POLICY BULLETIN 2, 2013

CENTRE FOR DISABILITY RESEARCH AND POLICY

THE UNIVERSITY OF SYDNEY

TRANSITION TO RETIREMENT

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TRANSITION TO RETIREMENT

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INTRODUCTION

Due to increased life expectancy, the number of older Australians with a long-term disability, such as intellectual disability, is increasing. More people with disability are facing retirement. Planning for retirement is part of the life cycle for most Australians, but people with intellectual disability can be reluctant to leave their familiar work environment, and may find it hard to envisage life in retirement. As well, older people with a intellectual disability meet significant barriers to enjoying an active retirement. These include a lack of planning, few opportunities to access mainstream retirement activities, absence of friends or companions for social activities, as well as practical and bureaucratic difficulties. Yet retirement planning is important for this group of older Australians as older people with disability often have health problems that necessitate them retiring years earlier than the nominal retirement age of 65.

Although disability-specific services offer support to younger people through school, transition to work, and work, there are few if any formalised and funded government supports or policies to assist older workers with a disability to transition to retirement.

This Policy Bulletin describes the implementation and evaluation of the **Transition to Retirement (TTR) Program** that was examined in a three-year collaborative program of applied research involving university researchers and disability service providers. The Bulletin ends with recommendations for policy and practice based on our research findings and on the practical experience of delivering the program.

Leone

Leone has attended a mainstream *seniors' group* once a week for over 18 months so far.

It took some time to find a local group that matched her interests. Members of the group gladly offered to mentor her.

She brings her knitting to the group, plays bingo and dominoes and cleans up after lunch. "I like everything. I enjoy everybody's company. We are one big happy family," she says. For the first time she had friends in the wider community: it was a new experience for her to bump into friends from the seniors' group at the local shops and stop to have a chat. [7]

The TTR Program offered older people with disability the opportunity to begin to build a retirement lifestyle by joining a general community group for one day a week instead of working on that day. Thus, the program fulfils an important goal of disability policy: the *social inclusion* of people with disability in Australian community life.

The program involved:

- talking to people with disability about retirement,
- investigating their interests,
- finding an appropriate community group for individuals to join,
- seeking and then training mentors from that group, and
- ensuring the people with disability were actively involved so they could contribute to the group.

The older workers involved in the TTR Program reflected the population who work in sheltered employment settings, known as Australian Disability Enterprises (ADEs). Their disabilities were all long term, often lifelong, and included intellectual, physical, psychiatric and sensory disability, as well as acquired brain injury. Most were people with intellectual disability.

In the course of the project 27 people with mild to moderate disability joined community groups. Nearly all had limited education, and had spent decades in sheltered employment. Most lived in disability-specific housing. In joining a general community group they experienced an increase in social connectedness, learned new skills, and made new acquaintances in the wider community.

THE AGEING POPULATION

Many people with a disability are employed in ADEs. In 2007 these programs employed 4,510 adults with a disability aged 50 or over, an increase of 103% since 2000. Half this workforce is forecast to be aged over 50 by 2050. [1 2]

Retirees in the general community often have grandparenting and other responsibilities that keep them connected to family and the community, whereas many older people with intellectual disability do not have these responsibilities. Usually, they have limited funds to spend on social activities. They rarely own a car and must rely on public transport or transport by service providers. As well, a lack of friends and acquaintances frequently limits their opportunities for social activities. Consequently, they are often isolated, bored and lonely.

There are many general community groups for retirees, such as seniors' centres, men's sheds, community gardens, and well women's networks. Active participation in the community brings many benefits for seniors: enhanced quality of life; a sense of belonging and accomplishment; increased feelings of physical and mental well-being; and social engagement. Yet, most older people with disability do not participate actively in such groups and so do not share these benefits.

The challenge for policy makers, disability service providers and mainstream community groups is to provide a pathway and a support system for the increasing number of seniors with disability who can experience those benefits. [1]

BARRIERS TO AN ACTIVE, INCLUSIVE RETIREMENT

The disability service system is struggling to resolve key dilemmas about retirement and the provision of support for social participation as those with disability age. Services have been left to make ad hoc provisions that are unfunded and, just as importantly, unevaluated. Finding a solution is further complicated by Australia having a dual system of participation support for adults with disability.

Day programs are funded by state governments and differ between the states, whereas the Federal Government supports ADEs. Transitioning to retirement means negotiating a path that involves both state and Federal governments.

Initial Views about Retirement:

"I've got my friends here (at work) you know I go home and I go to work that's enough for me …no-one thinks of retiring…"

"…you sit at home and you don't do anything"

Comments by focus group participants with disability.

Our research found that people with disability working in ADEs did not look forward to retirement. Older people with disability, their families and support staff saw retirement as irrelevant or as a risk. Nevertheless, they understood that activity and engagement, such as they experienced in their employment, were important. The participants in our study feared that retirement would lead to boredom and loneliness. They preferred to go to work than to sit at home and do nothing. They also worried that the friendship provided by work would be lost if they retired and would not be replaced by other social connections.

In the absence of any experience of more socially inclusive retirement options, people with disability, family members and disability staff tended to fall back on the types of programs they knew about. Thus, their stated preference was for ongoing programs that replicated the work situation, namely separate and special retirement activity groups for people with disability, despite the current disability policy that promotes social inclusion. [3]

THE TRANSITION TO RETIREMENT EXPERIENCE

COMMUNITY GROUPS

For most participants, this was the first time that they had joined a mainstream community group as an individual member. Of the 29 participants who attended a group at least once, 2 withdrew (one due to health problems, one tried several groups but opted to withdraw). The remaining 27 attended their group weekly for at least three months, with all but 2 going for at least six months (a 6-month success rate of 86%). Reasons for discontinuing included physical or mental health problems or, in one case, returning to work. Twenty one (72%) are continuing long term.

The participants each attended a different community or volunteer group for one to six hours a day with an average of 3.6 hours. All the groups had a communal morning tea and most had lunch together.

The groups included:

- eight different men's sheds
- two different community plant nurseries
- six different seniors' groups
- a community garden
- a Lifeline charity shop
- an aviation museum
- a seniors' choir
- the Cat Protection Society
- two different community kitchens
- an exercise and social group
- a walking and knitting group
- a seniors' ten pin bowling league, and
- a lawn bowls club.

The diversity of these groups demonstrates the potential capacity of local communities to provide socially inclusive outlets where older people with disabilities can join with others who have shared interests. However, this capacity needs to be harnessed to enable a person with disability to experience the full benefits of community group membership with support for active participation.

BENEFITS

Participants experienced significant benefits by making new social contacts and taking part in more mainstream community activities. They each gained an average of four new acquaintances and decreased their work hours as planned. After six months of going to their group, they reported being more socially satisfied than matched comparison group members who had continued to work. Occasionally, there was a one-off social contact outside the group, attending outings, running into other members while in the local shopping centre, or being given a lift home, but most participants only had contact with other members when attending the group.

The study demonstrated that participation in mainstream community groups is a viable option for developing a socially-inclusive retirement lifestyle for older individuals with a disability and relatively low support needs. [4]

There were also benefits for mentors, community groups and the broader community. These included greater awareness of disability, readier acceptance of people with a disability[5], and increased capacity for groups to support members with disability. People with a disability made an active and positive contribution to their group. In cases where the person served as a volunteer, such as by working in a charity shop, their voluntary work provided a benefit to the broader community.

MENTORS

Most people with disability require some support. This can come from paid workers, from unpaid individuals such as family members and friends, or a mixture of both. It is not financially feasible to have paid one-to-one support for individuals with disability to attend community groups. As well, the presence of disability staff can act as a barrier to natural social interactions, with group members deferring to staff rather than relating directly to the person with disability. But as the TTR Program demonstrated, support and interaction can also be achieved through mentoring by members of the community group, with initial training, ongoing monitoring, as-needed support from the TTR coordinator.

A key component of the TTR Program was the recruitment and training of 73 existing members of the community groups to provide support or mentoring to a person with a disability who joined the group. Mentor recruitment was mostly straightforward once group members started to get to know the person. Participants had an average of 2.7 mentors, with many mentors preferring to share the responsibility.

To teach the mentors how to support the person with disability, mentor training and support drew on a combination of (1) Active Support, which involves facilitative assistance to enable engagement in meaningful activities, and (2) Co-worker Training. The Co-worker Training model was adapted so that willing group members were trained as mentors for the person with disability attending the group, rather than external disability staff supplying needed on-the-job support to the person with disability.

Mentors supported two types of participation, social and activity. Social participation was an integral part of being a group member. Mentors included the person with disability in morning tea conversations, and prepared them for changes of routine. The mentors saw beyond the disability, recognising the person as an individual with a unique personality and interests.

Participants' comments after 6 months going to their community group

"I'll keep on doing it for the rest of my life, bowling (lawn bowls)."

"People are so nice ... We talk about all sorts of things (seniors' social group)."

"They're my mates...they look after me, they talk to me...and sometimes I help them (men's shed)."

Participation in activities was based on the principles of Active Support, selecting activities according to the person's strengths or existing skills. The mentors found that, over time and with the right amount of support, the person with disability became more comfortable with these tasks. For example, a person with disability taking on the role of setting the lunch tables at a seniors' group might need prompting and close supervision from the mentor in order to complete this task in the expected way. But with careful design of this activity and practice, the task becomes more familiar and mentor support is no longer needed.

The outcome of supporting the social and activity participation of the person with disability was social inclusion, what mentors called "fitting in". This included the sense that the disability was no longer an issue.

With the right type and amount of support from the TTR coordinator, community groups and their members were willing and able to support the inclusion of a person with disability.

Mentors were fundamental to the success of the project in achieving social inclusion. They enabled each person with disability to fully participate in their community group. [5]

KEY FEATURES OF THE TRANSITION TO RETIREMENT MODEL

The TTR Program has three components: (1) promoting the concept of retirement; (2) laying the groundwork for inclusion of intending retirees with disability in the community; and (3) constructing the reality.

Promoting retirement was essentially an information exercise to help people think about possibilities, to understand retirement better, and to gain confidence in the program.

Laying the groundwork in the community meant exploring community groups, and attempting to shape attitudes in the groups towards including a person with disability.

Constructing the reality had five stages, (i) planning, (ii) locating a group, (iii) mapping a new routine, (iv) recruiting, training and supporting mentors, and (v) monitoring and ongoing support.

It began with jointly *planning* or working out the kinds of activities the participant would enjoy, followed by *locating a group* to match the person's preferences as far as possible. The groups chosen met on a weekday, at the same time on the same day every week, to enable the participant, their carers and workplace to adapt to the new routine. Only one person with disability joined each group.

The community groups were very welcoming although one all-female group did not want a male participant. There was also some concern about risk; some men's sheds have equipment that if misused could be dangerous, and men worried about the participant's safety.

The next stage was *mapping a new routine* with the participant. The TTR coordinator helped arrange transport for the person to and from the group. This could include being driven by disability staff, family or friends; using community transport if available; or learning to travel to the group by public transport. If the person with disability used public transport, the coordinator provided travel training, often a time-consuming process.

For the first few weeks, the coordinator assisted the participant to settle in. Then in the *recruiting, training and supporting mentors* stage, members of the group volunteered as mentors. They received training and ongoing support from the TTR coordinator.

Graeme

For Graeme, a shy man, changing his routine and meeting more than ten new people at a community plant nursery was a confronting experience. He also had to learn a new travel route, involving a bus, a train and a walk. The other volunteers are teaching him to write, which has greatly improved his self-confidence.

"I like coming her to join in with all these ones [other volunteers at the community nursery]. I like having morning tea with all the others and having a joke with Martin [a mentor]," Graeme says. Support staff and family have noticed his increased friendliness and independence since volunteering at the nursery. [7]

The coordinator, having observed the group, suggested activities that utilised the participant's existing skills, for example setting the table for lunch, or mixing potting soil at a plant nursery. The coordinator also identified small potentially problematic issues and dealt with them before they became barriers. Over the following months the coordinator gradually withdrew support but continued to monitor the group intermittently, and to provide support where needed to help maintain the participant's attendance and active participation. This final stage was called *monitoring and ongoing support.*

Monitoring and ongoing support. This final stage involves intermittent monitoring and as-needed support. When group activities alter, mentors move on, or the person's needs or circumstances change, renewed short-term support from the TTR coordinator is often needed. Such support should be available *indefinitely*. Our research project only provided for ongoing support for six months, but participant support needs were not restricted to such an arbitrary time line.

Fortunately, our Sydney-based industry partner the Australian Foundation for Disability (AFFORD) secured some funding to employ a TTR coordinator. This provided the opportunity for the TTR Program to move from a time-limited research project to become part of ongoing service delivery. It also enabled long-term monitoring and support to be provided to all TTR participants, including research participants. This proved invaluable, and in a number of cases was the difference between an established placement continuing or not.

For example, a woman with disability had attended a seniors group for over two years when a drop-in visit by the TTR coordinator revealed that her mentors had moved on, and the woman often sat alone and rarely participated in group activities. [6] The TTR coordinator remedied these concerns by returning to the *mentor recruitment and training* stage, after which her new mentor supported her to increase her active participation. [6]

COMMUNITY CAPACITY AND THE TTR COORDINATOR ROLE

Training and supporting mentors within community groups develops their capacity to support people with disability to become active, socially included group members. Using existing community social infrastructure, rather than funding new retirement groups for people with disability, makes sense when promoting social inclusion and may well be highly cost effective over time (we did not evaluate cost). However, the TTR Program is *not* a low-cost option. The time needed to support each person is highly individual, and depends on circumstances and abilities. Therefore, the figures we gathered about a small subgroup of participants provide a rough guide at best. We found that *constructing the reality* for *each* person with disability required between 45 and 170 hours (average = 90 hours) of the TTR coordinator's time. [6]

The TTR coordinator's pivotal role requires a person with the capacity to negotiate opportunities for people with disability to be fully included in mainstream groups, by building capacity in those groups. [6] Because of the individual and time-consuming nature of supporting individuals to join community groups, a dedicated TTR coordinator position is needed to run the program. The coordinator needs a range of advanced skills in disability, case management and community development. Such skills are not well developed among most disability staff. Our research indicated that existing disability service staff have neither the skills nor time to do the job properly as an add-on.

RESEARCH TO PRACTICE AND SCALING UP

An important goal of disability policy involves people with disability being included and participating actively in the community. The challenge for service providers and families is how to achieve, and sustain, inclusion. Disability services and their staff need clear guidelines and evidence-based resources on how to meet this goal.

As part of our commitment to translating the TTR research findings into everyday practice, Sydney University Press will publish our manual in late 2013. The manual will provide a detailed and practical guide to each component of the TTR model. [8] Included with the manual is the DVD *Transition to Retirement,* featuring the individual stories of six men and women who took part in TTR Program. These participants can provide role models for others with a disability who are thinking about retirement, and the DVD provides concrete, easy-to-understand examples of socially inclusive participation.

Having good training resources like these is important, but resources are not enough to guarantee the scaling up of promising interventions. Too often practices like TTR remain as interesting one-off initiatives without lasting impact or widespread availability.

In its 2013-2017 long-range plan, the US National Institute on Disability and Rehabilitation Research (NIDRR) adopted a stages-of-research framework to guide its funding of disability research. [9] These stages include *Intervention Efficacy* which, like our TTR research, involves “testing whether an intervention is feasible, is practical, and can yield positive outcomes for individuals with disabilities” (p. 20,304) [9]. But the NIDRR framework also includes a further stage – *Scale-up Evaluation* – which “examines the challenges to successful replications and the circumstances and activities that contribute to successful wide-scale adoption of interventions” (p. 20,304) [9]. This final stage is intended to help generate widespread implementation of evidence-based practices.

Although successful, the research-based trial of the TTR Program involved fewer than 30 people with a disability who joined a community group. Participants were drawn from a small number of disability service settings. If the findings of Australian applied disability research of this kind are to be taken up nationally by disability services, then research and development funding is needed to find effective ways to scale up such interventions.

POLICY AND PRACTICE RECOMMENDATIONS

- *Disability industry capacity*: The skills needed to deliver the inclusive social outcomes that were provided by the Transition to Retirement (TTR) Program are poorly developed in many parts of the disability industry. Appropriate training resources and expertise are needed to build the skills required to deliver the program.
- *Dedicated TTR coordinator*: The highly individual and time-consuming nature of supporting individuals to join community groups, requires a dedicated TTR coordinator position.
- *Funding and auspice*: Having a TTR coordinator means that an appropriate funding source is needed, but in Australia it is unclear which level of government would provide the funding. It is also unclear which disability service type (employment, accommodation, community access) could auspice a TTR service most appropriately. [a] These issues need to be clarified.
- *Policy and funding are needed now*: Issues of funding and auspice could become clearer under the individualised funding arrangements envisaged for the National Disability Insurance Scheme (NDIS), with individual retirees presumably able to purchase a TTR service (if available). However, clear provision needs to be made now for people to retire, in preparation for the NDIS full roll out which is some years away.
- *Flexible access*: Older people with disability, who may also use disability services, require flexible access to services on an individually determined basis so that they can attend mainstream community groups, regardless of the funding source of that group.
- *Scaling up for widespread implementation*: Australia should adopt a *stages of research* model that provides disability research funding not only for small-scale research such as ours that demonstrates efficacy, but also offers funding for *scaled up* research that could result in wide-scale adoption of the intervention.[9]

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[a] The closest example is the *Transition to Work* (TTW) program which is funded at a state level and provides up to 2 years of funding per person for work preparation training. However, TTR cannot be time limited in the same way, because long-term monitoring and as-needed intermittent support is required to deal with problems that arise.

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