. Alpha was 0.65 for aleness and 0.80 for social dissatisfaction. We evaluated overall loneliness and social (dis)satisfaction, not just at work. We deleted 'at work' from every item, so that the original item 'Do you feel alone at work?' became 'Do you feel alone?' In constructing the Modified Worker Loneliness Questionnaire, we omitted all items unrelated to aleness or social dissatisfaction, leaving 12 items with a 3-point response scale (no = 0, sometimes = 1, yes = 2). We reversed the scoring for each social dissatisfaction item and renamed this scale social satisfaction because this construct made more sense for our study. There were six aleness items and six social satisfaction items. The latter concerned having friends and people to talk to, and receiving social support from others. Aleness and social satisfaction total scores each could range from 0 (not at all lonely/socially satisfied) to 12 (extremely lonely/socially satisfied).

Depression. The Glasgow Depression Scale (GDS; Cuthill *et al.* 2003) is a 20-item self-report scale developed for individuals with ID in language easily understood by them. It has demonstrated internal and test-retest reliability and criterion validity, and suggested clinical cut-offs.

Proxy report instruments

Depression

The Mini Psychiatric Assessment Schedules for Adults with Developmental Disabilities Checklist (Mini PAS-ADD; Moss *et al.* 1998) is a proxy assessment of psychiatric symptoms that has good reliability and validity. Because we only wished to assess depression, only those items were asked. The GDS (Cuthill *et al.* 2003) has a parallel 16-item proxy-informant version.

Life events

A checklist of 17 life events (including job loss and retirement) experienced in the last 2 years is part of the Mini PAS-ADD (Moss *et al.* 1998).

Weekly logs

Weekly logs were used to monitor the community participation and social contacts of intervention participants. In most cases, the informant was a caregiver (paid or unpaid) with frequent face-to-face participant contact. Typically, caregivers completed and faxed logs each week. However, some participants lived alone or in circumstances where the participant was the best informant. In these cases, a research assistant phoned the participant weekly and completed the logs by asking the participant questions.

Weekly data collection began before the participant joined their community group and continued until post-test. Because of the workload involved for informants in providing data for 7–8 months, we only gathered weekly data about intervention participants.

Community group participation and work hours log

Informants completed a weekly log recording the participant's time to the nearest half-hour spent at community groups and at work each day. This excluded travel time but the mode of travel to the group was recorded. The community group categories were (1) mainstream community group; (2) mainstream volunteering group; and (3) disability social group.

Social contacts log

Weekly, informants specified the duration (minutes) of each participant's contact with known individuals and new acquaintances (recorded separately), and the nature and context of the contact. Social contact was defined as (1) not involving people the participant lives with, (2) people other than work-mates at work, (3) not including contact with disability staff during their paid work hours, (4) contact lasting for 5+ minutes and involving a turn-taking conversation, and (5) not occurring during a residential facility outing solely with other housemates.

Procedure*Assessments*

Pre-test assessment happened prior to joining a community group and post-test assessment was completed after 6 months attendance. Matched intervention-comparison pairs were yoked in that (1) assessments occurred on a timeline determined by when the intervention participant joined a community group; (2) if the intervention participant did not finish 3 months community group participation then neither had a post-test assessment; and (3) if the intervention participant did not have a suitable proxy-informant (e.g. lived alone) then proxy data were not collected for either participant.

Proxy respondents were selected because they knew the participant well, were familiar with all aspects of their life (not just work) and had regular (at least weekly) face-to-face contact. All proxies had known the person for at least 2 years. Proxies included co-resident family members, and staff from the participant's group home or hostel. We tried to use the same proxy at pre-test and post-test (intervention = 55% consistent, comparison = 70%), but this was not always possible because of staff turnover or absences. Consistency of proxies did not differ significantly by group, $\chi^2(1, N = 42) = 1.06$, $P > .05$.

Intervention

Intervention group participants received the intervention described below. Comparison group members received no intervention and continued to attend work as usual.

Individual retirement planning meeting

A planning meeting was held for each intervention participant to discuss the details of dropping a day at work/day programme to attend a community group on that day. The consent process provided in-principle agreement to joining a community group, so the meeting's focus was on identifying the participant's interests to help find a suitable group. Meetings were typically held at the participant's home and attended by the participant, family, residential staff (if applicable), a researcher and staff from the disability employment/day programme provider. Participants were given a 12-month guaranteed right of return to work on their original working hours.

Locating a community group or volunteering opportunity

Only one participant with disability attended each community group.¹

Attending the group

Initial visits occurred with a research team member providing support and observing interactions. Researchers also taught the participant the new public transport route, or helped to arrange other methods of travel.

Training mentors

Mentor training consisted of two phases (1) disability interaction training and (2) hands-on training. Mentors were trained how to support the person at the group during social interaction and participation in activities.¹

Disability interaction training

All mentors from each particular community group jointly attended a small-group training session for 1–1.5 h, supported by written handouts and video clips of people with disability involved in activities with various forms of support. Topics included disability in Australia, disability-sensitive language, how to support and communicate with people with disability, and people with disability participating in

¹ A more detailed account of these processes is provided in a companion paper and manual (Stancliffe *et al.* 2013; Bigby *et al.* 2014).

their community and in mainstream community groups. There was also discussion of activities that the individual participant could be involved in at the group.

Hands-on training

In the weeks following the disability interaction training, a researcher (coach) attended the group for part of the time the participant was present. Mentors provided direct support to participants with disability, with the coach offering prompts, advice, suggestions and feedback to the mentor about activities and support. The coach assisted mentors to be aware of cues indicating that the participant needed support. For example, a participant sitting alone, doing nothing was a cue to approach the person and offer an activity. Occasionally, the coach would demonstrate a support technique or activity.

Depending on the group's culture, we sometimes introduced a written activity schedule, akin to an active support activity and support plan (Stancliffe *et al.* 2008, 2010), listing activities, approximate starting time, and who would provide support. This was useful in more formal groups with a schedule of structured activities. The coach also advised about responding to and managing behaviours that were outside the accepted norms of the group.

Activity restructuring

Job restructuring (job carving) is a supported employment procedure to tailor job activities to the person's unique skills and to create a personalised job for a person with disability. (Wehman *et al.* 2007). With assistance from mentors, we used this approach to identify appropriate activities, often with a joint decision to reserve the activity as the responsibility of the participant. For example, one participant enjoyed setting the lunch tables for the group. This role became her contribution to the group, a task for which she was jointly responsible with a mentor.

Monitoring and ongoing support

In addition to coaching, regular contact by the research team member meant small issues were identified and dealt with before they became barriers.

For example, ensuring that the participant brought the correct money.¹

Results

Outcomes for the intervention group

A number of outcomes were assessed for the intervention group only.

Attending community groups

Success rate, attrition and ongoing attendance. Overall, 27 (93%) of the 29 intervention participants joined a community group and attended for at least 3 months, with 25 (86%) attending for a full 6 months. Of these 25, four ceased attending at some subsequent point (see Fig. 1) with the remaining 21 (72%) still attending when data collection ceased after the final participant's post-test assessment (mid-May 2012).

Intervention participants each attended a different community/volunteer group, according to individual interest. Thus, there were 27 groups involved. The types of groups attended are shown in Table 2. Where multiple individuals attended the same group type, each person attended a separate group in a separate location.

Volunteers provide a service to others in the community whereas a community group's purpose is to serve its members. This distinction in Table 2 is important for several reasons. First, volunteers are seen as contributing positively to their communities. Second, a social security cash payment for travel (the mobility allowance, currently AUD\$43 per week) is paid to disability support pension recipients who work (e.g. in sheltered employment) eight or more hours per week. This allowance can be retained in retirement by volunteering eight or more hours per week.

Hours. Participants attended their group during the day on a weekday for 1–6 h (average 3.6 h, $n = 27$). Several extended their involvement in community groups. For example, three participants were each supported (independent of the research project) to join one additional group that met on a different day.

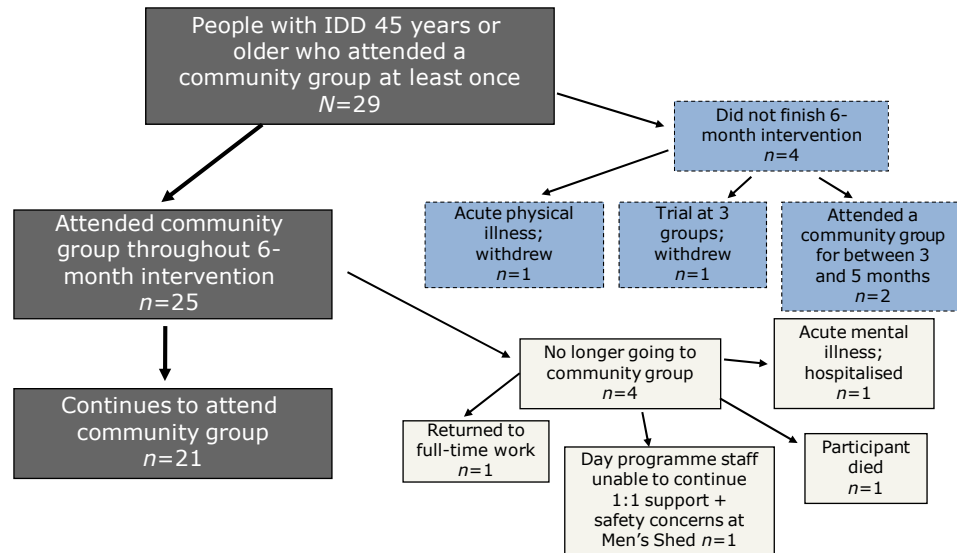


Figure 1 Community group attendance over time for intervention participants (N = 29).

Male (n = 17)		Female (n = 10)	
Group type	n	Group type	n
Volunteer groups			
Community (soup) kitchen	1	Cat protection society ^b	1
Community (plant) nursery	1	Community (plant) nursery	1
Aviation museum ^a	1	Frail-aged social group	1
Charity (thrift) shop	1		
Community groups			
Men's shed ^a	8	Exercise ^b and social group	1
Seniors choir	1	Community (teaching) kitchen	1
Seniors group	1	Seniors' group	4
Lawn bowls club	1	Walking and knitting group	1
Seniors 10-pin bowling league	1		
Community garden	1		

Table 2 Different types of community groups and volunteering groups attended by intervention participants by gender (N = 27)

^a All-male group.
^b All-female group.

Meals and snacks. Every group had a shared morning tea – a key opportunity for social interaction. Of the 27 participants, eight (30%) attended groups where there was no lunch or lunch was taken individually. A further seven (26%) were involved with groups where lunch was eaten together but individuals brought their own lunch. For two participants (7%), cooked meals were available on some but not all weeks (e.g. a monthly bar-

becue). For 10 participants (37%), an inexpensive healthy cooked lunch was provided each day, and this service was an important feature of the group's purpose.

Social contact outside of the group. Few participants had contact with community group members outside of group meeting hours. One man occasionally socialised with members of his 10-pin bowling

group. One woman attended some group outings held on days other than her usual attendance day. Two women occasionally encountered members of their respective community groups in a local shopping centre and said hello. Four participants sometimes were given a ride home from their group in a group member's car.

Ongoing attendance. As noted (Fig. 1), most participants continued to attend their community group long after post-test. At the time of post-test data collection for the last participant recruited, individual attendance ranged from 3 to 24 months (mean = 12.4, $n = 27$). However, these figures substantially understate ongoing attendance, in that most (21 of 27) participants continued to attend their group beyond cessation of data collection so their attendance duration is unknown. Participants with shorter durations (e.g. 12 months or less, $n = 10$) mostly were individuals who joined the project in its final year.

Weekly data logs

We contrasted the weekly average for the last three weeks of available data before joining a community group (pre-test), with the weekly average for the last 3 weeks of available data before post-test. Weekly data were available for 26 intervention participants of the 27 who joined a group.

Community group participation. Intervention participants' weekly hours of participation in mainstream community groups increased from an average of 2.18 ($SD = 3.08$) hours at pre-test to 5.35 ($SD = 3.83$) hours at post-test, a large significant increase, $t(1, 25) = -7.87$, $P < 0.001$, with a large effect size, $d = 1.54$. Pre-intervention participation mostly involved church attendance or going to bars or licensed clubs, independently or with family.

Social contacts. Participants had ongoing social contact with an average of 4.04 ($SD = 1.15$) new people at their community group ranging from 2 to 5. We were very conservative in identifying these new social contacts, and only included named people with whom the participant interacted regularly. These contacts were mostly mentors and other

group members who provided regular social or practical support.

Time spent with new social contacts increased from 0.03 ($SD = 0.13$) hours per week at pre-test to 3.30 ($SD = 1.64$) hours at post-test, $t(1, 24) = -9.94$, $P < 0.001$, $d = 1.98$.

Change in work hours. Most participants attended their community group on a former workday reducing their work hours by having that day off work each week. A few participants working part time opted to attend their group on a non-work day, so their weekly work hours did not change. Overall, the participants reduced their weekly work hours from an average of 26.64 ($SD = 9.77$) hours to 22.54 h, a significant reduction, $t(1, 25) = 3.44$, $P = 0.002$, $d = 0.67$.

Retirement

Three intervention participants (10%) retired fully during the course of the research project.

Outcome comparisons between intervention and comparison group participants

Comparative outcome data are reported in Table 3. At pre-test, there were no significant differences between intervention and comparison group participants on any of the nine outcome variables listed in Table 3. All analyses in Table 3 were completed using analysis of covariance with post-test score as the dependent variable and pre-test score as a covariate.

Missing data

A total of 27 of 29 intervention participants completed at least 3 months attendance at their community group and were therefore eligible for post-test assessment, so the maximum possible participant number for each variable in Table 3 is 54 (27 intervention, 27 comparison).

Missing data for self-report assessments were due mostly to participants being unable to respond to the assessment questions. The first two participants were not asked the Modified Worker Loneliness Questionnaire as this instrument was not added to the research protocol until after their pre-test assessment had been completed.

Table 3 Outcome data by variable and group

Variable	Group												Effect Size d^a
	Intervention						Comparison						
	Pre-test		Post-test		Pre-test		Post-test		Pre-test		Post-test		
	M	SD	M	SD	M	SD	M	SD	M	SD	M	SD	
Self-report variables													
GDS Depression ($n = 47$)	7.21	5.93	6.96	5.74	5.26	3.25	5.52	4.28	$F(1,44) = 0.03, P = .86$	0.28			
MWLQ Aloneness ($n = 45$)	2.78	2.39	2.26	2.54	2.45	2.58	2.64	2.65	$F(1,42) = 1.40, P = .24$	-0.15			
MWLQ Social satisfaction ($n = 46$)	10.57	1.75	11.43	0.95	10.48	1.88	10.17	1.90	$F(1,43) = 10.61, P = .002$	0.78			
UCLA Loneliness ($n = 20$)	36.13	12.78	31.25	7.11	33.67	9.08	33.50	8.99	$F(1,17) = 1.72, P = .21$	-0.28			
SF36 Quality of Life ($n = 34$) Physical	51.98	8.52	52.88	8.56	51.09	9.20	51.15	7.94	$F(1,31) = 0.55, P = .47$	0.21			
SF36 Quality of Life ($n = 34$) Mental	50.40	7.39	50.48	9.98	52.27	7.00	53.22	4.33	$F(1,31) = 0.37, P = .55$	-0.36			
Proxy report variables													
GDS Depression ($n = 36$)	3.20	5.04	1.65	1.87	2.56	2.73	3.25	4.09	$F(1,33) = 2.98, P = .095$	-0.51			
Mini PAS-ADD Depression ($n = 42$)	2.23	3.28	0.91	1.38	1.40	2.35	1.80	3.32	$F(1,33) = 2.76, P = .105$	-0.36			
Mini PAS-ADD Life events ($n = 42$)	1.27	0.88	1.23	0.92	1.50	1.15	1.20	1.15	$F(1,39) = 0.14, P = .71$	0.03			

^a Values of d calculated as follows: post-test mean (intervention group) – post-test mean (comparison group)/pooled SD. MWLQ, Modified Worker Loneliness Questionnaire; GDS, Glasgow Depression Scale.

Missing proxy assessments were due to several factors: (1) no suitable proxy was available because the participant lived alone and there was no other person with sufficient day-to-day knowledge of the participant's non-work life ($n = 4$); (2) the participant refused permission for a proxy, a family member, to provide data ($n = 5$) and (3) no post-test data available because one participant died and the surviving matched pair's data were not included; and (4) proxy-informant died between pre-test and post-test ($n = 1$). This left 42 participants with valid pre-test and post-test proxy data for most scales. In addition, some pre-test GDS proxy assessments were mislaid ($n = 6$), so there were 36 participants for the GDS proxy scale.

Depression

None of the depression assessments revealed a significant group difference. The low mean pre-test scores on all of the depression scales meant that there was very little room for improvement. Further, the small sample size limited statistical power and made type 2 errors more likely. Even so, the small number of intervention participants with high pre-test scores improved substantially at post-test. In addition, both the proxy-report (GDS and PAS-ADD) comparisons of depression approached significance ($P \approx 0.10$) on a two-tailed test.

Loneliness

There was no significant between-group difference in self-reported loneliness in response to either the Modified Worker Loneliness Questionnaire or the UCLA Loneliness Scale, although the latter scale had a large amount of missing data due to participants' inability to respond to its more complexly worded questions (see Stancliffe *et al.* 2014).

Social satisfaction

Intervention participants were significantly more socially satisfied at post-test than the comparison group. This was a robust finding ($P < 0.001$) with a large effect size ($d = 0.78$). Moreover, comparison of the pre-test and post-test scores showed that social satisfaction increased significantly for the

intervention group, $t(1, 22) = -2.36$, $P = 0.027$, whereas the comparison group's satisfaction did not change significantly.

Quality of life

There was no significant between-group difference in self-reported quality of life for either the physical or mental subscales of the SF-36.

Life events

Few life events were reported with total scores (maximum possible = 17) ranging from 0 to 4 at both pre-test and post-test. At pre-test, the most common events recorded were participant illness ($n = 9$, 15%) death of a relative ($n = 8$, 13%), relative ill ($n = 8$, 13%), problems with a friend ($n = 7$, 12%), death of a friend ($n = 10$, 17%) and moving house ($n = 7$, 12%).

Life events as a moderator variable

Some life events (retirement, being laid off) could be directly affected by the TTR intervention, but other life events may be seen as moderator variables rather than outcomes. Life events are related to depression (Esbensen & Benson 2006), so we confined our moderator analysis to the depression outcomes. Post-test life events was the moderator variable. We used a median split to recode this variable into two groups – low (0 or 1 life events) or high (2–4 events). A significant interaction is the criterion for moderation (Farmer 2012). There was no significant moderator effect (i.e. no significant interaction) for self-reported depression (GDS) or for proxy-reported depression (Mini PAS-ADD). However, there was a significant intervention group by life events interaction, $F_{1,31} = 4.95$, $P = 0.035$, for post-test proxy-reported GDS depression scores. Consistent with the presence of an interaction, the depression means for the intervention group were similar for both life events groups (low = 1.45, high = 1.89), whereas there was a marked difference in depression means by life events for the comparison group (low = 1.30, high = 6.50). The analysis also revealed a significant main effect for the TTR intervention, $F_{1,31} = 6.49$, $P = 0.016$, showing that intervention group participants were less depressed at post-test (mean = 1.65) than comparison

participants (mean = 3.25). As expected, depression scores differed significantly by life events group, $F_{1,31} = 9.96$, $P = 0.004$, with those with low life events being less depressed. Overall, these findings suggest that life events served as a moderator variable in this case, with the TTR intervention having protective effects on depression for individuals experiencing multiple life events. However, the inconsistency of these findings across the three measures of depression indicated that these effects were weak and need to be replicated.

Discussion

To our knowledge, this is the first controlled outcomes evaluation of older adults with disability joining mainstream community groups. The study demonstrated that participation in mainstream community groups is a feasible option for developing a retirement lifestyle for older individuals with disability, with 86% of participants joining a range of different groups on the basis of one person with a disability per group, and attending for at least 6 months. This success rate is particularly encouraging given previous reports that people with disability rarely attend mainstream community groups (Bigby & Balandin 2005; Verdonchot *et al.* 2009; McDermott & Edwards 2012) together with the difficulties reported in achieving lasting social inclusion (Harlan-Simmons *et al.* 2001).

Relative to pre-test (before joining the community group), by 6-month post-test intervention participants had made significant gains in terms of making new inclusive social contacts, spending more time with these new acquaintances, participating for more time in mainstream community activities and reducing their weekly work hours as planned. These outcomes contrast with previous findings that adults with disability experience little social contact with community members without disability (Ashman & Suttie 1996; Dusseljee *et al.* 2011; McCarron *et al.* 2011).

There was a significant moderator effect for life events on post-test proxy-reported depression (GDS only) suggesting that participation in the TTR intervention may have been protective for individuals experiencing higher levels of life events. However, this effect was not found for the other

two measures of depression (GDS self-report, PAS-ADD proxy report), so it needs to be treated with caution.

As befits a retirement lifestyle, the number of hours spent at the community group was less than a full work day, thus people could get up later and enjoy a more relaxed schedule for that day. Intervention participants' social satisfaction increased significantly from pre-test to post-test, whereas there was no significant change over time for comparison group members.

No significant between-group difference was found for loneliness, life events, depression or quality of life. In some cases, this finding can be taken at face value, but there are several methodological considerations that bear upon the interpretation of these results. These issues were (1) floor effects and (2) the related factors of sample size, statistical power and missing data. In relation to floor effects, the mean pre-test GDS scores for intervention participants were 18% (self-report) and 10% (proxy) of the respective scale maximums, well below the clinical cut-off. Thus, there was limited room for improvement (i.e. becoming less depressed as shown by lower scores). A better powered study might determine whether there were changes in depression. It is unknown if participants with more serious initial levels of depression would benefit. Research that involves individuals with disability with clinically important levels of depression would clarify this issue. Given the non-significant trend (P about 0.10 for GDS and PAS-ADD) towards improved depression scores, at least in the proxy data, it seems worth examining depression in a larger sample.

There were no significant between-group differences in quality of life, but those participants able to respond to the SF-36 ($n = 34$), had mean scores (all slightly above 50) typical for the general Australian population (both the physical and mental subscales have population means of 50).

Mentors and support

Mentor recruitment was mostly straightforward once group members started to get to know the person with disability. Many mentors preferred to share the mentoring responsibilities rather than be the sole identified support provider. Group

members, including mentors, had several things in common with intervention participants in that they (1) had a shared interest in the activities of the group (e.g. enjoyment of gardening); (2) were of a similar age and in many cases of the same gender; (3) had time to be involved; and (4) mostly lived in the same community. These factors may have helped each participant to be accepted into the group.

Social contact outside the group was not targeted or explicitly supported in our intervention. With limited exceptions, social contact by participants with other group members did not occur outside group hours. Our results do not mean that such contact would not occur if targeted, but do provide evidence that such contact rarely took place 'naturally'. One factor in the success of the mentor role and the willingness of mentors to provide support may have been that the mentors' responsibility was limited to group hours. Using detailed observational data for a small subsample of intervention participants, we have shown in a companion paper (Chng *et al.* 2013) that support from trained mentors was effective in increasing participation in activities at the community group.

A role in the group

As proposed by Reidy (1993) and Harlan-Simmons *et al.* (2001), having a specific role enabling the person to make a positive contribution to the group was important in a number of cases. It was easy to be selective about such activities because, unlike employment, in community groups or volunteering, there is no requirement to be 'working' constantly and there are few 'compulsory' activities. With support, the participants chose an activity for which they already had relevant skills (e.g. setting lunch tables) or were taught by a mentor how to do the task (e.g. mixing potting soil at a plant nursery). The mentor helped the person with disability take responsibility for the activity and this became a valued role in the group.

Limitations

This study has a number of limitations. Intervention participants self-selected to join the intervention group, so participant sampling was non-random.

Comparison group members were well matched on many characteristics, but were a few years younger than the intervention group. We cannot rule out between-group differences on characteristics we did not assess (e.g. health status). However, the effectiveness of matching is supported by there being no significant between-group differences at pre-test on any of the nine outcomes reported in Table 3.

For some of our pre-test:post-test comparisons, data were only available for the intervention group; therefore, those comparisons were uncontrolled. The viability of the transition to retirement approach in regional or rural areas rather than major metropolitan areas was not tested. Generalisability beyond Australia may be affected in countries where the minimum hours of attendance at sheltered employment are different. Further, some countries require police checks for individuals who work as a volunteer with vulnerable adults, including people with ID. This was not a requirement in the current study. Such checks may make it harder to recruit mentors.

Participants were drawn from only two disability employment/day programme agencies (but from multiple residential services, most operated independently of these agencies), so agency-specific factors may have influenced our findings. Our approach would be difficult to implement in work settings where the employer was not willing to reduce the person's work by 1 day per week.

Sixty nine per cent of participants had mild or moderate ID. Thus, we cannot generalise our results to individuals with more severe ID or to those with high support needs (see Craig 2013; Craig & Bigby in press). No participants had significant challenging behaviour or self-care needs that they were unable self-manage.

Our study did not use blinding, but a number of important outcomes, such as attendance at community groups, are objective indicators that are unlikely to be affected by blinding. It is not possible to blind participants, but future research should consider using independent blinded assessment at pre- and post-test.

We supported participants to begin their transition to retirement. With longer follow-up, more participants may well have retired fully. During the research project our Sydney-based industry partner, the Australian Foundation for Disability

(AFFORD), began ongoing implementation of transition to retirement as part of its service delivery. Therefore, intervention group participants received ongoing monitoring and support after they finished their 6 months of support within the research project. It seems likely that the ongoing involvement of the AFFORD transition-to-retirement coordinator contributed to the long-term effectiveness of the programme.

A final limitation is that, for reasons of space, we do not report data on staff hours used to implement the TTR intervention. These findings are reported in a companion paper (Bigby *et al.* 2014), which notes that significant individual support was needed from project staff to begin with, but that over time, this support diminished as mentors provided day-to-day support at the group. Because participants attended existing community groups without the support of disability service staff, once established, these activities were very low cost for both the participant and for disability services. This suggests that the TTR approach is potentially feasible for more widespread implementation. Even so, it is important to note that we needed to provide ongoing monitoring and episodic support to the participants, the groups and to mentors to keep things on track and to help deal with issues that arose, such as participants missing periods of group attendance through illness and needing support to rejoin the group (see Stancliffe *et al.* 2013).

Conclusion

The majority of participants with disability succeeded in joining and continuing to attend a mainstream community group, with support from trained mentors. Participants experienced lasting socially inclusive participation and no negative outcomes. Our transition to retirement approach takes advantage of existing community social infrastructure, and further develops community capacity to support people with disability. This approach appears to be a feasible way of enabling people with disability to begin an inclusive, active retirement lifestyle. It remains to be seen if similar techniques could be used to support younger people with disability at other life stages to join community groups.

References

- Ashman A. F. & Suttie J. N. (1996) The social and community involvement of older Australians with intellectual disabilities. *Journal of Intellectual Disability Research* **40**, 120–9. doi: 10.1111/j.1365-2788.1996.tb00613.x.
- Australian Bureau of Statistics (2011) *Retirement and retirement intentions, June 2010–July 2011*. Catalogue No. 6238.
- Australian Institute of Health and Welfare (2007) *Disability Support Services 2005–06: National Data on Services Provided Under the Commonwealth State/Territory Disability Agreement*. Australian Institute of Health and Welfare, Canberra.
- Balandin S., Berg N. & Waller A. (2006a) Assessing the loneliness of older people with cerebral palsy. *Disability and Rehabilitation* **28**, 469–79.
- Balandin S., Llewellyn G., Dew A. & Ballin L. (2006b) We couldn't function without volunteers': volunteering with a disability, the perspective of not-for-profit agencies. *International Journal of Rehabilitation Research* **29**, 131–6.
- Balandin S., Llewellyn G., Dew A., Ballin L. & Schneider J. (2006c) Older disabled workers' perceptions of volunteering. *Disability and Society* **21**, 677–92.
- Bigby C. (2008) Known well by no one. Trends of the informal social networks of people with intellectual disability five years after moving to the community. *Journal of Intellectual and Developmental Disabilities* **33**, 148–57.
- Bigby C. & Balandin S. (2005) Another minority group: a survey of the use of aged care day programs and community leisure services by older people with lifelong disability. *Australasian Journal on Ageing* **24**, 14–18.
- Bigby C., Wilson N. J., Balandin S. & Stancliffe R. J. (2011) Disconnected expectations: staff, family and supported employee perspectives about retirement. *Journal of Intellectual & Developmental Disability* **36**, 167–74. doi: 10.3109/13668250.2011.598852.
- Bigby C., Wilson N. J., Stancliffe R. J., Balandin S., Craig D. & Gambin N. (2014) An effective program design to support older workers with intellectual disability to participate individually in community groups. *Journal of Policy and Practice in Intellectual Disabilities* **11**, 117–27.
- Chadsey-Rusch J., DeStefano L., O'Reilly M., Gonzalez P. & Collet-Klingenberg L. (1992) Assessing the loneliness of workers with mental retardation. *Mental Retardation* **30**, 85–92.
- Chng J. P. L., Stancliffe R. J., Wilson N. J. & Anderson K. (2013) Engagement in retirement: an evaluation of the effect of Active Mentoring on engagement of older adults with intellectual disability in community activities. *Journal of Intellectual Disability Research* **57**, 1130–42. doi: 10.1111/j.1365-2788.2012.01625.x.
- Craig D. (2013) *'She's been involved in everything as far as I can see': supporting the active participation of people with*

- intellectual disabilities in community groups*. Unpublished Doctoral Thesis. La Trobe University, Melbourne.
- Craig D. & Bigby C. She's been involved in everything as far as I can see': supporting the active participation of people with intellectual disabilities in community groups. *Journal of Intellectual & Developmental Disability* (in press).
- Cuthill F. M., Espie C. A. & Cooper S.-A. (2003) Development and psychometric properties of the Glasgow Depression Scale for people with a learning disability: individual and carer supplement versions. *The British Journal of Psychiatry* **182**, 347–53.
- Dusseljee J. C. E., Rijken P. M., Cardol M., Curfs L. M. G. & Groenewegen P. P. (2011) Participation in daytime activities among people with mild or moderate intellectual disability. *Journal of Intellectual Disability Research* **55**, 4–18. doi: 10.1111/j.1365-2788.2010.01342.x.
- Esbensen A. J. & Benson B. A. (2006) A prospective analysis of life events, problem behaviours and depression in adults with intellectual disability. *Journal of Intellectual Disability Research* **50**, 248–58.
- Farmer C. (2012) Demystifying moderators and mediators in intellectual and developmental disabilities research: a primer and review of the literature. *Journal of Intellectual Disability Research* **56**, 1148–60.
- Farris B. & Stancliffe R. J. (2001) The co-worker training model: outcomes of an open employment pilot project. *Journal of Intellectual & Developmental Disability* **26**, 143–59.
- Harlan-Simmons J. E., Holtz P., Todd J. & Mooney M. F. (2001) Building social relationships through valued roles: three older adults and the community membership project. *Mental Retardation* **39**, 171–80.
- Ingvaldsen A. K. & Balandin S. (2011) If we are going to include them we have to do it before we die': Norwegian seniors' views of including seniors with intellectual disability in senior centres. *Journal of Applied Research in Intellectual Disabilities* **24**, 583–93.
- Judge J., Walley R., Anderson B. & Young R. (2010) Activity, aging, and retirement: the views of a group of Scottish people with intellectual disabilities. *Journal of Policy and Practice in Intellectual Disabilities* **7**, 295–301.
- Llewellyn G., McConnell D. & Mayes R. (2003) Health of mothers with intellectual limitations. *Australian & New Zealand Journal of Public Health* **27**, 17–19.
- McCarron M., Swinburne J., Burke E., McGlinchey E., Mulryan N., Andrews V. *et al.* (2011) *Growing Older with an Intellectual Disability in Ireland 2011: First Results from the Intellectual Disability Supplement of the Irish Longitudinal Study on Ageing*. School of Nursing and Midwifery, Trinity College Dublin, Dublin.
- McDermott S. & Edwards R. (2012) Enabling self-determination for older workers with intellectual disabilities in supported employment in Australia. *Journal of Applied Research in Intellectual Disabilities* **25**, 423–32. doi: 10.1111/j.1468-3148.2012.00683.x.
- Moss S., Prosser H., Costello H., Simpson N., Patel P., Rowe S. *et al.* (1998) Reliability and validity of the PAS-ADD checklist for detecting psychiatric disorders in adults with intellectual disability. *Journal of Intellectual Disability Research* **42**, 173–83.
- Reidy R. (1993) Friendships and community associations. In: *Friendships and Community Connections between People with and Without Developmental Disabilities* (ed. A. N. Novak), pp. 351–71. Paul H. Brookes, Baltimore.
- Russell D. W. (1996) UCLA Loneliness Scale (Version 3): reliability, validity, and factor structure. *Journal of Personality Assessment* **66**, 20–40.
- Stancliffe R. J., Lakin K. C., Taub S., Doljanac R., Byun S. & Chiri G. (2007) Loneliness and living arrangements. *Intellectual and Developmental Disabilities* **45**, 380–90.
- Stancliffe R. J., Jones E., Mansell J. & Lowe K. (2008) Active support: a critical review and commentary. *Journal of Intellectual & Developmental Disability* **33**, 196–214.
- Stancliffe R. J., McVilly K. R., Radler G., Mountford L. & Tomaszewski P. (2010) Active Support, participation and depression. *Journal of Applied Research in Intellectual Disabilities* **23**, 312–21. doi: 10.1111/j.1468-3148.2009.00535.x.
- Stancliffe R. J., Wilson N. J., Gambin N., Bigby C. & Balandin S. (2013) *Transition to Retirement: a Guide to Inclusive Practice*. Sydney University Press, Sydney.
- Stancliffe R. J., Wilson N. J., Bigby C., Balandin S. & Craig D. (2014) Responsiveness to self-report questions about loneliness: a comparison of mainstream and intellectual disability-specific instruments. *Journal of Intellectual Disability Research* **58**, 399–405. doi: 10.1111/jir.12024.
- Storey K. (2003) A review of research on natural support interventions in the workplace for people with disabilities. *International Journal of Rehabilitation Research* **26**, 79–84.
- Verdonschot M. M. L., de Witte L. P., Reichrath E., Buntinx W. H. E. & Curfs L. M. G. (2009) Community participation of people with an intellectual disability: a review of empirical findings. *Journal of Intellectual Disability Research* **53**, 303–18. doi: 10.1111/j.1365-2788.2008.01144.x.
- Ware J., Snow K. K., Kosinski M. & Grandek B. (1993) *SF36 Health Survey Manual and Interpretation Guide*. The Health Institute, New England Medical Centre, Boston, MA.
- Wehman P., Inge K. J., Revell W. G. & Brooke V. A. (2007) Supported employment and workplace supports. In: *Real Work for Real Pay* (eds P. Wehman, K. J. Inge,

- W. G. Revell & V. A. Brooke), pp. 117–38. Paul H. Brookes Publishing Co, Baltimore.
- Wilson N. J., Stancliffe R. J., Bigby C., Balandin S. & Craig D. (2010) The potential for active mentoring to support the transition into retirement for older adults with a lifelong disability. *Journal of Intellectual & Developmental Disability* **35**, 211–14. doi: 10.3109/13668250.2010.481784.
- Wilson N. J., Bigby C., Stancliffe R. J., Balandin S., Craig D. & Anderson K. (2013) Mentors' experiences of using the Active Mentoring model to support older adults with intellectual disability to participate in community groups. *Journal of Intellectual & Developmental Disability* **38**, 344–55. doi: 10.3109/13668250.2013.837155.

Accepted 4 November 2014

This document is a scanned copy of a printed document. No warranty is given about the accuracy of the copy. Users should refer to the original published version of the material.