

27: An Effective Program Design to Support Older Workers with Intellectual Disability
Participate Individually in Community Groups.

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Keywords: retirement, intellectual disability, transition, inclusion, program logic, mentoring, active support, volunteering, community groups, participation

Acknowledgements

This research was supported under the Australian Research Council's Linkage Projects scheme (Project number: LP0989241) and with the assistance of two industry partners. The views expressed are those of the authors and are not necessarily those of the Australian Research Council or the industry partners.

Conflicts of interest: No conflicts of interest are declared.

Running title: Transition to retirement

Abstract

Background: The foreshadowed increase of older people with intellectual disability has become a reality in many western countries. Policy aims of inclusion and participation applicable to all age groups should guide development of retirement programs to support older people to have a good quality of life.

Aims: A transition to retirement program (TTR) developed for employees of a large multi-site disability employment service in Sydney, Australia has been shown to be effective. Twenty- four older employees replaced one day a week of work with membership of a community group and group members were supported as mentors to facilitate involvement of a participant in their group. This paper presents the program logic of the TTR, detailing its conceptual components as the first step to enabling it to be tested and replicated in other settings.

Methods: Detailed field notes were compiled by one researcher and the TTR Co-ordinator about the processes used to implement the program, the time, costs and challenges encountered. The textual data were analysed using thematic content analysis, and descriptive statistics were used to analyse the quantitative data.

Findings: The TTR program has three components: promoting the concept of retirement; laying the groundwork for inclusion of would-be retirees with intellectual disability in the community and; constructing the reality. The third component comprised five stages, planning, locating a group, mapping new routine, recruiting and training mentors, and monitoring and ongoing support. The range of activities was the responsibility of the Co-ordinator who had to work in collaboration others involved in the person's life, and required skills in generic case management and specific disability interventions such as active support.

Discussion: By detailing the program logic that under pins the TTR program we have exposed the hidden work of supporting meaningful inclusion of people with intellectual disability in community groups and added to the limited stock of evidence-informed programs in this field.

Transition to Retirement: An Effective Program Design to Support Older Workers with Intellectual Disability Participate Individually in Community Groups

The foreshadowed increase of older people with intellectual disability as a result of increased life expectancy and the demographics of the post war baby boom is fast becoming a reality in countries such as Australia (Bigby, 1992; Bittles et al. 2002). In 2010 for example, it was estimated that people aged over 50 years comprised 21 percent of the 20,000 employees in Australian Disability Enterprises (ADE) and that this number would increase to 50 percent by 2025 (McDermott, Edwards, Abello & Katz, 2009). ADEs are funded by the Federal government to provide employment support for people with disabilities but must also be sustainable businesses. They usually operate as segregated settings, such as large processing and packaging factories, but may also take the form of smaller service or retail enterprises. The majority of ADE employees have an intellectual disability, although ADEs also provide support for people with other disabilities such as chronic health conditions, acquired brain injury and mental health problems (McDermott et al., 2009). For over two decades the Australian government has flagged the retirement of ADE employees as an issue of concern, both in terms of the rights of older employees to pursue a more leisurely lifestyle and the potential threat to business viability incurred by having a workforce that includes a large proportion of older employees with reduced stamina and increased health needs (Bigby, Fyffe, Balandin, Gordon & McCubbery 2001; McDermott, et al., 2009; ARTD Consultants, 2012). Researchers in Australia and internationally have demonstrated the necessity for people with intellectual disability to receive education about ageing, support with planning for retirement and transition, and assistance to participate in meaningful community-based activities (Bigby, 1992; Heller, Miller, Hsieh & Sterns, 2000; Bigby, 2004). Yet to date there is little policy or resources to guide either transition or retirement programs for older employees of ADEs (McDermott et al., 2010). A primary reason for this is that in Australia older employees with intellectual disability are effectively caught between two levels of government, the Federal that is responsible for employment related services and the States that are responsible for day programs, and neither has been willing to take responsibility for funding retirement initiatives.

In contrast, the day program sector, which in Australia provides services for people with more severe intellectual disability who are not employed, has adapted its programs to meet the changing needs of ageing participants, and developed a range of programs to facilitate a 'retirement lifestyle' (Bigby et al., 2004). In a national study of programs used by

older participants, Bigby (2005) found that despite different structures most had similar objectives; to support the exercise of choice, develop and maintain social relationships and facilitate participation in meaningful activity.

It is difficult for an older employee of an ADE to retire to a day program as effectively this entails transfer from a Federal to a State funded service system in which few places are available due to the level of unmet need. Policy in some states also prevents attendance at both a day program and an ADE which means an employee must give up work entirely before being able to “retire” to a day program with no possibility of a gradual transition. On the other hand, there is no financial disincentive to an ADE (in terms of losing some disability funding) to enable employees to gradually reduce the work days/hours as the threshold hours of work required to receive full funding for an employee is 8 hours (Australian Government, 2012).

The absence of transition to retirement programs and support for continued participation post retirement may account for research findings that older employees, their families and service providers regard retirement as a risky proposition that may lead to social isolation, inactivity and reduced income (McDermott et al., 20009; Bigby, Wilson, Balandin & Stancliffe, 2011). Older employees have limited expectations of a retirement lifestyle, and service providers have limited perceptions of the types of programs that might be offered. For example, fourteen service providers who participated in focus groups suggested that segregated disability specific programs might be more suitable for older employees (Bigby et al., 2011). This reflects the fact that many of the small transition to retirement programs established over the last decade with pilot funding have used group rather than individual approaches to supporting inclusion in mainstream community groups (Burke, 2006; ARTD Consultants, 2012).

Segregated and group based retirement programs are contrary to the ideas of inclusion in mainstream community life articulated in Australian disability policy, and person centeredness that is a central principle of service delivery (Commonwealth of Australia, 2011). Consequently, it is important to demonstrate the possibilities offered by transition to retirement programs that reflect an inclusive and person centered approach to community participation for older employees of ADEs. The place of some form of ‘linkage’ to act as a bridge between older people with intellectual disability and community groups, to facilitate inclusion has been a continuing theme in the literature (LePore & Janicki, 1990; Bigby, 1992; ARTD Consultants, 2012;). To date, the challenges of translating this broad concept into the practice, or identifying the processes and skills required have not been clearly articulated. On

one hand older people with intellectual disability are likely to require support to plan retirement and choose, locate, negotiate access and participate in community groups (Bigby, 1992). On the other community groups may be willing to include older people with intellectual disability, but lack the confidence and resources to do this successfully (Bigby & Balandin, 2005; Ingvaldsen & Balandin, 2011; Bigby, et al., 2011).

In disability services a plethora of uncontrollable variables, such as personal characteristics, social or policy context, and location make it difficult to undertake the gold standard method of determining evidence-based interventions through use of randomized control trials. However, careful documentation of program components and processes together with research on outcomes can lead to evidence-informed effective designs. One way of doing this is to construct what Rossi, Lipsey and Freeman (2004) term the *program logic*, which sets out the plan of operation; the logic that conceptualises the program's components and connects it's various activities to intended outcomes, thereby providing the rationale for why and how a program does what it does, based on theory and content knowledge about the area, and experience of implementing the program.

The Transition to Retirement Program

This paper draws on the data from a study that developed and tested a transition to retirement (TTR) program for employees of a large multi-site ADE in Sydney, Australia. The program aimed to enable participants' to make a gradual reduction in work hours and concurrently develop an inclusive retirement lifestyle. Acknowledging the literature that suggests community groups are willing but lack the skills and confidence to include people with intellectual disability, the program also sought to increase the inclusive capacity of mainstream community groups. ADE employees who participated were supported, by the TTR Co-ordinator (one of the researchers who acted in this capacity and a full time appointee at a later stage of the project), to join a mainstream community group one day a week, on the basis of one person per group. Their inclusion in the group was facilitated by the recruitment and training of volunteer mentors drawn from existing members of the group. This training design, coined *Active Mentoring* (Wilson, Stancliffe, Bigby, Balandin & Craig, 2010; Chng et al., 2012), was informed by the literatures on active support, the co-worker training approach to supported employment, volunteering and programs for older people with intellectual disability (Farris & Stancliffe, 2001; Storey, 2003; Bigby, 2005; Trembath, Balandin, & Togher, 2009; Mansell & Beadle Brown, 2012) and a series of focus groups with older workers, their families and service providers (Bigby et al, 2011).

Twenty six ADE employees participated in the intervention group of the study, and were supported to replace one day a week of work with attendance at a community group as a member or volunteer. For the purposes of this paper we excluded 2 of these 26 participants because they attended their community group for less than 3 months (respectively due to illness and withdrawal from the project - see Stancliffe et al. 2013) so their very limited experiences provided no information about the process of group attendance and participation. Table 1 sets out the characteristics of the participants. The seventeen participants who had intellectual impairment as their primary disability were all reported to have mild or moderate impairment, consistent with the fact that they all worked in a disability-specific workplace.

Insert Table 1 about here

The TTR program was shown to be effective in enabling older adults with intellectual disability to attend a mainstream community or volunteering group (Stancliffe et al., 2013). Specifically, 93% of the intervention group went to their community group one day per week for a minimum of 3 months, 86% attended for at least 6 months, with 72% still attending at the time data collection ceased, when some had been a part of their group for as long as two years. On average, participants spent almost four hours each week at their group. These individuals experienced a number of noteworthy positive outcomes. Compared to their situation at baseline, they significantly increased their participation in inclusive community groups, gained an average of four new social contacts (acquaintances and friends), spent substantially more time with these social contacts, and decreased their work hours as planned. Relative to a matched comparison group who remained working their usual hours, intervention group participants were more socially satisfied post intervention, in the sense that they were more likely to report having friends and people to talk to, and receiving social support from others.

In addition to these positive outcomes for individual participants, success was also clearly evident in the recruitment of community groups and volunteering opportunities for participants to join, and the enlistment of mentors from within the membership of these groups. Overall 24 different community groups accepted an individual with an intellectual disability as a long-term member (i.e., one group for each participant). A total of 64 mentors were recruited to support these 24 individuals, ranging from 1 to 6 mentors per participant. More specific information about mentor recruitment and their perceptions about the

supporting a person with a disability is set out in a further companion paper (Wilson, Bigby, Stancliffe, Balandin, Craig & Anderson, 2013). The purpose of the present paper is to explain in detail the components of the TTR program, and the policy, funding and service delivery environment in which it operated. This is a first step to enabling the program to be replicated or adapted to other policy settings. A manual that provides a more detailed and practical guide to each component is currently in preparation and will be published by Sydney University Press in 2014.

Method

Ethical approval for the project was granted through the Human Research Ethics Committee of La Trobe and Sydney Universities. Each participant provided written informed consent, or written proxy consent was obtained from the person who normally made decisions on behalf of the person. Likewise, community group members who volunteered to be mentors provided informed consent to receive mentor training and to mentor the participant with intellectual disability.

The second author was employed as a full time researcher by the University research team and sixth author as a TTR Co-ordinator by the Sydney industry partner in the second half of the project (with pilot funding from the NSW government). These authors were primarily responsible for implementing the program, and as such both acted as TTR Co-ordinators, undertaking the tasks integral to the program design. The third author conducted several mentor training sessions but was involved to a lesser extent in the implementation, while the first, fourth and fifth authors supported regular reflection on the processes in team meetings.

Although the aims and broad approach of the program were determined at the outset, the processes were refined during its implementation phase, as unforeseen issues were experienced and solutions identified. For example the original program activities had been conceptualised as: (i) recruiting participants, (ii) supporting the development of a person-centred transition to retirement plan, (iii) helping to locate a community or volunteer group for each person based on the plan, and (iv) training members of each group to mentor the participant. This did not foresee things such as difficulties potential participants had in visualising something “new” without concrete examples to guide their decision-making, and thus the need to promote more vigorously the concept of retirement. Neither did the original design take into account the complexity of negotiating a changed routine and coordinating a new pattern of support for participants, or the dynamic nature of group membership and

participants' lives which necessitated long term intermittent support to sustain group involvement.

Descriptive data were collected about processes used to implement the program and, for nine participants, the time involved. The second author kept detailed field notes of the various activities he undertook, and paid particular attention to any obstacles encountered, and the skills and methods required to carry out these tasks (e.g., barriers to successful integration into the group and solutions).

The data consisted of field notes, time logs and minutes of the regular reflective discussions between team members, during teleconferences over the 3-year period of the research project. A content analysis (Patton, 2002) was conducted to identify and describe the activities involved in implementing the program, the roles fulfilled by the researcher who was the initial de-facto Co-ordinator and the TTR Co-ordinator after she was appointed, and the time taken to implement various aspects for nine participants. This involved compilation of descriptive statistics, and a thematic analysis to derive the key processes involved in the program.

Findings

The conceptual model of the emergent program logic developed from the data had three components; 1) promoting the concept of retirement, 2) laying the groundwork for inclusion of would-be retirees with intellectual disability in the community and 3) constructing the reality. The range of activities in each component was the responsibility of the Co-ordinator. Figure 1 provides a diagrammatic representation of these, and the wide range of people with whom the Co-ordinator worked to implement the program.

Insert Figure 1 about here

Promoting Retirement

The difficulty of recruiting potential retirees as unforeseen, and the initial method of recruitment to the program by poster-style noticeboard advertisement and briefing staff in the ADEs did not work as anticipated. It failed to take into account the perceived risky nature of retirement held by older employees, staff, and family members that had earlier been identified in the focus groups (Bigby et al., 2011). In these large ADEs there was an absence of positive retiree role models or stories about successful retirement to provide incentives to retire. Indeed, on one ADE site an employee had retired and then returned to work dissatisfied with her retirement lifestyle; her story was often cited and well known.

Advertisements did little to counter the difficulties people with intellectual disability had with thinking about the abstract concept of retirement or imagining what it might be like to participate in a community group rather than be at work. Acknowledgement of these factors meant that *promoting retirement* rather than recruiting participants had to be the first component of the program.

This promotion process involved more active engagement with older employees and their social network members by the Co-ordinator. Small-informal information sessions about the program were held during morning tea at several factories with invited employees who staff thought might benefit from reducing days at work and who were adventurous and willing to try something new. The sessions aimed to help employees think about the possibilities of retirement and begin to translate the idea of retiring into something concrete, positive and meaningful. At these meetings the Co-ordinator described the mechanics of the program, its possibilities and the safety net built into it, issuing a personalised and direct invitation to 'give it a go'. The program was explained in straightforward terms; the notion of dropping one day at work, replacing it with a day of doing something new, the likelihood of meeting new people, the support that would be provided, and the guarantee of returning to work at any time within the first 12 months if the person so wished. Concrete examples were given of different groups that participants might join and the activities they might be involved in.

A second stage of promoting retirement followed with employees who expressed an interest in the program. A meeting was arranged with their family members and/or accommodation provider to gain the cooperation and support of the significant others in their life through a direct personal introduction to the Co-ordinator. The aim of the meeting was to address any concerns the significant others might have and gain a sense of any barriers to participation they might perceive or solutions that they might offer to ease the employee's transition to retirement. The meeting also began a collective conversation between the participant and those who knew him or her well and helped create a person-centred notion of their future as potentially being a time for meaningful participation. Both the participant and their significant others reflected upon what had given the participant's life meaning in the past. One example involved an older man who lived in a hostel; he was unable to articulate any specific interests or hobbies, but was willing to give most things a go. He talked about how he used to tinker with and ride bicycles when a younger man – a meaningful activity that involved bikes somehow became the guide for finding a community group for this man.

Promoting retirement was a marketing exercise to help employees think about possibilities, gain confidence in the potential of the program and promote the model as being failsafe. The campaign was conducted with an upbeat and positive spin that it was worth giving retirement a go - there was little to lose and much to gain. The need to spend significant time promoting retirement in this way is reflected in the very slow response to our initial pre-promotion recruitment efforts – no participants joined community groups in the first six months of the project’s intervention phase. Even after we began promoting retirement uptake was sluggish, with only four individuals joining groups in months 7 to 12. Thereafter, as these pioneers provided successful role models, recruitment accelerated.

Laying the Groundwork in the Community

This component was necessary in order to understand and begin to shape the broad canvas on which the program would operate and to gain a sense of the possibilities available to retirees within a reasonably accessible travelling distance of their home. It involved mapping and investigating the nature of community groups, getting to know communities, and the program becoming known by seniors’ networks. Establishing the bona fides of the program with the leaders of these networks was an important means of spreading word about its credibility through their regional and state-wide meetings. Sydney occupies a large geographic area and as participants’ homes were scattered across its urban sprawl the Coordinators had to get to know many areas unfamiliar to them. However, creating a stable footing among community groups helped to ensure as broad a choice of groups as possible was open to participants, and as many as possible initial attitudinal barriers to inclusion were reduced.

Community directories, local newspapers, neighbourhood centre noticeboards, seniors’ bulletins, internet searches and networking helped to identify potential groups. The subsequent ‘cold calling’ or ‘door knocking’ required excellent communication skills, capacity to analyse and gain a quick sense of the many different types of groups, and ability to adjust language and style to the differing cultural and gendered context of groups. Important too was acquisition of knowledge about entry criteria for groups to avoid giving misleading information to participants. For example, some seniors groups require members to be over a certain age, groups funded by local government often have criteria that only local residents can attend, and many groups have a gender-specification.

The process of laying the groundwork involved both exploring and attempting to shape attitudes of community groups towards inclusion of a person with intellectual

disability. The initial approach focussed on people as individuals with particular interests and abilities rather than on intellectual disability per se. Although most groups were open and supportive of the idea of having a member with intellectual disability, in some cases they were hesitant as a result of previous negative experiences or unrealistic demands placed on them by disability service providers. Such instances required the Co-ordinator to have the capacity to create a positive and non-threatening impression on group members. At times this also meant acting as an advocate, demystifying disability or countering previous negative experiences. For example, one male-specific group had previously experienced a minibus full of men with disabilities arriving to ostensibly join the group. Members had been very put out by the assumption that their group would provide substitute care-giving for the disability service these men attended and had formed a lasting negative impression of inclusion of people with disability.

Constructing the Reality

This component had five interrelated stages; 1) planning, 2) locating a group, 3) mapping a new routine, 4) recruiting, training and supporting mentors, 5) monitoring and ongoing support. Each required the multiple people who played different roles in the participants' support network to work together in a collaborative relationship. Despite involvement with the participant, members of their support network did not always know about or have a relationship with each other. It fell to the Co-ordinator to orchestrate their actions in order to achieve a successful and person-centred outcome for each participant in the transition to retirement process. Table 2 shows the average and range of Co-ordinator time spent at each of these five stages of construction reality for a sub sample of nine participants for whom detailed data about support hours were collected.

Insert Table 2 about here

Planning

Building on earlier conversations that had taken place during the process of promoting retirement, planning was focussed on teasing out each participant's interests and the kinds of activities he/she might like to pursue. The meetings and associated discussions usually included others who knew the participant well. For example, one participant loved to sing and had a clear idea that he wanted to join a singing group. For him it was easy to decide on finding a singing-related group. In contrast, for another participant who had no identifiable

hobbies or interests, it was necessary to trial involvement in various activities to see if any were of interest to him.

For participants who lived in supported accommodation or used other support services the 'transition to retirement' plan was only one of several in their life. Those responsible for other plans needed to be identified and brought into the planning process to avoid potential conflict later on and to allocate responsibilities during the implementation phase. For some participants who lived with family members and only used the ADE, this type of future planning based on personal interests was a relatively unfamiliar concept.

Locating a group

The process of locating potential groups that might meet the relevant criteria developed in a participant's plan built on the groundwork already done in local communities. It involved clarifying the way groups operated and discussing with group leaders and members the idea of the person with a disability joining them. Groups were chosen that met every week, during the day on a weekday (so it could 'replace' work for that day) at the same time, on the same day and at the same place to ensure 1) people had regular opportunities for participation and inclusion, 2) that the new routine could be easily understood by the person with intellectual disability, and 3) that the new routine could easily be accommodated by the ADE and the participant's accommodation support provider.

Community groups were very welcoming with almost no refusals. One all-female community kitchen declined to accept a male participant as a volunteer. Another group withdrew their support after a 4-week trial placement (this participant subsequently joined a similar group in a nearby suburb). Some groups requested an informal presentation to the entire group so that any decision was made collectively. In such situations the Co-ordinator had to pitch the idea to the group, offer guarantees of support over the six month period of the study, draw on successful examples, and make convincing arguments about areas of concern such as safety and accountability. For example, some Men's Sheds had equipment that was dangerous if mishandled and consequently group members were concerned about ensuring the participant's safety. Some groups needed reassurance that members were not being asked to act as a surrogate support workers. These processes required the Co-ordinator to read the group and adapt the pitch to its unique socio-cultural context. Visiting a knitting group in an inner suburban library for example required a very different approach to visiting Men's Shed in a socially disadvantaged outer-suburban area. Lateral thinking on the part of the Co-ordinator was required in some instances, for example one participant had an interest in local history but contact with all local museums and associated centres indicated they had an over-

supply of volunteers. The Co-ordinator continued the search and located a local heritage site that was being restored. He negotiated that the employee could participate in the gardening group that was creating a community garden on the site.

Given the often uncertain availability of particular types of groups and their unpredictable responses, it was difficult to estimate how long the planning and locating stages would take. For some people, particularly those with few well-established interests, these were iterative processes. Generally a trial period was negotiated for participants, and four tried more than one group before finding a suitable one. As Table 2 shows, for the nine participants about whom detailed time-related data were collected, the planning stage took an average of 4.5 hours of Co-ordinator time (range 3-9 hours) and the locating stage an average of 10.5 hours (range 5.25 -17 hours).

Mapping a new routine

Once it was agreed to trial attendance at a group, the Co-ordinator's pivotal task was to facilitate the ensuing changes to the employee's weekly routine. This included re-assessing finances, modifying work schedules, adjusting staff rosters, arranging new travel regimes, and conducting travel training. Frequently, this meant family members or accommodation service providers had to alter their routines or take on new responsibilities. For example, in order to arrive on time at the group a participant might have to leave the house earlier or later in the morning, which had implications for staff rosters or other residents.

The ADE where participants worked was a partner in the research project, so arranging to drop the participants' required day at work was the easiest part of mapping a new routine. For those who lived with family changing their routine was usually straightforward and could be negotiated directly with the person involved. In contrast, for participants who lived in a supported accommodation setting, a change to routine had implications for other residents as well as staff, and required negotiation with several levels of management in the organisation. Although the participant's desired change was at the forefront, these discussions they could be complex and tense.

As Table 2 shows the Co-ordinator's time required to negotiate and establish a new routine depended on the skills, confidence and social circumstances of each participant, and ranged from 9.75 hours to 59.75 hours with an average of 26 hours. For example, one participant had lost confidence to travel independently by public transport since his move from his family home to an accommodation service. An intensive period of negotiation by the Co-ordinator was required to help staff manage their anxiety about the risk of him travelling alone, as well as provision of direct support during travel training to restore the participant's

self-confidence. By contrast, another participant – an experienced traveller – required little support to learn the new public transport route to her community group.

Recruiting, Training and Supporting Mentors

As a new routine was being established, participants began to attend their chosen group. During the first few weeks the Co-ordinator spent considerable time at the group to assist the settling in process for both the participant and the group. Groups were invited to identify at least one member to act as a mentor for the retiree. How this role was filled varied; mentors included ordinary members who had volunteered, the group leader, or in one case the whole group. Here we detail the role of the mentor, while their personal reflections on undertaking their role are dealt with elsewhere (Wilson et al. 2013). Mentor training commenced several weeks later so it could be grounded in the mentors' experience of interacting with the participant and their ideas about what they and others in the group might be able to offer. The training had two parts, (1) Disability Interaction Training, (2) onsite observation and hands-on Active Support training. A concise Disability Interaction Training package was developed that involved, on average, a 1-hour classroom-style discussion with all the mentors from that group using short DVD clips and a printed learning package summarising the material. DVD clips were used as discussion points to demystify disability, introduce person-centred principles, and focus on the different ways to support a person with intellectual disability using Active Support. The training often triggered wider discussion about the group, the range of activities on offer, the possibilities for the participant to engage in those activities, and methods to help him or her to do so.

Hands-on Active Support training occurred in a less structured way in the weeks following the classroom session, and took place in the ordinary flow of activities within the group. It provided a chance for mentors to see examples of Active Support in action, as it was modelled by the Co-ordinator, to receive some coaching and to raise specific queries. The Co-ordinator also observed the group and analysed the range of activities involved in its functioning and suggested ways mentors might construct opportunities to enable an individual to participate in an activity or restructure activities to fit the abilities and interests of the participant. For example; the Co-coordinator demonstrated how to support a participant in an art group by providing regular verbal prompts plus guidance at the different stages of the task; setting up, drawing, painting, then packing away. In another group, the Co-ordinator suggested that a participant took responsibility for a specific regular task, such as helping to clean up after lunch at a frail-aged activity group, which created a consistent opportunity to

participate and interact socially by going around to every group member and socialising, albeit momentarily, while wiping mats or collecting plates

Monitoring and Support

Ongoing monitoring of participation in the group was provided in recognition that changes could occur in both the lives of participants and in the composition of community groups. Monitoring was low level, but built into this stage was a capacity for a quick response of the intensity necessary to sustain a participant's involvement in the event of change. For example, the death of one participant's wife threw his life into turmoil. When he was ready to return to his group, an intensive episode of support from the Co-ordinator was necessary to re-establish attendance and a routine. As well as identifying problems that required immediate attention, monitoring helped to ensure that the relatively poor lines of communication between community groups and the accommodation or other services involved in participants' lives were kept open. One participant for example, had attended a senior citizens' activity-centre group for 12 months when a drop-in visit by the Co-ordinator identified that the membership and dynamic of the group had changed significantly. The mentor no longer attended, there were fewer members, the ethnic composition of the group has changed, and the centre Co-ordinator, who had previously acted as an unofficial mentor, had moved to another role. The participant had become disengaged from group activities and sat alone. Revisiting the mentor recruitment and training stage was necessary to re-establish support for her by a new mentor from within the group, and thus increase her active participation. It was also apparent that better channels of communication needed to be established between the various service providers involved with the employee. The service providers had been aware of the changed level of the employee's participation in the group but had taken no action to address this at the seniors' activity centre.

Another example of earlier processes needing to be revisited occurred when a participant who volunteered at a museum experienced an acute health problem. On his recovery the Co-ordinator provided refresher courses of travel training and mentor support, and established a closer liaison between his family and the accommodation service about his ongoing health status. In his case a return to the planning and locating processes may be necessary if the lengthy and complex journey by public transport to the museum becomes too exhausting for this employee and he needs to find a new group closer to his home.

Coordinator support hours needed

The time required to complete each stage of constructing reality is difficult to predict as there are so many variables affecting it. Varying degrees of self-confidence, travel abilities,

personality traits, levels of independence, ability to conceptualise possible retirement activities, skilfulness of mentors and commitment from community group members, and others involved in a participant's life all impacted on the level of support required from the Co-ordinator. As Table 2 shows, for the nine participants about whom coordinator support hours data were collected, the constructing reality component took an average of 89.75 for each participant (range 44.25 – 167.75 hours).

Figure 2 illustrates vividly this variation showing the estimated week-by-week hours of support for two participants. Weeks -10 to - 1 represent the stages of planning, locating and mapping a new routine, prior to attending the group, while week 1 represents the person's first week at the group and the subsequent stages of recruiting and training of mentors, monitoring and ongoing support. Participant 1 required a large amount of support with travel training (weeks 3 to 10) whereas participant 2 needed no support with travel (he was driven by a family member). It is also notable that for both these participants, after initial intensive coordinator involvement, the support hours dropped, falling to a low level once the participant had attended the group for a number of weeks, a new routine had been mapped and mentor training had been completed. Equally importantly however, after weeks of low Co-ordinator involvement, both participants experienced issues that necessitated a short-term increase on the amount of Co-ordinator support. The latter finding underlines the need for ongoing support to be available as required to help maintain the person's attendance and participation.

Insert Figure 2 about here

Transport and Program Costs

Transport difficulties and costs to the individual of participation are often noted as obstacles to participation in community-based activities for people with intellectual disability (Bigby et al., 2001; 2011). Table 3 shows that participants travelled to and from their group in a number of ways. Travel arrangements required planning, but there were no instances where lack of transport prevented the participant from attending their group. If transport was provided by disability staff (e.g., group home) then the existing transport schedule for the day often had to be rearranged to accommodate the different time or route needed to go to the community group. Transport provided by the community group itself was available to all group members and typically transported members to/from their homes to the group venue. This form of transport offered additional opportunities for socialisation and inclusion with other group members. Travelling to the group by public transport necessitated both planning

and training. Planning involved selecting a route with careful consideration of safety, ease of way finding, and time of travel. Depending on the complexity of the journey and the pre-existing travel skills of the individual, varied durations of travel training were required.

Insert Table 3 about here

The community groups ranged in degrees of formality from incorporated clubs to completely informal groups that met in a community venue. Most members of all groups had limited income because they were retired, elderly, pensioners or unemployed. Consequently, the cost of participation was low. Six groups (25%) charged an annual membership fee, which amounted to an average annual cost of \$ 22.83 (based on 48 weeks attendance) and ranged from \$0.04 to \$1.46 a week. Ten groups (42%) charged a daily fee to cover the costs of food and/or materials. These daily fees typically ranged from \$2.50 to \$8.00, with one participant paying \$24.00 at a ten-pin bowling group that met at a commercial bowling alley. Overall the 10 participants who paid daily fees averaged \$6.16. Because participants attended the group one day per week, they only had to pay this cost weekly. The remaining 14 groups (58%) charged no daily fees. For example, none of the volunteers paid daily fees and the organisation hosting the volunteers paid for incidental costs such as coffee and tea. Overall, the costs of being a group member were low and were readily affordable for all participants. The average total cost of attending the group once each week (membership fees and daily fees combined across 24 participants) was \$2.69 each week. Cost was not a barrier for any participant and was never raised as a concern once group attendance started.

The TTR was a demonstration program established as part of a research study, and the program activities were undertaken by a full-time researcher, who also undertook other duties, and for the later part of the study a full-time TTR Co-ordinator, who eventually took over full responsibility for the program when the study ended. These circumstances mean the necessary data are not available to calculate with certainty the overall program costs, the per-capita cost, or the optimal number of participants that can be supported by one full time Co-ordinator. Based on the available data (time taken to support 9 participants in the constructing reality component, and the rate of recruitment of participants into the program over a 29 month period), we estimate that one full time Co-ordinator would have the capacity to support 27 ongoing and 7 new participants in a twelve month period. This is a total of 34 participants each supported one day per week to participate on an individual basis. This program represents a significant investment of resources, but is likely to reflect the real costs

of supporting meaningful inclusion of people with intellectual disability in the current Australian social context. As programs such as this become more common, costs may reduce as the skills and attitudes needed to support inclusion become more common in ordinary community groups, their staff and members.

Discussion

This paper has provided a detailed account of the program logic for TTR, a linkage program that was demonstrably effective for a group of older employees of an ADE in Sydney. Participants were enabled to develop a retirement lifestyle for one day a week in place of going to work. A full retirement may not necessarily involve simply more of the same type of inclusion in community groups facilitated by this program but rather an individually determined lifestyle made up of an array of different elements.

The limitations of this study are the relatively homogenous group of participants, most of whom had mild to moderate intellectual disability and were independent in terms of personal care. The TTR program may not be as effective with people who have higher support needs as community group members may regard them somewhat differently, and the task of locating groups with the potential capacity for inclusion, and supporting mentors may be more demanding and complex. Indeed a doctoral study undertaken in parallel with this project is identifying the additional challenges of supporting people with intellectual disability and higher support needs to be included as members of community groups (Craig & Bigby, 2012). The program was developed in a large city with reasonable public transport and a wide variety of community groups. It may not be directly replicable in smaller towns with more limited public transport and few community groups. There may also be constraints on the one person per group approach in small rural localities or places which have a high number of older employees with intellectual disability relative to the number of community groups or volunteering opportunities.

The detailed analysis of the components has demonstrated the breadth of activities required to implement a program of this nature and exposed the usually hidden work required when supporting social inclusion of people with intellectual disability. The study has illustrated that range of factors, individual, social contextual and serendipitous that impact on the volume of Co-ordinator time required to successfully establish an older person with intellectual disability as a participating member of a community group. The findings indicate the fragility of being included in the community, and the threat posed by factors associated with the social and health circumstances of the person with intellectual disability, poor communication between members of a person's support network, as well as the changing

nature of community groups. This reinforces the value of an ongoing monitoring role for a Co-ordinator and the value of building into a program, the capacity to respond as required both quickly and intensively. Without this component change in the person's life or the community group can result in loss of the significant investment of resources in supporting inclusion along with the loss of important social and community participation opportunities.

The program described here involved change for the participant's with intellectual disability at a personal level, change at the organisational level in the services already involved in their life, and change by members of community groups who took on the role of mentor in the way they behaved in their group. In this paper we have used the term Co-ordinator to refer to the pivotal position in the program that was responsible for orchestrating and supporting these changes. This may not be the best term to convey this multi-dimensional role and the breadth of knowledge and skills required to perform it; other terms such as 'local area coordinator' 'community builder' or case manager may be more appropriate but may carry with them preconceived ideas about tasks or confusing professional baggage. Articulating the various facets of this position, and considering the pre-requisite knowledge it requires is however more important than determining the correct nomenclature. The position is more than one of a direct support worker and might be characterised as one that negotiates the rights of people with intellectual disability to be included in mainstream community groups by building the capacity of community allies in the form of mentors and other members of community groups. Some parts of the task require traditional casework skills such as identification and negotiation with formal and informal key players in a person's life, flexibility and sensitivity to community sub-cultures and gender while other parts require community development skills such as mapping local resources and networking with groups. These generic skills need to be underpinned by specific disability related knowledge, about things such as intellectual impairment, community attitudes and discrimination (Bigby, Fyffe & Ozanne, 2007; Bigby, 2013). Important too are the very specific set of skills associated with the practice, training, coaching, and modelling of Active Support, which lie at the heart of equipping mentors to support engagement and participation of the retiree and differentiate this program from more generic co-ordination, case management or community linkage program (Mansell & Beadle-Brown, 2012).

In many ways this program demonstrates the range of skills and knowledge necessary to negotiate rights to inclusion in practice for older people with intellectual disability. It may also provide some insights into design of programs for younger people with intellectual disability. The foreshadowed National Disability Insurance Scheme, to be launched in

Australia in 2013 will significantly change the landscape of disability services and funding. For the first time there will be an entitlement to ‘reasonable and necessary’ disability related support for eligible individuals, and the responsibility for funding the purchase of disability services will rest with one central agency (National Disability Insurance Scheme Bill, 2012). The scheme will bring additional funding, and liberate issues such as retirement from argument about where responsibility for funding lies. This will benefit existing users of ADEs. As individualised funding to purchase services becomes available through the scheme, programs to support transition to retirement of older employees in ADEs are likely to be developed. At the same time, the insurance-based nature of the scheme will add to existing pressure to demonstrate effectiveness and outcomes of services, and increase the necessity for evidence-informed practices and programs. The rapid ageing of the population of people with intellectual disability and the development of a National Disability Insurance Scheme mean it is very timely to detail the program logic of an effective transition to retirement program such as this which adds to the limited stock of evidence-informed programs in this field and will inform both the new Scheme’ funding body and community organisations interested in supporting older employees of ADEs to retire.

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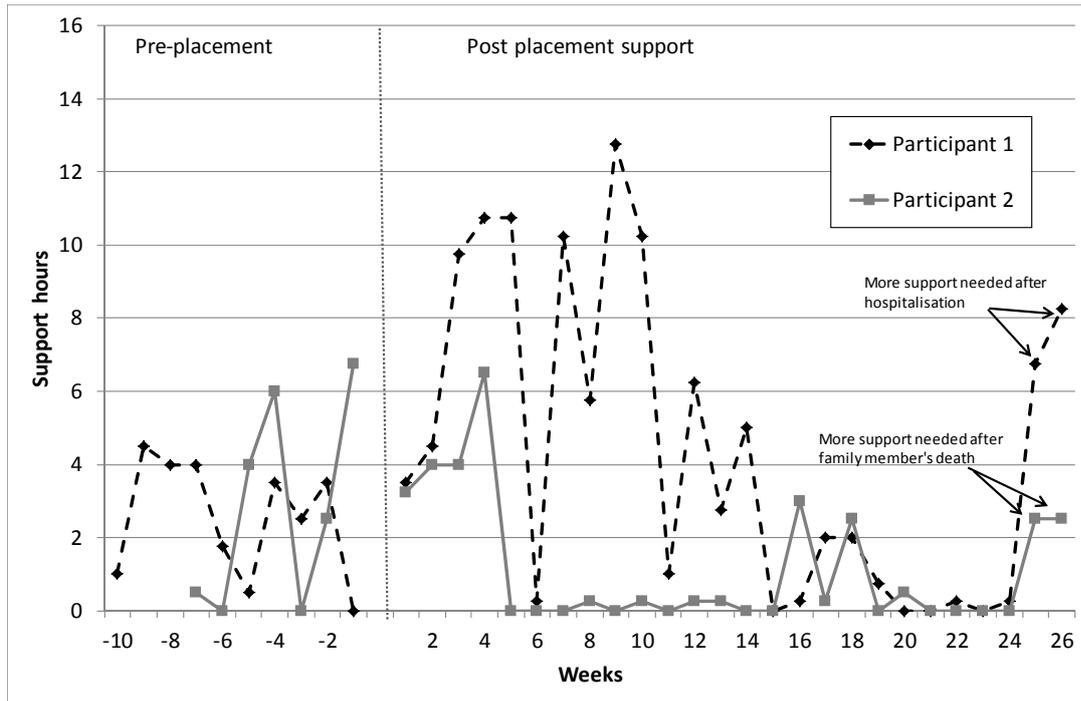


Figure 2 Comparison of Co-ordinator hours required during 'Constructing Reality' component for two participants.

Table 1

Characteristics TTR Participants ($N = 24$)

Variable	Number
Level	(%)
ADE employment	
Full time	8 (33%)
Part time	16 (67%)
Primary disability diagnosis	
Intellectual	17 (71%)
Mental health	1 (4%)
Physical	3 (13%)
Vision	1 (4%)
Hearing	1 (4%)
Acquired brain injury	1 (4%)
Living arrangements	
Independent	3 (13%)
Group home	9 (38%)
Hostel	8 (33%)
Family	4 (17%)
Gender	
Male	15 (63%)
Female	9 (38%)
Age (years)	
Mean	57.5
Range	46.0 - 72.2

Table 2: Co-ordinator hours used in constructing the reality component of the TTR program ($n = 9$)

Activity	Staff travel hours					
	Not included			Included		
	Minimum	Maximum	Average	Minimum	Maximum	Average
Planning	3	9	4.5	4.5	15	7
Locating	5.25	17	10.5	9	24.25	15.5
Mapping a new routine (3 months)	9.75	59.75	26	23.25	96.75	50.5
Recruiting and Training Mentors	2.25	5.25	2.75	3.25	11.25	5
Monitoring & Ongoing Support (3 months onwards)	2.25	10.75	4.5	4.25	20.5	11.75
TOTAL	22.5	101.75	48.25	44.25	167.75	89.75

Note. The total row represents the total hours for individual participants. The figure in this row is not the sum of the figures above it in the minimum or maximum columns because no individual's support hours were the minimum (or maximum) in every activity category.

Table 3. Type of transport used by participants to travel to and from their community group ($N = 24$).

Transport type	To group		From group ^a	
	<i>n</i>	%	<i>n</i>	%
Walk	3	12.5%	3	12.5%
Public transport (bus and/or train)	12	50%	10	42%
Taxi	1	4%	2	8%
Car/van driven by disability staff	5	21%	3	12.5%
Car/van/minibus provided by community group	0	0%	3	12.5%
Car driven by family or friend	3	12.5%	3	12.5%

Note. Where the numbers differ within a row for travelling to and from the group, one or more participants used different modes of transport to travel to and from. For example, one participant travelled by bus to his group but there was no bus available at the time the group finished, so he was picked up by disability staff.

^a Four participants sometimes were given a ride in a group member's car for part or all of the journey home after the group meeting, but this mostly occurred intermittently, so the form of transport listed in the table was the predominant form.

Figure 1. Program Logic Transition to Retirement Program

