



EVALUATION OF THE AUSTRALIAN DISABILITY ENTERPRISE TRANSITION TO RETIREMENT PILOT

Final Report

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Community Services and Indigenous
Affairs (FaHCSIA)

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Abbreviations and acronyms

Abbreviation	Acronym
ACROD	Australian Council for Rehabilitation of Disabled (Now called National Disability Services)
ACT	Australian Capital Territory
ADE	Australian Disability Enterprise
COAG	Council of Australian Governments
CRCC	Commonwealth Respite and Carelink Centre
DoHA	Department of Health and Ageing
EAP	Employment Assistance Plan
HACC	Home and Community Care
FaHCSIA	Department of Families, Housing, Community Services and Indigenous Affairs
NRCP	National Respite for Carers Program
NDA	National Disability Agreement
NDIS	National Disability Insurance Scheme
NSW	New South Wales
SPRC	Social Policy Research Centre, University of New South Wales
SRV	Social Role Valorization
TTR	Transition to Retirement
QUT	Queensland University of Technology

Executive summary

This report presents the findings of an independent evaluation of a small-scale pilot of transition to retirement for older employees with disabilities of two Australian Disability Enterprises (ADEs) operating in regional and rural Australia. The findings are presented within the broader context of the ageing Australian population, including the ADE workforce, and measures to support people moving to retirement.

The pilot

The pilot operated between October 2010 and October 2011 and was funded by FaHCSIA. The pilot placed ADEs in a central role of a) educating the 12 older employees involved about retirement, b) facilitating retirement planning, and c) identifying options for community activities and linking employees into these. CRS Australia provided training for all the ADE staff involved in the pilot. A third ADE was funded for six months to develop and provide community education workshops for community groups, with the aim of raising their awareness of disability and increasing their ability to include older people with disabilities in their activities. A total of 17 community group staff members attended these workshops.

The pilot provided an opportunity for FaHCSIA to understand and document the retirement and ageing issues of ADE employees more comprehensively, and to determine the capacity of ADEs to assist in retirement planning and the capacity of communities to include older people with disability in mainstream activities.

The evaluation

The evaluation used a mixed-methods design, with qualitative data collection from a range of sources and a review of key documents, including those about other transition to retirement initiatives. We talked to 8 ADE staff members, 12 ADE employees (using specially trained researchers) and 11 family members or support persons, 4 'retirees' from work, 10 community organisation representatives and 8 state government representatives. Four community organisations returned a survey. We also interviewed federal disability and ageing policy officers. The evidence from the pilot was supplemented with evidence from other sources. FaHCSIA hosted a *Retiring from an Australian Disability Enterprise Forum* in June 2011 (TTR Forum), which included 12 disability services with other transition to retirement initiatives, state government officers, academic researchers and peak groups. The discussion covered the challenges and possible solutions to retirement for people with disabilities working in ADEs.

Although the pilot is small the participants and their situations were diverse enough to understand the complexities of the pathway to retirement, and the findings are fairly consistent with evidence from other sources. As such, we are confident the evaluation

will provide FaHCSIA with insights into what might be needed to establish effective pathways to retirement for people with disabilities who work in supported employment.

Findings

Although the ADE workforce is ageing, the expectation that those in supported employment could retire is a relatively new idea for older employees and their family members.

Older people with disabilities can be successfully prepared for retirement

The pilot suggests it is feasible to better prepare older employees with disabilities for retirement. While none of the pilot participants retired over the period of the evaluation, a number had made substantial progress in the transition—seven employees were optimistic or somewhat optimistic about life after retirement, eight were more able to access social supports, and all were more confident about participating socially. All the employees enjoyed having a choice about how to spend their time and most had identified interests that they might pursue when they no longer work. The ADEs report that employees will continue to need some level of ongoing support to access community services. Being active in the community has benefits for retired Australians—maintaining health, improved physical and psychological wellbeing and social connectedness—and we saw these same benefits among employees in the pilot, particularly those linked into community activities that fitted their interests.

Lifelong person-centred planning for retirement is needed to reduce the risk of social isolation on retirement

In July 2011, the Senate Community Affairs Reference Committee highlighted the need for lifelong planning to ensure people with disabilities receive appropriate support over their whole life¹. But lifelong planning for retirement for people with disabilities in supported employment appears not to be occurring consistently. Prior to the pilot the employees had not planned for retirement and, as a result, faced many challenges to retiring, including not knowing about what life after work could be like, limited social connections in the broader community, lack of life skills and, for some, financial insecurity. Although some of these impediments to retirement are similar to those faced by other older workers, people with disabilities have fewer personal resources to find solutions, and, generally, ADEs appear not to have provided much assistance about retirement for their employees. Like other ADE employees of a similar age, the pilot participants had not considered fully retiring before the pilot, even though they may have slowed down at work, had declining health and productivity and/or no longer enjoyed being at work. When first approached about participating in the pilot some employees were confused or distressed about the idea of ceasing work, highlighting the

¹ Disability and Ageing: lifelong planning for a better future report.

importance of introducing the idea early and gradually, providing education about retirement, and involving employees in the decision to retire.

Older workers need intensive individualised education and support to plan for retirement and be linked into mainstream community services and activities, as well as the chance to experience activities

The findings suggest that intensive and personalised lifestyle planning, commenced early and reflecting the person's own needs and aspirations, is effective in helping people with disabilities understand the challenges they face in retirement and the opportunities available. Older workers need emotional and practical support to think about retiring, to explore options for spending their time post-work, and time to practice and develop life skills so they can participate in community activities with less or no support.

The pilot confirms that a key person is needed to take on a coordination role between the individual with a disability, their family and community services to enable a successful transition to retirement. In the pilot this support was provided by a specially funded linkage coordinator position (called a 'life coach' at one site).

Other studies identified that the most effective approach for a transition coordinator to take is person-centred case management. The pilot provides further evidence that such an approach works because when it was used employees were able to pursue individual interests and address their concerns such as managing money and using public transport. Consistent and intensive support over almost 12 months provided employees in one site with enough time and opportunity to begin to develop the greater autonomy and confidence needed to take part in mainstream community activities and choose how they spend their time. Where employees had less choice in their activities, family members felt it unlikely they would find activities to enjoy in their retirement or develop a degree of autonomy.

Transition to retirement is a gradual process and progress will depend on the individual's needs and situation and the skills of the person providing the support.

Having a chance to try out an activity is a very important way of learning for people with intellectual disabilities and was highly valued by the pilot participants. It was what employees talked about most in their interviews and where they gained the most social and emotional benefits.

As employers, ADEs have a role in lifelong planning for retirement for older workers but they may not be the most appropriate organisation to assist employees to transition to retirement

ADEs are employment providers for people with disabilities, and sustaining this role depends on the strength of their business operations. The experience of the pilot shows that substantial dedicated staff hours and resources are needed to assist employees to transition to retirement.

As employers, ADEs have the opportunity and an obligation to address planning for retirement over the whole of an employee's work life, as part of the individual employment planning processes already in place. But the experiences of the pilot suggest that ADEs might not have the capabilities, the skills and knowledge, or the systems in place to effectively prepare employees for transition to retirement, in particular to fill the role of linking employees to community activities and address post-retirement issues. As such, ADEs may not be the most appropriate organisations to assist employees to transition to retire. However, to varying extents, the participating ADE teams did acquire the necessary skills and knowledge over the course of the pilot to effectively support their employees.

While ADEs have trusted relationships with employees that are important to allay employees' fears of retirement and help them identify potential community options for their retirement, other skills are also needed. Specific skills are vital in bridging the gap between employment and post-work activities, but these key competencies are not required for ADE trainer, supervision and support worker positions. The key competencies are the ability to implement person-centred planning and to see the whole person rather than the person in their work role, and skills in working with the community and other stakeholders to achieve the post-work goals of the person with disability. The ADE staff in the pilot needed to acquire these skills. In addition, some ADE staff other than the pilot team lacked an understanding about employees' rights to retire and the processes involved in the transition to retirement, which may or may not be the case for other ADEs. Another disadvantage of ADEs taking on responsibilities for the transition to retirement program is that, as employers, they no longer have a role in the person's life when work ceases.

The ADEs involved in the pilot initially had no systematic processes in place to recognise when an employee might be ready to retire; they did not have a template for retirement planning; and lifelong planning and skill development had not taken place for the participating employees. But the pilot demonstrated that it is possible for an ADE to build capacity in this area. One ADE developed a picture retirement planning template, which was successful and has potential for wider application.

Regardless of whether ADEs have the main carriage of transition to retirement programs, the evidence suggests that ADEs are in a good position to recognise when an employee is slowing down and to make an early start to their education about retirement. But people with disability need an understanding of what retirement is and of the options other than work so they can be the primary instigator of a transition to their next life stage. In addition, a move to a greater focus on consumer choice in disability policy indicates that the person with the disability should be able to choose who assists them to transition to retire; this is incompatible with the assistance role being taken automatically by the ADE.

Mainstream community services have differing levels of ability to include older people with disabilities

Mainstream community services in the pilot had differing levels of ability to include older people with disabilities in their activities, but their capacity to do so was improved with education and through experience of having the pilot participants attend.

Most community groups were generally welcoming of the employees. We saw instances where an organisation had experience and skills to include people with disabilities, and employees fitted easily into these groups. Other community services or groups had no experience including people with disabilities and little understanding, which meant that an opportunity to participate was closed. These groups tended to be organisations for older people that relied on volunteers.

How much education is needed to promote inclusion depends on the existing level of understanding and the ability of other members of the community group to support the person with a disability to participate. Evidence from the pilot suggests that both community education and community development can be effective approaches to working with community organisations. One pilot ADE took a community development approach to educating and engaging community organisations, which was very effective in increasing the capacity of organisations to assist employees. Over time, the linkage coordinator formed close relationships with a number of organisations and passed on advice about how to assist people—they saw this advice implemented and a growth in the capabilities of the community organisations' members to assist the pilot participants. The community education workshops resulted in conceptual and instrumental learnings, with participants indicating the workshops added to their knowledge about disability and the challenges older people with disabilities face.

Given the long-term segregation of older people in supported employment and their lack of visibility in the community, broad community education to raise awareness about disability and social inclusion may be needed. In two groups, a couple of community members left because they were uncomfortable about sharing activities with a person with a disability—a situation that might be avoided if the community was more aware of the challenges faced and more familiar with seeing older people with disabilities.

Residency in smaller population centres provides additional challenges for linking employees into mainstream activities

The two pilot sites took very different approaches to implementing the service components. As such, it is unclear how much the differing impacts in each pilot site are due to the differing implementation approaches and how much to the differing local contexts.

But residency in a small town meant there were fewer community groups suitable for older people so that the community options were more often, but, not limited to, social outings. The options for using public or community transport were also very limited in

these settings. The employees based in the larger population centre tried out a broad range of activities, including social outings, volunteering, skills training and recreational activities. They also had the opportunity to receive travel training and to learn to use public transport to access social supports.

Potential for wider application of the approaches used

The pilot and other evidence suggests that for an employee with a disability to be successfully assisted to transition to retirement requires government agencies, employers, disability services and family members to collaborate in planning and supporting the person to retire. Education about and planning for retirement should start early.

There is potential to apply key components of transition to retirement approaches used.

Person-centred individualised planning to identify retirement issues and possible community options for retirement. The education and retirement planning process used in the pilot, with pictorial plans and regular planning and education meetings, may be a good model to help the employee understand the opportunities in life after work and help address any concerns or barriers for them in retiring, particularly for employees with intellectual disabilities.

Linkage activities using a community development approach to engage and educate community services and give the employee an opportunity to try out and experience the activity.

Conclusion

All Australian governments are committed to including people with disabilities into all aspects of community life. To achieve this, the National Disability Insurance Scheme, when implemented, will allow people with disabilities to choose services and supports to meet their needs and participate in the community. But the pilot suggests that the issue of retirement transition for older employees with disabilities in supported employment is urgent and cannot wait for this major reform to be delivered. In the short-term all governments should continue to work together to create pathways for supporting employees to transition to retirement

1. Introduction

This chapter describes the rationale for the pilot, its design and the evaluation approach and methods. Information on the disability and ageing policy context and on retirement issues for the broader community are summarised in chapter 2.

1.1 The Transition to Retirement pilot

Older employees with a disability working in supported employment should have the same opportunities to retire with dignity afforded to other Australians. But there is strong evidence that they do not currently have the same opportunities and that they are reluctant to retire, often retiring when they are no longer physically able to work.

Retirement for older workers with a disability has wide-ranging implications for their quality of life, including the nature of support required at home, maintaining a network of friends, financial wellbeing and having a sense of purpose and social participation. Older workers with a disability are particularly resistant to change, which makes retirement harder to achieve.

The Transition to Retirement (TTR) pilot was an opportunity for FaHCSIA to understand and document the retirement and ageing issues identified by *Occasional Paper 27: Ageing and Australian Disability Enterprises* (2010). The pilot was intended to determine the capacity of ADEs to assist in retirement planning, and of communities to include older people with a disability in mainstream activities.

In 2010, FaHCSIA funded the small six-month TTR pilot for employees aged 45 years or more in two Australian Disability Enterprises (ADEs) based in regional and rural areas. The two ADEs piloted education, planning and linkage activities—Vantage Incorporated (Victoria) and Tulgeen Disability Services (New South Wales). The pilot was subsequently extended for another eight months to allow more time to implement the components to ensure the participants are supported in the long-term.

A third ADE, Koomarri (ACT), was funded for six months to develop and provide community education workshops for community groups with the aim of encouraging them to include older people with disabilities in their activities.

The pilot placed the ADEs in the central role of facilitating retirement planning and identifying options for community activities and linking participants to these. The aims of the pilot were to

- assess whether this new role can be integrated into the organisations' usual operating practices with a small amount of additional funding for linkage activities

- develop a better understanding of how suitable retirement pathways can be created for older employees of ADEs, pathways that will allow these employees to retire with dignity when they choose
- further document retirement and ageing issues in ADEs.

Details about the design of the pilot are given in chapter 2 and the program logic for the pilot in appendix 1.

1.2 The evaluation

1.2.1 Purpose: to assess appropriateness and effectiveness

The purpose of the evaluation is to provide information to the Department about the appropriateness and effectiveness of the Transition to Retirement service model in two different state contexts and service systems. The information will assist FaHCSIA to develop further policy responses to the issues associated with ageing employees in ADEs.

1.2.2 Key evaluation questions

The pilot addressed the following key evaluation questions.

- What is the ability of the current service delivery system to assist older employees with a disability to retire from Australian Disability Enterprises?
 - Are mainstream community services able to include retired ADE employees in their activities? Are there any barriers to make mainstream services unwilling to take on people with a disability?
 - What kinds of support do older workers need to help them move to retirement and what systematic changes to services should be implemented?
- Can Australian Disability Enterprises effectively prepare employees for the transition to retirement?
 - Is it feasible for ADEs to effectively prepare employees for the transition to retirement?
 - How successful was the model in different contexts (location, service availability, state service system)?
- Is there potential for wider application of the model and a permanent transition to retirement program?

1.2.3 Evaluation planning

ARTD and the then Disability Studies and Research Centre (University of NSW) prepared an evaluation strategy and plan in June–July 2010 in consultation with FaHCSIA, the participating ADEs and Victorian and NSW Government officers. The Disability Studies and Research Centre has subsequently merged with the Social Policy Research Centre.

The University of NSW Human Research Ethics Community reviewed and approved the methods for collecting data from the ADE employees and their carers.

1.3 Methodology

The evaluation used a mixed methods approach drawing on qualitative data from a range of sources and reviews of key documents. We talked to key staff and employees involved in the pilot and some of the community organisations they worked with.

All employees' names have been changed when a first name is mentioned in this report.

The data collection methods are summarised in appendix 2.

1.4 Comments on the extent of evidence for the evaluation

The pilot provides one source of evidence about possible approaches to address the structural and personal impediments that ADE employees face when retiring. The evidence comes from two pilot sites with 12 participants in total who represented a fairly diverse group in terms of age and health issues and living arrangements. One of the sites had more participants with higher needs and who suffered from poor mobility, than the other. The pilot sites were situated in regional and rural areas in two states and 8 participants lived in small towns with limited community resources. To improve the applicability of the findings we were able to draw on the experiences of ADEs from other contexts (see below).

Interviews with employees with intellectual disabilities depend on the interviewee understanding the questions and feeling comfortable about giving honest answers, not responding in the way they feel the interviewer wants to hear. Interview guides for the evaluation were developed by disability experts, and we are confident about the quality of the data, but some employees are non-verbal and so did not discuss their experiences in any detail.

Data about pilot activities, costs and staff hours were not consistently recorded and were sometimes estimated retrospectively, but, given the regular structure of the pilot activities we are confident the data are fairly reliable for one of the sites and have included the analysis in this report.

To gather data from employees who had experienced transition to retirement we also spoke to four participants in the Koomarri Gateway Retirement Program. Of the four, just one participant had retired from an ADE, two participants had not been in the workforce for a long time but had an association with Koomarri, and one participant had very limited expressive communication. As a result we are unable to be confident that the interviews are representative of ADE employees' experience of transitioning to retirement through this program. Even so, their experiences were similar to those of the TTR pilot participants.

The evidence from the pilot was supplemented with evidence from other sources, which was fairly consistent with the findings from the pilot. One of these sources was the FaHCSIA hosted *Retiring from an Australian Disability Enterprise Forum* in June 2011 (TTR Forum), which included 12 disability services delivering other transition to retirement initiatives, state government officers, academic researchers and peak groups. The discussion covered the challenges and possible solutions to retirement for people with disabilities working in ADEs.

We also reviewed publicly available information about other transition to retirement programs (TTR) delivered by disability services.

- AFFORD videos of participants giving testimonials and discussing their experiences in the AFFORD transition to retirement pilot on the AFFORD website, <http://www.afford.com.au>
- Albrecht, D. (2006), 'Planning for Retirement: Improving Service Options for Aged South Australian People with Disability', ACROD (SA)
- Albrecht, D., 'Retirement across the life course', paper published on NDS website, not dated
- Koomarri, 2011, Gateway Retirement Program Information Sheet (Version 1, January 2011)
- Minda Incorporated, Retirement Lifestyle Services <http://www.mindainc.com.au/services/lifestyle-services/day-options/retirement-lifestyle-services>
- Preston, N., 2008, Greenacres Retirement Options, Presentation at National Disability Services Forum, Brisbane
- Wilson N.J., Stancliffe R.J., Bigby C., Balandin S. and Craig D., 2010, The potential for active mentoring to support the transition into retirement for older adults with a lifelong disability, *Journal of Intellectual and Developmental Disability*, 35 (3):211–14.

The evaluation findings were also compared with the findings from *Occasional Paper 27: Ageing and Australian Disability Enterprises* (2010), completed by the Social Policy Research Centre, University of New South Wales.

2. Context and background

This chapter outlines the policy and service system context of this small scale pilot. To properly understand the evaluation findings it is also necessary to understand the opportunities and challenges of the current disability and ageing systems.

Both FaHCSIA and state governments recognise that there is a need for cooperative planning and policy responses to meet the impact of an ageing Australian Disability Enterprise workforce.²

2.1 Disability services and policy

The Commonwealth Government and the state and territory governments share responsibility for funding specialist disability services under the Commonwealth State Territory Disability Agreement. The Commonwealth Government is responsible for planning, policy setting and managing employment assistance for people with disabilities. The state and territory governments have similar responsibilities for other disability services, such as accommodation support services, respite care services and community access programs (e.g. day programs). Governments share responsibility for several programs, including advocacy and print disability services.³

The Commonwealth Government directly funds a range of programs to assist people with disabilities, including employment services, employer incentives, advocacy, respite, print and caption and translation services. Services are funded under the *Disability Services Act 1986 (Commonwealth)*.

The state and territory governments are moving towards a model of individualised funding packages for people with disabilities⁴. The disability system is hard to navigate and not well integrated nationally. Even within one jurisdiction, people deal with a multitude of programs and agencies. It is also complex for people with disabilities and carers to move between the disability and aged care sectors.⁵

2.1.1 The National Disability Strategy

Recognising the sometimes fragmented approach to service delivery for people with disabilities and their carers, the Council of Australian Governments (COAG) has

² Victorian Framework for the Transition to Retirement Pilot, 2010.

³ Additional Procedures and Information for the Disability Employment Assistance (DEA) Program, 2007–2012.

⁴ NDS, 2010, Submission to Australian Disability Enterprises Vision Process.

⁵ Australian Productivity Commission, 2011, Report No. 54 on NDIS; the Senate. Community Affairs. References Committee. 2011, 'Disability and Ageing: Lifelong Planning for a better future', July 2011.

committed to a National Disability Strategy 2010–20 for improving life for Australians with a disability, and for their families and carers. It represents a commitment by all levels of government, industry and the community to a unified, national approach to policy and program development. This new approach will assist in addressing the challenges faced by people with disabilities, now and into the future.

The Strategy is the result of a nation-wide public consultation process involving more than 2,500 people, and was formally endorsed by COAG on 13 February 2011.

The Strategy sets out six priority areas for action.

- Inclusive and accessible communities: the physical environment, including public transport; parks, buildings and housing; digital information and communications technologies; civic life, including social, sporting, recreational and cultural life
- Rights protection, justice and legislation: statutory protections such as anti-discrimination measures, complaints mechanisms, advocacy, the electoral and justice systems
- Economic security: jobs, business opportunities, financial independence, adequate income support for those not able to work, and housing
- Personal and community support: inclusion and participation in the community, person-centred care and support provided by specialist disability services and mainstream services; informal care and support
- Learning and skills: early childhood education and care, schools, further education, vocational education; transitions from education to employment; lifelong learning
- Health and wellbeing: health services, health promotion and the interaction between health and disability systems; wellbeing and enjoyment of life.

The National Disability Strategy will guide public policy across governments, and aims to bring about change in all mainstream services and programs as well as community infrastructure. It is the first time the Commonwealth Government and the state and territory governments have agreed to such a wide-ranging set of directions for disability services. It will be important for governments to consider how people with disabilities who are ageing fit in the service system and how their needs can be met; especially people with intellectual disabilities, who tend to encounter the effects of ageing sooner than others.

2.1.2 National reform agenda

On a large scale, COAG has agreed to a national reform agenda (enacted through a series of National Agreements) that includes reform of the disability and aged care systems in Australia, which may have implications for the way services are delivered to people with disabilities who are ageing.

The National Disability Agreement (NDA), effective from 1 January 2009, sets out the responsibilities of the Commonwealth Government and the state and territory governments (the states) in regard to disability services and funding:

- the Commonwealth is responsible for the provision of employment services and income support for people with a disability, and for contributing funding to the states for specialist disability services
- the states are responsible for the provision of specialist disability services.

The National Health and Hospitals Network (NHHN) Agreement alters the split in responsibilities for aged care and disability. Under the NHHN Agreement,

- the Commonwealth has full funding, policy, management and delivery responsibility for a national aged care system
- from 1 July 2011, aged and disability services for those aged over 65 (over 50 for Indigenous Australians) will be managed by the Commonwealth, while the states will be responsible for specialist disability services for those aged under 65 (under 50 for Indigenous Australians)
- the Commonwealth will continue to contribute funding for specialist disability services provided under the National Disability Agreement
- no substantial changes to service delivery mechanisms are expected before 1 July 2015.

In addition to the above agreements, the Productivity Commission has recently completed two enquiries into the disability and aged care systems.

1. The 'Disability Care and Support' report recommends that, given the split due to come into effect under the NHHN Agreement, people aged over 65 (over 50 for Indigenous Australians) have the option of migrating to the support system that best meets their needs, carrying with them their funding entitlement. That is, people with disability are able to move to ageing support services
2. The 'Caring for Older Australians' report recommends an Australian Seniors Gateway Agency replaces a range of currently disparate elements in the system, including the Commonwealth Respite and Carelink Centres (CRCCs).

Both of these inquiries highlight the challenges faced by older people with disabilities in the workforce to retire with dignity, and support reform in how older people are supported.

2.1.3 National Disability Insurance Scheme

On a larger scale, the most important single reform proposed for the disability services sector is the introduction of a National Disability Insurance Scheme (NDIS), as canvassed in the Productivity Commission's Disability and Care Support Inquiry.⁶ The NDIS would provide insurance cover to all Australians in the event of significant disability. The insurance would be paid via the tax system and would fund long-term care and support.

⁶ Australian Productivity Commission, 2011, 'Disability and Care Support Inquiry', Report No. 54.

It has been estimated that 410,000 people would receive funding under the NDIS, and that disability funding would be doubled under the new scheme to acknowledge that disability support is currently underfunded.

The Productivity Commission's report recommended that disability funding be provided directly to individuals as opposed to services. Potential NDIS recipients would be assessed by a local assessor, leading to an individualised support package based on need. Using their support package, NDIS recipients will be able to: choose their own service providers, ask a disability support organisation to develop a care package on their behalf, and cash out their funding allocation and direct the funding to areas of personal need. This allows recipients to exercise choice in their support package, and encourages service providers to use innovative approaches to best meet the needs of recipients. Funds would be portable across state and territory borders, and regional management structures will reduce service fragmentation.

The National Disability Insurance Agency (the Agency) would oversee the delivery of the NDIS, and would be a federal agency created by, and reporting to, all Australian Governments. The Agency would be run by an independent board, monitored by Treasury, and a council of stakeholders (including people with disabilities, carers and providers) will provide ongoing advice and guidance to the board. This will ensure strong governance of the Agency and allow people with disabilities more control in the care they receive. The Agency will also provide information and advice to NDIS recipients and their families, providing a single access point to information. It will be important this agency can provide directions about addressing the disconnect in policy and services for people with disabilities who are ageing.

The Labor Government officially backed the NDIS on the International Day of People with Disability, December 3 2011, and will focus on the Scheme as one of its key reforms. The Labor Government also announced a commitment of \$10 million towards setting up an agency to design the launch of an NDIS⁷.

2.2 Challenges with the current disability system

*The current disability support service system is 'underfunded, unfair, fragmented and inefficient, and gives people with a disability little choice and no certainty of access to appropriate supports'.
[Australian Productivity Commission, 2011, 'Disability Care and Support Inquiry', Report No. 54]*

Recent reports from the Australian Productivity Commission and a Senate Inquiry⁸ highlighted the following human rights issues, and identified challenges for the disability support system.

⁷ ABC News, 2011, 'Labor endorses new National Disability Insurance Scheme', December 4 2011 <http://www.abc.net.au/news/2011-12-03/labor-endorses-national-disability-insurance-scheme/3710744>.

⁸ Australian Productivity Commission, 2011, 'Disability and Care Support Inquiry', Report No. 54; Australian Productivity Commission, 2011, 'Caring for Older Australians'; the Senate. Community Affairs. References Committee. 2011, 'Disability and Ageing: lifelong planning for a better future', July 2011.

- Current funding for disability makes it hard to give people with disabilities any certainty they will get reasonable care and support over the long run. People have no confidence about the future and what services will or will not be available.
- There are not enough resources and there are many gaps in certain services in all jurisdictions and most locations.
- Inadequate services can hit certain communities particularly hard—such as people in regional and remote areas, people from NESB and Indigenous people.
- Rationing is an unreasonable burden on people with disabilities and their families. It means lower levels of wellbeing and large foregone life chances.
- People with disabilities have too little control over what happens to them and limited choice of service providers.
- Split funding and responsibilities between the Commonwealth Government and the state and territory governments make navigating the system difficult. So does the complexity of moving between the disability and aged care sectors, which is a particular issue for people aged under 65 years who suffer from a degenerative condition or premature ageing and who require support from aged care service providers. Even within one jurisdiction people deal with a multitude of programs and agencies. Difficulties exist in accessing information about the service and support system.
- Disability exacerbates disadvantage. People with a disability often also experience low levels of income, educational attainment, employment, superannuation, health and wellbeing.
- The sector is characterised by a culture of crisis (planning often only occurs in a crisis), lack of clear responsibilities, and lack of long-term thinking by government.
- There is a significant gap in what is aspired to and what is being delivered on the ground. ‘People are reluctant to relinquish one form of care, not because it suits them, but because they feel that there is nothing to replace it’.⁹
- A historical underinvestment in housing means that many individuals with disabilities who are middle-aged continue to live at home because they find it difficult to access independent supported accommodation.

2.3 Transition to retirement in the mainstream community

Ageing is a policy challenge across all industries and sectors in the developed world.

The Australian workforce is ageing, an effect that is largely attributed to falling mortality and fertility rates, and the baby boom generation moving to the older age bracket. Workforce ageing now exceeds ageing in the general population, as a result of more women joining or remaining in the workforce into older age, and younger people joining the workforce later due to continued education and training¹⁰. With the baby boom generation now nearing or reaching retirement, workforce ageing has considerable risks for society, in particular for workers, businesses and government. Despite these risks, mature workers face significant barriers to ongoing participation in the labour force

⁹ The Senate, Community Affairs, References Committee. 2011, ‘Disability and Ageing: lifelong planning for a better future’, July 2011, page 16.

¹⁰ Parliament of Australia, March 2005, Australia’s ageing workforce. No. 35, 2004–05, ISSN 1449-8456.

after they reach the standard retirement age, and they report limited flexibility in transition to retirement options.

In 2011, three million Australians are aged over 65 years and of these 65% are on the aged pension. The Australian Government has in place measures to ensure that Australians have a decent standard of living and support through income support, which includes the aged pension and a range of concessions in health care, pharmaceuticals, rates, utilities and transport.

Older people who retire hope for an active retirement where they have choices about what they do and control over the retirement process¹¹. Essentially, older people want a good quality of life and the security to be able to participate in social, economic, cultural, spiritual and civic affairs. Many older people enjoy volunteering when they retire—for the social aspects and to give back and continue to contribute to the community. All of these opportunities should also be open to older people with disabilities.

2.3.1 Transition to retirement—issues for mature workers

- **Many mature workers retire early due to retrenchment and inflexible working hours**

Few people who retire early report doing so by choice. Many mature workers retire after businesses close down or they are retrenched or they might face inflexible work arrangements, temporary positions or ill health^{12 13}. Even when voluntary redundancy is taken, mature workers often only accept this offer because of the uncertainty around their jobs and a fear that future redundancy offers might not be as favourable¹⁴.

When mature workers leave a position before retirement age, many have a limited understanding of the difficulties they will face in re-employment^{15 16}. Employers are less likely to employ mature workers because their level of experience will be financially costly and they are likely to work for only a few years. Mature workers may have fewer relevant or current qualifications than their younger counterparts, and employers may see them as having poorer modern-world skills, such as computer literacy¹⁷. Mature workers may find it hard to find a position requiring the specific skills they have

11 Buys L., Boulton-Lewis G.M., Tedman-Jones J.S., Edwards H.E., Knox M.F., and Bigby C., 2008, 'Issues of active ageing: perceptions of older people with lifelong intellectual disability', *Australasian Journal On Ageing*, 27(2), pp. 67-71.

12 Wallis Consulting, 2000, 'Workforce circumstances and retirement attitudes of older Australians Survey'.

13 OECD, 2006, 'Live Longer, Work Longer', ISBN-92-64-035877.

14 The Parliament of the Commonwealth of Australia, 2000, 'Age counts: an inquiry into issues specific to mature-age workers'. House of Representatives. Standing Committee on Employment, Education and Workplace Relations.

15 Carey, D., 1999, Coping with population ageing in Australia: Economics Department Working Paper No. 217. OECD.

16 The Parliament of the Commonwealth of Australia, 2000, 'Age counts: an inquiry into issues specific to mature-age workers'. House of Representatives'. Standing Committee on Employment, Education and Workplace Relations.

17 The Parliament of the Commonwealth of Australia, 2000, 'Age counts: an inquiry into issues specific to mature-age workers'. House of Representatives'. Standing Committee on Employment, Education and Workplace Relations.

accumulated over many years, resulting in large wage losses in their new position¹⁸. Potential employers are often as unlikely as past employers to offer flexible work arrangements, which can be particularly important for workers with caring commitments or ill health¹⁹. As a result, many mature workers remain unemployed or take early retirement.

▪ **Unplanned retirement can lead to social and emotional issues**

Unplanned retirement can cause emotional and social problems. Mature workers often experience grief, anxiety and reduced self-esteem following involuntary unemployment or retirement. Some feel that their skills and knowledge have been undervalued, causing them sadness and frustration. They may also feel a sense of shame and loss in losing their role in supporting their family²⁰.

Workers may suffer social isolation after long-term unemployment or retirement, given that work colleagues provided opportunities for social interaction. Losing work contacts also makes it difficult for mature workers to find out about potential job opportunities, as many opportunities are shared through word-of-mouth²¹. Social isolation can be exacerbated by not having family close by, poor mobility and a lack of hobbies, interests and community networks outside of work. Male workers in particular may suffer from social isolation, as they have generally had less time out of employment to create community networks²².

Mature workers leaving the workforce involuntarily may also find their personal relationships affected. Partners of newly unemployed persons may feel pressured to return to work, particularly if they have been out of work for some time. There is some evidence that the pressures of involuntarily unemployment can lead to relationship breakdown²³. The children of mature workers might also suffer from poorer opportunities as a result of reduced family income²⁴.

A lack of routine following retirement and the stress of job seeking can lead to psychological ill health, including anxiety and depression²⁵. Physical ill health can also ensue for those in more physically active jobs before they ceased to work²⁶.

18 Borland, J., 2004, 'Transitions to retirement — A review', Accessed online on 9th November 2011:

http://melbourneinstitute.com/labour/Social%20Policy%20Contract/34_FinReport.pdf.

19 OECD, 2006, 'Live Longer, Work Longer', ISBN-92-64-035877.

20 The Parliament of the Commonwealth of Australia, 2000, 'Age counts: an inquiry into issues specific to mature-age workers. House of Representatives'. Standing Committee on Employment, Education and Workplace Relations.

21 The Parliament of the Commonwealth of Australia, 2000, 'Age counts: an inquiry into issues specific to mature-age workers. House of Representatives'. Standing Committee on Employment, Education and Workplace Relations.

22 The Parliament of the Commonwealth of Australia, 2000, 'Age counts: an inquiry into issues specific to mature-age workers. House of Representatives'. Standing Committee on Employment, Education and Workplace Relations.

23 Studencki, H. and Encl, S., 1996, 'Job search experiences of older workers', NSW Consultative Committee on Ageing, Sydney.

24 The Parliament of the Commonwealth of Australia, 2000, 'Age counts: an inquiry into issues specific to mature-age workers. House of Representatives'. Standing Committee on Employment, Education and Workplace Relations.

25 The Parliament of the Commonwealth of Australia, 2000, 'Age counts: an inquiry into issues specific to mature-age workers. House of Representatives'. Standing Committee on Employment, Education and Workplace Relations.

- **Involuntary unemployment or retirement can lead to financial challenges for retirees**

Becoming unemployed at an older age can have a considerable financial impact, as older people have less time to make up their shortfall in earnings before retirement. Many older people rely on income sources beyond their public pension to maintain a suitable standard of retirement living. Involuntary early retirees are more than twice as likely as voluntary early retirees to depend on social security payments²⁷, suggesting that they were not as prepared for their retirement. Few people who have been in low-income jobs have sufficient superannuation or other financial resources to draw on in their retirement.

A number of societal changes, including delayed marriage and childbirth and increased incidence of re-marriage mean that people have families to support and mortgage and education expenses to pay into older age. Mature workers may also be caring for ageing parents, further increasing their financial and social obligations.

- **Low-income workers may be more affected by transition to retirement issues**

Evidence suggests that low-income mature workers are more likely to experience many of the issues outlined above. The information revolution and technological advancements have seen a reduction in blue collar jobs, making early redundancy more likely for this group of workers. These workers are less likely to find another position, given that their skills might have become obsolete or not applicable to other roles.

Low-income earners are also more likely than higher-income earners to retire due to ill health. Workers in trade professions have physically demanding roles, meaning that many find their work harder as they get older. They may not have the skills or qualifications needed to participate in less active work, and often lack general qualifications and training, including poorer language, literacy, numeracy and computer skills than younger workers²⁸. In contrast, professional workers often have similar base qualifications to their younger counterparts.

Low-income workers are less likely to be able to reduce their working hours or implement more flexible work arrangements as they approach retirement. Lower-income employees are 50–100% less likely to be able to use flexi-time, teleworking or to determine when to take work breaks.²⁹

26 The Parliament of the Commonwealth of Australia, 2000, 'Age counts: an inquiry into issues specific to mature-age workers'. House of Representatives. Standing Committee on Employment, Education and Workplace Relations.

27 Fitzgerald, V. and Rooney, C., 1999, 'Rethinking work and retirement', pp 33–34.

28 Griffin, T. and Beddie, F. (Eds), 2011, 'Older workers: research readings', NCVET.

29 WFD Consulting, 2006, 'Workplace Flexibility for Lower Wage Workers'. Available on 10th November 2011, <http://www.cvwf.org/system/files/lowerwageflexreviewreport.pdf>.

The financial impact of retirement is also more likely to affect low-income earners, given that high-income earners are likely to have contributed more to their superannuation fund and have other financial assets, such as their own home, shares and other investments.

All of these issues are likely to apply equally to older people with disabilities in supported employment.

2.3.2 Transition to retirement—issues for government and community

- **Increase in pension and health payments**

Increasing numbers of retiring baby boomers and mature workers retiring early will have a considerable impact on the Government's public pension expenditure³⁰. Evidence in the past 10 years suggests that only half of the increase in pension expenditure is due to rising ages, with half due to an increase in the number of people receiving income support payments³¹. This suggests that mature workers are less prepared for their retirement than they used to be.

The ageing population will also lead to greater health care expenditure, given the higher need for health services in later life. Without an increase in labour force participation, these costs will have to be financed by an increase in tax contributions or a reduction in benefits.

- **Slowing economic growth and productivity**

The loss of essential skills as mature workers retire may lead to a skills shortage, and changes in the aggregate employment/ population rate will affect overall productivity and economic growth.

The NDS reports these issues are also being faced by ADEs and their employees, with ADEs also facing the consequences of the global financial problems and a slow economy.³²

2.4 Ageing and disability³³

People aged 65 years and over are more likely to have disabilities than younger people, and the likelihood of acquiring a disability as well as the severity of disability increases with age. Consequently, as people age they tend to need greater assistance with health-related and day-to-day activities, and greater access to health and community services.

³⁰ OECD, 2006, 'Live Longer, Work Longer', ISBN-92-64-035877.

³¹ The Parliament of the Commonwealth of Australia, 2000, 'Age counts: an inquiry into issues specific to mature-age workers'. House of Representatives. Standing Committee on Employment, Education and Workplace Relations.

³² NDS, 2010, Submission to the Australian Disability Enterprises Vision Process.

³³ Retiring from an Australian Disability Employment Forum, 2011 Report.

With increasing numbers of people living to an older age, questions of how best to meet the needs of greater numbers of older people with disabilities are becoming more acute.

2.5 Retirement, ageing and the ADE workforce³⁴

'Ageing', for older people with a lifelong intellectual disability, is a relatively new phenomenon and more adults with a lifelong intellectual disability are reaching old age.³⁵ Many are now surviving to their mid-60s, and some are living well beyond this age. Older people with a lifelong intellectual disability represent a small but growing cohort of our ageing population and today many are living independently in the community, or are cared for at home or in supported living accommodation. This has brought new challenges as older workers with disabilities face retirement from ADEs and, subsequently, as they move through this new phase of their lives.

Like all working Australians, ADE employees have the right to enjoy a meaningful life after work and to experience independence and choose what they do in retirement. The issues for retirement are much the same for people with disabilities as they are for everyone facing retirement.³⁶ The literature for the general population suggests that people want to have a choice and have control over the (retirement) process; and research by QUT³⁷ found that older people with disabilities have similar wants and aspirations to those of the broader ageing population.

But people with disabilities working in ADEs are not retiring at the expected rate. For example, one of the pilot sites had few of their employees retire in the past. As shown in the report, older ADE employees and their carers need support to make an informed choice about how and when retirement takes place, as well as support to link in with community-based activities.

Just as the Australian population is rapidly ageing so too is the ADE workforce. Research commissioned by FaHCSIA in 2009 anticipates that the number of people with a disability aged over 50 years working for ADEs will increase from one-fifth of the workforce in 2010 to one-third in 2015, and be close to half in 2025.³⁸

People with an intellectual disability, on the whole, experience the effects of the ageing process earlier than people without disability— suffering memory loss, decreases in

³⁴ Source unless otherwise referenced is the Information Paper from the June 2011 Retiring from an Australian Disability Employment Forum.

³⁵ Buys L., Boulton-Lewis G.M., Tedman-Jones J.S., Edwards H.E., Knox M.F., and Bigby C., 2008, Issues of active ageing : perceptions of older people with lifelong intellectual disability. *Australasian Journal On Ageing*, 27(2), pp. 67–71.

³⁶ Buys L., Boulton-Lewis G.M., Tedman-Jones J.S., Edwards H.E., Knox M.F., and Bigby C., 2008, Issues of active ageing : perceptions of older people with lifelong intellectual disability. *Australasian Journal On Ageing*, 27(2), pp. 67–71.

³⁷ Buys L., Boulton-Lewis G.M., Tedman-Jones J.S., Edwards H.E., Knox M.F., and Bigby C., 2008, Issues of active ageing : perceptions of older people with lifelong intellectual disability. *Australasian Journal On Ageing*, 27(2), pp. 67–71.

³⁸ Social Policy Research Centre (SPRC), 2010, 'Occasional Paper No. 27: Ageing and Australian Disability Enterprises'.

cognitive abilities and ill health³⁹. They should be able to retire early enough to enjoy good health and control what happens in their retirement.

The ageing ADE workforce also means there will be greater demand for specialist and associated government services. Changes in the capacity of ageing family members to continue in their caring role are also an issue.

Research commissioned by the Department and undertaken by the SPRC⁴⁰ in 2009 found that services to support older people with disability in retirement are essential if transition to retirement programs are to be meaningful. The same research identified that there are significant structural impediments to retiring for older people with disabilities working for ADEs.

Division of responsibilities, along with the separation of ageing and disability policy, has the effect of creating disconnect in policies, services and funding for older people with disabilities, particularly for people who age early and who are in supported employment. A practical example is the difficulty in getting aged care assessments for people with a disability aged less than 65 years. Examples of other structural impediments to retiring identified in the SPRC report include

- lack of funded appropriate support services to transition to retirement and after retirement
- lack of public and/or community transport
- lack of financial security in retirement, for example, limited superannuation or other financial assets (the Supported Employment Services Award 2010 contains a superannuation provision for supported employees that specifies a minimum weekly contribution)
- ageing carers who are less able to provide support
- loss of advantages of paid employment
- living arrangements of people with disabilities, particularly for those in supported accommodation; group homes may not have sufficient staff to support people at home during parts of the day; those in supported accommodation are unable to access Home and Community Care (HACC) services
- availability and cost of accessing day programs or community access programs.

At the personal level, at least two papers cite a lack of understanding of the concept of retirement by some people with disabilities working for ADEs. Employees interviewed for the SPRC research found it difficult to imagine how they could spend their time meaningfully if they stopped working.⁴¹ Buys et al reported that few workers with

39 Social Policy Research Centre (SPRC), 2010, 'Occasional Paper No. 27: Ageing and Australian Disability Enterprises'.

40 Social Policy Research Centre (SPRC), 2010, 'Occasional Paper No. 27: Ageing and Australian Disability Enterprises'.

41 Social Policy Research Centre (SPRC), 2010, 'Occasional Paper No. 27: Ageing and Australian Disability Enterprises'; Albrecht, D., 2006, 'Planning for Retirement: Improving Service Options for Aged South Australian People with Disability', ACROD.

intellectual disabilities in their study had thought about retirement and speculated that this may relate to the context being somewhat different from the broader population.⁴²

The Buys et al study found that achieving an active retirement for older workers with disabilities was also impeded because of the controlling influence of others. They found that 'empowerment' or 'disempowerment' were key factors underpinning the attainment of active ageing for the service users in their study, and that older workers wanted to maintain their routines, keep being active and doing the things in life which interested them.⁴³

Many of those working in ADEs have been there for a long time and have strong connections to the people they work with. Employees in ADEs fear social isolation and the loss of friendship and company if they retire^{44 45}, as do many older workers in the broader community. But, because of the history of ADEs, some employees have limited social connections with broader community activities or community members. Safety concerns compound this problem—ADEs report that carers worry about safety and discourage people from being involved in activities because of this concern.⁴⁶

Many of these known structural and personal barriers to retirement also emerged in the pilot (chapters 3, 4, 5 and 6).

The ageing workforce has implications for the productivity of ADEs, creating a tension between maintaining a competitive edge over other businesses and providing appropriate support to an ageing workforce.

2.6 Pathways to retirement for older people with a disability working in ADEs

This section describes the design of the Transition to Retirement (TTR) pilot and compares the approach with other initiatives being implemented by ADEs in the ACT, NSW and South Australia.

People with disabilities who work at ADEs have moderate to severe disabilities and need substantial ongoing support to maintain employment; 74% have intellectual disabilities.⁴⁷

42 Buys L., Boulton-Lewis G.M., Tedman-Jones J.S., Edwards H.E., Knox M.F., and Bigby C., 2008, Issues of active ageing : perceptions of older people with lifelong intellectual disability. *Australasian Journal On Ageing*, 27(2), pp. 67–71.

43 Buys L., Boulton-Lewis G.M., Tedman-Jones J.S., Edwards H.E., Knox M.F., and Bigby C., 2008, Issues of active ageing : perceptions of older people with lifelong intellectual disability. *Australasian Journal On Ageing*, 27(2), pp. 67–71.

44 Social Policy Research Centre (SPRC), 2010, 'Occasional Paper No. 27: Ageing and Australian Disability Enterprises'.

45 Albrecht, D., 2006, 'Planning for Retirement: Improving Service Options for Aged South Australian People with Disability', ACROD.

46 Retiring from an Australian Disability Employment Forum 2011, discussion group notes.

47 NDS, 2010, Submission to the Australian Disability Enterprises Vision Process.

2.6.1 The design of the Transition to Retirement pilot

The TTR pilot was established to understand and further document the retirement and ageing issues for employees in supported employment and to trial possible pathways to retirement and solutions to barriers to retirement. ADEs were given the responsibility for supporting employees to transition to retirement.

FaHCSIA, in consultation with the Victorian and NSW Governments, designed a framework and components to address some of the barriers to retirement. This section describes that design. Chapter 4 describes the extent to which the components were delivered.

The participating ADEs were required to provide a *minimum support guarantee*—that is, support hours in retirement activities should be equivalent to the number of hours/ days spent at work.

The design and the main components that were tested by the pilot are outlined below.

- **Capacity building for ADE staff**

CRS Australia⁴⁸ was contracted to train ADE support workers or training officers identified by pilot sites to educate employees and their families and carers about retirement and to assist them to plan for retirement. The training centred on the use of the ‘*When I’m at work: Retirement planning*’ resource developed specifically for use with ADE employees.

CRS was also to provide a consultation service for up to three months after the training to provide advice for ADE staff and increase their skills and confidence. Training officers who attended the CRS training were expected to provide training for support staff involved in the pilot.

- **Education for employees and carers about retirement**

ADE support workers were expected to provide formal education and training for retirement to selected older employees and their families and/or carers using the training resource, ‘*When I’m at work: Retirement planning*’.

The resources also included a workbook, which employees participating in the program were expected to complete at home: ‘homework’. Many of the education sessions would require employees’ family members and/or carers to attend.

⁴⁸ Formally known as the Commonwealth Rehabilitation Service.

- **Individual retirement plans for employees wishing to retire**

ADEs were to assist employees to develop retirement plans after completing the training component. These plans could be created separately from existing Employment Assistance Plans (EAP) that ADEs are already required to develop with their employees. The retirement plans were expected to outline a variety of activities suited to the needs and wishes of each participant.

Ideally, the retirement plans were to

- encompass the desires, needs and vision of the employees, which should then be matched to what is available in the community
- be person-centred and consider the needs and desires of the older employee, whilst including input from family members and carers.

As part of the retirement plan, employees had the option to select some activities available in the local community and try these out. The 'linkage coordinator' would connect the employee to the service. Where nominal service fees exist, these would be the retiree's responsibility.

- **Funded 'linkage coordinator' position**

FaHCSIA funded a 'linkage coordinator' position (part-time) to identify and source suitable local retirement services/ programs and activities, appropriate to the needs of participating employees. The coordinator was expected to

- contact community providers and discuss the possibility of including employees in their organisation's activities
- connect employees with local community providers/ services, once retirement plans were developed so they could be implemented.

CRS Australia regional staff provided initial guidance to ADEs to identify programs and activities.

Although education of community service providers is not an explicit component of the pilot, the ADEs expect that community providers will learn about the needs of people with disabilities during discussions with the 'linkage coordinator' and when employees are trying out activities.

- **Retirement outcomes**

Workers had the opportunity to a) retire after the pilot, or b) reduce their work hours and start part-time retirement activities, or c) continue working. Employees choosing a gradual retirement option were to have six months to decide whether they wished to retire or whether they wished to resume employment as before.

FaHCSIA required employees to have the right to return to employment with the ADE if, for whatever reason, they were not happy with the activities they were undertaking as part of retirement. But FaHCSIA would work with the state governments to identify alternate options if the employee was unhappy with existing activities.

- **Monitoring and review**

ADEs were to develop a system to monitor and review participant outcomes after employees retired. This was to assess whether participants enjoy a satisfying lifestyle rather than simply being transitioned into a new service type. How the system works depends on the individual participant and their circumstances. The pilot was to test whether this strategy is practicable and feasible from the perspective of the ADE.

- **Education of community service providers—one ADE only (Koomarri)**

Koomarri has a transition to retirement program—Gateway Retirement Program, which began in October 2009 and aims to partner with mainstream organisations to encourage them to provide opportunities for employees.

The pilot funded a series of community education workshops for community providers to help them better understand and work more effectively with the needs of people with disabilities and other marginalised groups. They planned to offer two courses: the Social Role Valorization and Advance Instructional Methods.

The training process aimed to develop positive attitudes towards ageing and devalued people in the community and, in doing so, increase the opportunities for people with disability to participate in the local community. By removing some of the impediments to accessing mainstream community services (i.e. by increasing understanding and removing stereotypical views of disability), the training component was to help establish new and lasting retirement pathways for people with disability within the community.

2.6.2 Other TTR programs in Australia

Other disability organisations have developed transition to retirement programs or activities for people with disabilities working in ADEs. The sources of information about these programs are listed in section 1.4 and description provided in appendix 3.

Retirement programs for older workers with disabilities in ADEs have some common characteristics but also important differences (table 2.1). They focus on the interests of the person retiring and involve parents and carers. Some focus on the transition to retirement process, while others have a greater focus on support after retirement. Common themes are planning and education elements, but how these are delivered differs, ranging from formal to informal processes. Most are delivered via disability services, rather than ADE staff. Another commonality is having activities to link participants into broader community social activities, but how this is done differs. Some

use a case manager, working closely with the employee to ensure their wishes are known and assisting them to achieve these. Others use a model where community access or lifestyle services coordinate packages for individuals. Most include retirement planning but only some have formal planning and education processes.

Table 2.1: Comparison of transition to retirement initiatives for employees of ADEs

Initiative	Model	Main focus	Coordinated by	Retirement education	Planning	Community linkage activities	Capacity building for disability service support staff	Flexible employment conditions for employees	Community development/ education
TTR pilot	Education, person-centred formal planning and linkage to community activities	Transition	ADE staff	Yes, using FaHCSIA resource + informal discussion	Individual formal plans	Linkage coordinator position, links employees to mainstream groups and social activities	Yes	Yes	Not part of original pilot design
Koomarri Gateway Retirement Program	Skills development and linkage with community activities	Transition	Gateway coordinator, Social Access Branch	Yes, own resource + informal discussion	Planning meetings ⁴⁹	Coordinator and support workers link employees to community groups for older people, social activities and life skills courses	No information	Yes	Community education workshops + partnership program with services for older people
AFFORD/ University of Sydney and La Trobe University	Case management, person-centred planning, linkage to community activities (in	Transition	AFFORD coordinator	No information	Planning meetings	TTR coordinator links employee to a community group. Support	No information	Yes	Yes, training for mentors

⁴⁹ Based on feedback from four Gateway program participants and three family members.

Initiative	Model	Main focus	Coordinated by	Retirement education	Planning	Community linkage activities	Capacity building for disability service support staff	Flexible employment conditions for employees	Community development/ education
	particular volunteer work) with support of mentor based in community organisation					provided by volunteer mentor			
Minda Inc	Combination of retirement planning and home, centre-based and individual activities	Transition to retirement and after retirement	Minda	Yes	Formal planning	Yes, funded life style service packages; individuals linked	No information	Yes	New mentoring program
Greenacres Retirement Options	Centre-based day service supported by an in-house case management service	After retirement	Community participation programs	No information	Individual plan on joining the program	Centre-based day program	No information	Not applicable	No information

3. Older employees in supported employment transitioning to retirement

This chapter describes the needs and experiences of ADE employees transitioning to retirement. The focus is on the pilot, but the discussion is set within the wider context of other older ADE employees and their retirement experiences. It looks at the results of the pilot at the individual level, and provides evidence for assessing whether ADEs can prepare employees for retirement.

3.1 Policy challenges

The ageing of the supported employee workforce raises human rights and equity issues and has implications for the productivity of ADEs (the average hours worked by employees is steadily declining)⁵⁰. Employees with disabilities risk delaying their retirement beyond the time when it is most beneficial for them, and being socially excluded once they retire. The sector reports that employees commonly delay fully retiring even when affected by declining health and productivity and when they no longer enjoy being at work. Employees face many challenges to retiring and ageing in-place, including a lack of knowledge about life after work and limited social connections in the broader community. By retiring only when they are in poor health a person's ability to enjoy an active retirement is limited.

The pilot explored these issues in some detail with a small sample of older ADE employees. This chapter presents findings on the employees' needs and experiences, while the following chapters describe how the two ADEs addressed the employees' transition to retirement and the scope for linkages with the wider community.

3.2 An ageing ADE workforce

Current evidence indicates that the ADE workforce is ageing rapidly. The typical ADE employee was born in Australia, is male and has an intellectual disability (the primary disability for 72%). Just 36% of the workforce is female. The average age of ADE employees is 39 years; ages range from 15 to 83 years; and 11% are aged over 55 years.⁵¹

50 NDS, 2010, Submission to Australian Disability Enterprises Vision process.

51 Social Policy Research Centre (SPRC), 2010, 'Occasional Paper No. 27: Ageing and Australian Disability Enterprises'.

Table 3.1: Age profile of all ADE employees

Age	Number	%
<35 years	6,999	37%
35–44 years	5,294	28%
45–54 years	4,476	24%
55–64 years	1,864	10%
65+ years	235	1%
Total	18,868	100%

Source: SPRC Occasional Paper No. 27 FAHCSIA 2010.

While there is little information about the age profile of ADE employees at retirement, the evidence suggests delays and difficulties in shifting to retirement. A 2006 survey of South Australian ADEs by ACROD (SA) found most employees (57%) retired between 51–60 years of age but almost one-third did not retire until they reached 61 years or more (table 3.2). Other evidence comes from the Greenacres Retirement Options, which is for ADE employees over 55 years of age but younger people can be admitted by exception. In 2008, 14 (41%) of the 34 older people with disabilities in this program were aged over 60 years⁵². Many of the Greenacres' employees aged in their 50s and early 60s had lost their work skills and needed to retire.

Whilst chronological age does not necessarily align with ageing, it is interesting to contrast the profile and experiences of the twelve employees who participated in the pilot. As discussed previously, people with intellectual disability tend to experience the effects of ageing earlier than other people. While there was a relatively small number of participants in the pilot (eight were at the ADE at site 1 and four at site 2, six were male and six female), it was an opportunity to describe their views and experiences in detail. The ADEs also had limited prior experience with TTR—at one, only one person had ever retired previously and this was because of ill health.

Given the challenges to retiring, it is not unexpected that the employees involved in the pilot are comparatively old. They ranged in age from 43 to 68 years of age, with the median age of 58 years. Ten of the twelve employees were older than 55 years; three of these were 65 years or older. These three employees are working past the historically accepted age of retirement in the wider community and had not considered retirement before the pilot.

⁵² Preston, N., 2008. Greenacres Disability Services, Greenacres Retirement Options, NDS Employment Forum Brisbane.

The age distribution of the pilot participants was, however, reasonably similar to the retirement age of the South Australian ADE employees (table 3.2), suggesting that their circumstances and experiences are relevant for many older ADE employees.

Table 3.2: Retirement age of ADE employees (South Australia), compared with employees in the pilot

Age	Age of ADE employees at retirement in SA*	Age of ADE employees in pilot
<50 years	12%	2 (17%)
51-60 years	57%	7 (58%)
61 years +	31%	3 (25%)
Total	100%	12 (100%)

*ACROD (SA) survey of SA ADEs⁵³. No date given for survey.

3.3 Disability type, support needs, work and living arrangements

National Disability Services (NDS), in their submission to the Australian Disability Enterprise Vision process (2010), stated that people with intellectual disabilities find it difficult to sustain employment and have a significant rate of drop-out from the workforce after the age of 30.

The pilot reflected this, with 10 (83%) of the 12 participants having an intellectual disability, although this varied in terms of the severity of disability and the ability to communicate. Two of the younger participants with intellectual disabilities were in their forties—they had high support needs and were experiencing difficulties coping with work, partly due to mobility problems. One pilot participant had cerebral palsy and one an acquired brain injury.

The twelve participants needed support in a range of areas, to varying degrees, including to

- handle their money (only four said they need no help with this)
- talk with people/ social support (only three said they need no help with this)
- deal with things that happen to me (all said they needed help with this)
- making decisions (only four said they need no help with this).

⁵³ Albrecht, D., 'Retirement across the life course', paper published on NDS website. Paper undated.

The employees from site 2 had higher support needs and were working fewer days than those from site 1. All pilot participants were in receipt of a Disability Support Pension, as is the case for most employees working in supported employment.

Almost all the employees had worked for the ADEs over the long-term.⁵⁴ At site 1, one employee had worked for the ADE for more than 40 years, two for between 30 and 40 years, and the others for more than 10 years.

The pilot participants lived and worked in or close to the three towns where the ADE business sites are located (one ADE in the pilot site had business premises in two locations.) Two of the towns are relatively small country towns and the third is a regional centre.

The pilot reflected the broader evidence that as employees with disabilities get older they are less likely to live with a family member and more likely to live with others or alone. Just three (25%) of the employees in the pilot lived with family members; the others (75%) lived in group homes or independently. One employee lived independently in private rental, two lived in private rental with support packages, and one lived in public housing with 24-hour support; the other five (42%) lived in group homes. These living arrangements are the norm for older employees working for ADEs, as they face changes in support systems as their carers age and can no longer support them. This compares with the Greenacres Retirement Options program in 2008, where 19 (56%) of the 34 employees lived in group homes or independently.

None of the employees in the pilot were experiencing changes in their support system during the pilot that meant they were likely to become more socially isolated, a common risk for older people with disabilities; but one was living with their elderly mother. Just one employee decided to change her living arrangements to live in a smaller group home as a result of planning for her retirement.

3.4 People's experiences of ageing

People with intellectual disabilities tend to age at an accelerated rate, with the effects of 'memory loss, decreases in cognitive abilities and higher medical needs'⁵⁵. Employees who participated in the *Ageing and Disability Enterprises Study (Occasional Paper No. 27)* suffered from a wide range of health problems, such as hearing problems, weight and joint problems, diabetes and poor mobility.

The pilot participants mirrored these health problems with ailments such as diabetes, obesity, sleep apnoea, epilepsy, joint problems (one had a hip

⁵⁴ NDS,2010, Submission to Australian Disability Enterprises Vision process.

⁵⁵ Social Policy Research Centre (SPRC), 2010, 'Occasional Paper No. 27 Ageing and Australian Disability Enterprises'.

replacement and another is scheduled for a hip replacement), memory loss, anxiety and mobility issues. Four workers (three at site 2) used walkers because joint problems mean they are unstable on their feet. Their poor health was impacting on their ability to manage or concentrate at work because of pain or fatigue. For some, these difficulties were creating anxiety about work.

In the pilot, ADE staff observed that most employees had started to experience deteriorating health and functioning and were slowing down at work and less able to do their job. This is similar to the experience of older employees working at other ADEs who are reported to tire more quickly at work and are less productive.

Even those most enthusiastic about work seemed to be more tired and capable of less work in recent years. Unlike reports from some other ADEs, the employees in the pilot did not report 'teasing' from their workmates about their loss of productivity. But two had experienced conflict with other employees at work and one was showing an increase in challenging behaviour associated with ageing—a problem noted by stakeholders interviewed for the *Ageing and Disability Enterprises Study (Occasional Paper No. 27)*.

Although most employees in the pilot had not explicitly talked about retiring before being offered the chance to join the pilot, three had expressed sentiments that they were 'sick of work' and five had reduced their days at work in recent years. There is clear evidence the employees were slowing down and moving gradually towards stopping work completely.

Fiona indicated that she is 'sad' at work. (Employee)

Mary said that dropping her days at work has meant 'I'm not so tired'. (Employee)

3.5 Recognising it's time to retire and making the decision to transition to retirement

Just how and when the need to retire is identified and then broached with the employee is not widely discussed in the available literature, but the 2006 paper by ACROD (SA)⁵⁶ indicates that the decision to retire is often made by the carer/ employer and is not the employee's personal decision. Furthermore, the decision to retire is likely to be triggered by failing health and/or a loss of productivity. In addition, the transition to retirement often occurs in a de facto manner, where employees gradually reduce their working hours but without explicitly discussing stopping work.

⁵⁶ Albrecht, D., 2006, 'Retirement across the life course', paper published on NDS website.

Both the ACROD paper (2006) and Occasional Paper No.27 (2010) emphasise the importance of engaging the employee in the decision-making process to maximise their opportunity to control and contribute to their decision to retire and how they transition to retirement. The importance of the employee having control over decision-making is also noted by Buys et al in their study, which looked at issues of active ageing for people with disabilities.⁵⁷

The ACROD/ Minda study developed a checklist, focusing on functioning at work, to indicate if an employee might be ready to transition to retirement.

In the pilot, the ADEs initially identified possible participants based on their age (older than 45 years), health status and functioning, and attitude to being at work. This broader approach is more person-centred and explicitly took into account the person's emotional and health status, as well as the interests of the organisation.

The two ADEs in the pilot chose employees who were potentially ready for retirement and sought their interest in being part of a transition to retirement program. Many of the employees had been gradually reducing their days at work prior to the pilot so that they were working less than the average for the overall ADE workforce (table 3.3). The employees appear to have reduced their working hours because of fatigue, ill health or a desire to work less (section 3.4).

The reduction of hours reflects the trend seen across all ADEs where the average number of hours that supported employees work per week is steadily decreasing, as is the number of full-time employees. As the NDS commented in their 2010 submission to the ADE Vision process, '...the trend towards reduced hours of employment in all likelihood reflects the ageing of the supported workforce. As most people age they will tend to work reduced hours and this reflects societal norms.' The SPRC (2010) reported that ADEs are commonly allowing employees to work fewer hours and do different types of work.

Table 3.3: Total days employees worked prior to the pilot

Days worked	Participants		ADE workforce*	
	No	%	%	%
1 day	2	18%	45%	20%
2 days	3	27%	10%	22%
3 days	1	9.5%	45%	58%
4 days	4	36%		
5 days	1	9.5%		
Total	11	100%	100%	100%

57 Buys L., Boulton-Lewis G.M., Tedman-Jones J.S., Edwards H.E., Knox M.F., and Bigby C., 2008, Issues of active ageing : perceptions of older people with lifelong intellectual disability. Australasian Journal On Ageing, 27(2), pp. 67-71.

Days worked	Participants		ADE workforce*
	No	%	%

Sources: Interviews with employees and support persons, missing information on one employee and *NDS Submission to ADE Vision process 2010.

The pilot provides further evidence that it is important that individuals be involved in decisions about transitioning to retirement. The initial conversations with employees and support persons revealed anxiety about not being in control of the decision. The employees or their support person had not been the ones to initiate the idea and some employees at first did not feel they had a choice about leaving work. In the mainstream workforce employees facing forced early retirement or retrenchment also face such anxieties and suffer from stress-related conditions caused by not having control over major life decisions.

The pilot ADEs took a consultative approach, involving individual employees in discussions and also talking with family members or support persons to gauge interest and assess the person's suitability for participation in the pilot.

(Tom spoke to his family about participating in the pilot) They said, "you've been out there a long time... it's about time, you can take a couple of days off and have a couple of days at work." (Employee)

The ADEs framed their discussions about the pilot in terms of things to do when you stop working or activities you can do in the community. They also talked about the process being gradual and involving less time at work replaced by community activities, and being supported by the ADE. Other ADEs involved in TTR programs also identified gradual transition as a key factor in retiring successfully.

When first approached about being involved in the pilot, some of the employees were confused and distressed and their support persons ambivalent. Some had little understanding of the concept of retirement; others recognised it meant they would no longer be able to go to work. By contrast, a few of the employees were keen to take part in the pilot if it meant less time at work. Support persons were concerned about the employees losing social networks and becoming bored and unhappy, but they did like the idea of introducing the possibility of retirement and helping the employees prepare for this eventuality.

'I've encouraged her to get involved in this program they're doing, and to go on working for as long as she can...Just in the general idea that goes with working today; people are working and staying in the workforce longer. I think going to work and having that purpose every day for (Elizabeth) is - I think that's important'. (Support person)

'He would come home and say they're trying to push me out of the workshop was what initially first is what he said, and we had to really reassure him that he was not being asked to leave the workshop...that it was only to have a look at life after work, that there were other choices, but it was quite difficult initially to do that. But once he accepted the

reassurance that he wasn't being pushed out of the workshop, he sort of settled down and wasn't so resistant to it'. (Support person)

As the employees in the pilot gained confidence about having a choice in their hours spent at work and in community activities, they became more engaged in, and better understood, the transition to retirement process, and their level of anxiety was reduced.⁵⁸ Early planning for retirement could be expected to reduce these anxieties on retirement.

Because of the importance of the employee and support person being well informed, we explored whether the pilot participants were given sufficient information. On the whole, support persons were comfortable with the amount of information they had about the pilot at its inception. But a few of the support persons would have liked to have had the information in written form rather than only through informal discussions, as was sometimes the case. Another support person felt that the language used to explain the pilot and employees' rights was too hard to understand.

3.6 Impediments to retirement

People with disabilities in supported employment face similar impediments to retirement as other Australians, but can also face additional challenges—limited social connections, low confidence and skills, limited or negative understanding of the concept of retirement, uncertain living arrangements and lack of financial security and options and funded supports.

Social isolation

For employees in supported employment (including the pilot participants), the workplace is one forum where they make friends and connect and socialise with other people, as is the case for other Australians. The employees and their support persons in the pilot, and those interviewed for the *Ageing and Disability Enterprises Study (Occasional Paper No. 27)* all talked about the sense of meaning associated with work and their strong connections to their co-workers. The challenge all working people face on retiring is replacing the social connections at work and the meaningful activity that work provides with other activities. The pilot participants and support persons feared that if the employees retired completely from work they might stagnate at home and lose their social supports and sense of self worth they gain from working.

'He loves his work. He has been there for many, many years. It's his family; it's his social contact and is everything to him'. (Support person)

⁵⁸ Particularly the case for site 1 participants.

Support persons, in particular, also worried about the short-term nature of the pilot program and what would happen to the employee at the end if support to participate in community activities was withdrawn too early or completely. As discussed in chapter six, the pilot provides more evidence that people with disabilities need a case manager or a designated person to coordinate and support their transition to retirement.

People with disabilities working at ADEs are at greater risk of social isolation than many other older people. At some ADEs, the workforce comprises only people with disabilities, and some people have spent their whole life in this setting. These employees tend to have fewer social connections with people outside the workplace and are less likely to participate in mainstream community groups.⁵⁹

The pilot highlighted this issue. For example, two employees had been involved with the disability service for much of their adult life, working at the ADE, staying in supported accommodation provided by the disability service and spending their spare time in the ADE's training and education service (day program). Only one employee in the pilot appeared to be well connected into mainstream activities prior to the pilot. He regularly attended local sports team training and events and helped out doing maintenance. He had always had a busy social life. Another employee (living with a family member) had a good social life before having a serious health incident that had made her housebound. Others were spending many of their days off work at home because their mobility problems or health problems made it difficult to go out without support. Without support to transition to retirement and, for some, ongoing support to participate in community activities, these employees are at risk of becoming socially isolated. Establishing social supports early is important if older people with disabilities are to have social networks outside work to draw on.

'It's just that without a support person it would turn pear-shaped quickly'. (Support person)

Confidence and skills

Another key difference to older workers in the broader community is that some employees in supported employment lack the life skills (such as catching public transport and handling money or going out on their own to eat) and confidence to take part in community activities. The pilot was able to directly address such issues—for example, some employees caught public transport for the first time in their lives. Without these skills the goal of social inclusion would be hard to achieve. On this score, supported employment and the disability system appear to let down many older people with disability in the workforce. While young people with disability are now more integrated into schooling and other aspects of

59 Wilson N.J., Stancliffe R.J., Bigby C., Balandin S. and Craig D., 2010, 'The potential for active mentoring to support the transition into retirement for older adults with a lifelong disability', *Journal of Intellectual and Developmental Disability*, 35 (3):211-14.

society, this was not the case when this group of supported employees were younger.

When ADE employees retire they will not always have access to a support person, so being able to access social supports or just being able to be alone is important. The AFFORD/ University of Sydney/ La Trobe University TTR and one of the TTR pilot sites included travel training as part of their activities. Koomarri also recognised this lack of life skills among older supported employees, in developing their own transition to retirement program. The Koomarri program has a focus on life skills and increasing autonomy. They have also recognised that teaching life skills to older employees is just too late and are introducing a 'frontier program' to start the process much earlier.

Living arrangements

Some impediments to retirement could not be addressed by the pilot activities or other TTR programs lead by disability services. The Productivity Commission's Inquiry into Disability, Care and Support (report no. 54, 2011) highlighted the under-investment in independent supported accommodation and the negative impacts of this on the lives of people with disabilities. As identified in various studies, and as the experience of the pilot found, living arrangements can be a structural impediment to retirement for older people with disabilities in the workforce.

- Employees living in group homes (supported accommodation) can find it difficult to stay at home between 9am and 3pm, because the way supported accommodation is funded impacts on support worker staffing levels. In the pilot, at site 2 the employees living in supported accommodation had support staff available during the day but when staff are on leave or sick, staffing levels are not always adequate. As a result, employees have limited choice about where they go during the day, and being at work is a common option.
- Employees no longer wanting to live with others—the case for one employee in the pilot.
- Employees living with family members who would be unable to provide sufficient support if the employee retired, or who faced significant changes to their lifestyle to do so and who themselves may be ageing.

For example, one of the pilot participants lives with a relative who works full-time, so for this employee retirement is not an option in the short-term. One support person said she feared she would need to move towns to support her brother when he fully retired (involving selling her business and moving away from her partner), and another had fears about having to manage her sister's boredom and resultant behaviour. Another support person had retired to care for her sister but valued the respite provided by her sister being at work. Respite supports, therefore, are an important mechanism for overcoming barriers to being at home

for people with disabilities living with family members. Some employees will need support to participate in community activities and their carers will need respite.

Financial security

Lack of financial security and limited retirement savings (superannuation) is another structural impediment to retirement for people on low incomes, which also applies to employees with disabilities working for ADEs. The new Supported Employment Services Award 2010 contains a superannuation provision for supported employees. But the new arrangements do not address the lack of retirement savings of the pilot participants and older employees with disability. The government provides income support in the form of the aged care or disability support pension but the loss of even a modest amount of additional income was important to employees in the pilot because wages (and mobility allowances) help pay for recreational activities and contribute to weekly living costs. Income loss meant that a few employees anticipated they might not be able to fulfil retirement interests such as travel. For others, however, family members commonly 'look after' financial matters for the employees and money was 'not a worry'. Employees and their support persons feared the loss of the mobility allowance may limit the employee's ability to access community activities.

The ADEs in the pilot were aware of the need for financial planning advice (an area covered in the education resource provided to the ADEs) and one site developed links with Centrelink to meet that need. In the mainstream community, some employers provide access to financial planning for retirement, particularly public sector employers.

The pilot shows that lifelong financial planning is important to an employee's financial security in retirement.

3.7 Achieving readiness for retirement and retirement outcomes

The personal experiences of the pilot participants described above reveal their needs for retirement and some of the impediments to achieving this, and how these are likely to mirror wider trends in the sector. To complete their personal stories this section looks at the extent that the pilot contributed to the employees' readiness for retirement and their retirement outcomes.

Preparation for retirement

For the pilot, four out of the seven employees with lower needs indicated they think retiring will be good and three that retiring will be sometimes good and sometimes bad (no information could be gathered on this question for the five with

high needs). Of those who were asked about their concerns about retiring, and answered,

- three employees worried about making changes to what they do
- one employee was very worried about getting sick; four were a little bit worried
- one employee was very worried about getting cross with the people they live with and about spending too much time with them; one employee was a little bit worried
- two employees were a little bit worried about being able to spend time with their friends.

The pilot evaluation defined eight personal attributes of adequate preparation for retirement, and used them to analyse the views of stakeholders at each site.

Table 3.4: Attributes of being adequately prepared to retire and extent these were present for pilot participants at the different sites

Attribute	Site 1 participants (8 employees)	Site 2 participants (4 employees)
<i>Understand the concept of retirement</i>	6 employees agreed they have learned a lot about retirement; able to say what retirement means in general, e.g. stopping working, need to consider money and health, being active, deciding how to spend your time. 1 employee agreed they learnt a little bit and basic understanding only.	Employees did not link community access activities with retirement and had very limited understanding of the concept of retirement. ADE framed messages about the pilot as 'doing something other than working'.
<i>Chose how to spend spare time</i>	Enjoyed choosing what to do in the time off work; able to articulate what they would and would not like to do. Some activities were part of group, others individual choice.	Enjoyed choosing how to spend time off work. But two employees said that they did not always have a choice about what activities to do. Would have liked more decision-making opportunities so they could choose the activities for the day.
<i>Feel in control of decision about when to retire</i>	All employees at end of pilot.	No information.
<i>Skills to access social supports independently</i>	Employees developed/ improved skills, e.g. catching public or community buses, handling money. ADE gradually withdrawing support and some attending community groups independently. But some will need ongoing support. Employees asked if they are confused about who will help them when they retire: 3 not confused; 3 a little bit confused; 1 very confused; 1 no information.	None able to access social supports independently due to severity of disability, health problems. No information about whether confused or otherwise about who will help them when they retire. ADE expects disability service to provide some support.
<i>Identify interests might pursue in retirement</i>	Largely achieved. 6 employees agreed they tried out all activities they wanted; 2 some activities. Employees generally well accepted into community groups. 5 employees agreed they were not worried about how to spend their time when they retire; 2 employees a little bit worried.	Partly achieved. Employees identified social activities that they enjoy doing in their spare time. But limited connections with community groups.
<i>Formed relationships with others that can be</i>	Strengthened relationships between members of the retirement group. Some relationships made with other members	Strengthened friendship between two of the participants. No evidence of new relationships with individuals in the

Attribute	Site 1 participants (8 employees)	Site 2 participants (4 employees)
<i>continued outside work</i>	of the community groups they attended.	community.
<i>Confidence to access social support</i>	Appear more confident.	Reported to be more confident. Enjoyed socialising.
<i>Skills to participate in community activities (with relevant support)</i>	Able to participate successfully.	Did not participate in community organisations.

Notes: Based on interviews with employees and their support persons.

At this stage, none of the employees have retired, but the likely retirement outcomes are that some employees will

- fully retire and go on to enjoy an active retirement
- reduce hours at work and eventually retire
- fully retire and move into day programs.

The workplace, the family carer and the employee may have differing views about whether the person is ready to retire. This again points to the importance of planning for retirement and making sure that everyone has a shared understanding and that the employee feels in control of the decision. When we talked to family/ carers and employees about their decision to retire, around a month before the end of the pilot, we found their views did not always coincide (table 3.5). In some cases, the family member/ carer believed that the employee was well prepared, but the employee felt that they were not ready. In other cases, the reverse occurred. We can only speculate about the reasons for these differences where they occurred but suspect that the family/carer had seen the progress employees had made in linking into the community but that employees were still somewhat attached to going to work.

Table 3.5: Whether the family member/ carer and the employee agree the employee is ready to retire as of July 2011, site 1 and October 2011, site 2

Person	Support person's view Extent agrees employee is adequately prepared for retirement	Employee's view Extent feels ready and able to retire
1	Uncertain about how well prepared even though seen many positive impacts.	Not ready to completely retire. Intends to continue volunteering and some other community activities.
2	Well prepared.	Not ready just yet. Intends to continue attending some community activities.
3	Well prepared.	Not ready to completely retire.
4	Well prepared.	Ready to retire. Intends to continue volunteering.
5	Somewhat prepared. More independent. Needs someone to motivate him to be active but has been exposed to new things. Will need support to access community activities.	Ready to retire. Intends to continue volunteering and some other community activities.
6	Well prepared.	Not ready just yet. Intends to continue going to some community activities.
7	Somewhat prepared. Will need support to	Ready to retire. Intends to continue

Person	Support person's view Extent agrees employee is adequately prepared for retirement	Employee's view Extent feels ready and able to retire
	access community activities.	attending some community activities.
8	Somewhat prepared. Needs more time to get used to changes and practice skills.	Ready to retire. Intends to continue involvement in some community activities.
9	Uncertain; helped social participation skills.	No opinion given.
10	Not prepared; not found anything she can continue to do in the community.	No opinion given.
11	Not prepared; does not understand retirement.	No opinion given.
12	Somewhat prepared; helped think about the options when retired.	Not ready to retire.

Other benefits for employees from participation in the pilot

Being part of the pilot has many benefits for the employees, apart from preparing them for retirement.

Friendships between some employees were strengthened; other employees also made social connections with people outside of their workplace. Employees and their families reported that the employees were happier and more confident about organising their own activities and to go out and about in the community by themselves. Family members cited benefits of the pilot, including reduced worry, gradual transitions, increased independence, decreased stress and tension at work, increased social contact and the employees' happiness. The pilot gave employees something to look forward to outside of work and being at home.

'It's been marvellous that she's been a happier person because she's been a lot more social...I haven't been as worrying about her because she rings me up and...she's "tomorrow's our day off and we do this and we do that", and I think it's just had such a positive effect on both of us actually'. (Family member)

'It's good it gets you out of the house and you can go around the streets talk to people and [the linkage coordinator] got you going everywhere. Yes, it's good. It's been good since they've done that'. (Employee)

'Because, like I said, I love the people here and you go out for coffee and you go out, not just coffees...and you meet other people there and have a talk to some people you haven't seen for a while and you sort of come—they come up and you haven't seen them for a long time and you have a good yak to them'. (Employee)

Comments from informants in the community groups involved in the pilot demonstrate the progress some of the employees made over the life of the pilot.

'Everyone has got a reward out of it – the guys in the Shed can take the experience into their general life, e.g. many of the guys from (the pilot site) approach guys from the Shed in the street and they wouldn't have done this before. Some of the guys from (the pilot site) will just come in for a chat. The guys pick up tasks quickly – they are tending to be self-managed

nowadays. I have seen this change over time – see this for able-bodied people and for people with disabilities’. (NFP community service)

‘Originally the employees only came in with [the linkage coordinator] but now they come in by themselves—one employee collects up all the coffee cups that are dirty; another of the employees walks past the café every morning and waves to us through the window—he feels comfortable to do that’. (Private business)

‘I’ve liked seeing them develop in the short time we’ve had them. I see one of the participants around town and he always says hello. I get the impression the 3 are enjoying it. One of them is self-sufficient in the task he does here now’. (Community organisation)

‘I do notice changes in them—they are freer in their talk, they didn’t say much at the beginning but once they got to know me they talked more. They enjoyed the activities, definitely’. (Community organisation)

One of the benefits highlighted by the pilot was the great value the employees placed on being able to choose what they did and how to spend their time outside of work. Where employees had less choice than they might have liked, or were obliged to do what another employee wanted, this was seen as a negative.

‘The benefit of the pilot is he got the opportunity to go out and do something that he wants to do on a week day’. (Support person)

Some family members remained concerned about the impact of the employee’s retirement on their own lives. This was mainly because they anticipate greater caring responsibilities and because they are unsure whether the person they support will maintain their involvement in the community activities after the pilot. For example, one carer feared she would become more housebound, another that she may have to move towns to support her relative; another had already retired to provide care. Other family members were not concerned at all and some felt they would ‘cross that bridge’ when they came to it.

Families and support persons were also concerned about where the support will come from for employees in their retirement. A disadvantage of ADEs taking on responsibilities for the transition to retirement program is they no longer have a role in the person’s life when work ceases. As discussed in chapter six, the employees were given support to participate, including transport to and from places, as well as moral support and this support has now been withdrawn for some. In particular, participants at one site were transported to and from activities for the life of the pilot because of health and/or mobility problems and the lack of public transport options.

‘It frightens me if there’s nowhere for her to go or something for her to do, that she will just vegetate’. (Family member)

‘I am unsure though about what will happen when “Mary” retires for good; and scared that she will be moping around and I will have to arrange more trips for “Mary”...have to deal with her boredom’. (Family member)

3.8 Conclusion

People with disabilities working in supported employment have the same right to retire with dignity as other Australians and to get the benefits of an active retirement.

But because they may need more support to achieve a meaningful and active retirement than other Australians, that right has been out of reach for many employees in supported employment. Indeed, the evidence from the pilot confirms that older people in supported employment do not naturally think about retirement; it is the onset of the effects of ageing that prompts a reduction in work hours and recognition by employers that the person should retire. The needs and experiences of the pilot group are likely to reflect the cohort of older workers across the ADE sector.

The pilot confirms the findings of earlier studies that older people with disabilities working in supported employment need emotional and practical support to think about retiring, to explore options for spending their time in retirement and then retire with dignity. Some employees need support to practice and develop life skills to increase their ability to participate in community activities with less or no support. Older workers can be socially isolated and support is needed to break that isolation.

The evidence of the participants in the pilot has demonstrated that it is feasible for ADEs to prepare older employees for retirement with dedicated linkage coordinator position/s. While none of the participants had retired over the period of the evaluation, a number had made substantial progress in the transition. Being active in the community has benefits for retired Australians—maintaining health, and improved physical and psychological wellbeing and social connectedness, and we saw these same benefits among some of the employees in the pilot.

The pilot also shows that transition to retirement must be a gradual process and progress will depend on the individual's needs and situation; it also raises the question about what impact running these programs might have on the business.

Building upon this, the following chapters look at the capacity for ADEs to do this work, in terms of resources, knowledge and skills in the sector, the role of education, and making linkages with the wider community.

4. Capacity of ADEs to support older employees with disabilities to retire

This chapter considers the evidence from the pilot, and other evidence about funding and resources, to discuss whether ADEs encompass the skills and capabilities to support older employees with disabilities to transition to retirement, and what their role could be.

4.1 Policy issues

Older employees working in supported employment need support to overcome barriers to retirement and to access social support, particularly people with an intellectual disability who tend to rely heavily on routine and who require time to adjust to change.

Under the National Disability Agreement, state and territory governments are responsible for providing community access disability services and the Commonwealth Government for funding employment services. But it is unclear which agency has the responsibility for implementing support to transition to retirement or where jurisdictional responsibility lies.

An additional complication is the split between aged care and disability responsibility at the state and commonwealth level, which means there are disconnects in ageing and disability policy and older people with a disability who are less than 65 years can experience difficulties accessing aged care services.

As a result, people with disabilities have no certainty about where and how to access assistance to retire with dignity.

4.2 Resourcing transition to retirement support

There is no consistent approach to providing transition to retirement support for employees in supported employment and no consistently dedicated resources for this role under the current funding model for disability services. This highlights how critical the issue of an ageing workforce is for ADEs at the moment. As a consequence, some ADEs/ disability services are actively seeking funding from government and other sources for TTR activities. We have no information about how many disability services have made such attempts or how many have been successful.

A number of TTR models identified in this study were funded through grants from the relevant state and territory government, for example, Greenacres Retirement Options, Minda Retirement Lifestyle Services and AFFORD/ University of Sydney/

La Trobe University. The AFFORD model is also in receipt of a research grant awarded jointly to academic researchers (University of Sydney and La Trobe University) and the disability service. Smaller informal activities are likely to be entirely funded from with an ADE's own resources.

The TTR pilot was funded by FaHCSIA at relatively modest levels to enable ADEs to employ part-time staff to take on the role of linking employees to community activities. One of the ADEs in the pilot chose to contribute additional funding for the pilot and is now seeking funding from philanthropic sources to continue a transition to retirement program.

Table 4.1: Funding sources for TTR programs

Program	Main source of funding	Cost per individual place (total)
TTR pilot (site 1)	ADE (50%) and FaHCSIA (50%)	\$10,644
TTR pilot (site 2)	FaHCSIA	\$6,250
Koomarri Gateway Retirement Program	ACT Government and Koomarri	No information
Greenacres Retirement Options	NSW Department of Ageing, Disability and Home Care (75 places)	No information
Minda Retirement Lifestyle Services packages	ACROD (SA) and ADE	No information
AFFORD/ University of Sydney/ La Trobe University	NSW Department of Ageing, Disability and Home Care and the Australian Research Council	No information

We have limited information about the amount of funding available for existing programs and the cost of individual places. However, costs will vary for each individual depending on their needs, on the model being used and on the time the transition takes. In its submission to the ADE Vision process (2010), the NDS quoted average costs of a place in a retirement program in two unnamed ADEs as \$8,530 per annum and \$8,166 per annum (for 2.5 days service) respectively.

For the pilot, the cost of transition to retirement support varied from an average of \$10,644 per individual at one site to \$6,250⁶⁰ at the other site. Excluding the cost of establishing the program, the average cost per person at site 1 was \$8,751 per annum, but cost will vary for each individual depending on the time taken to transition. As the NDS noted, the costs are relatively low compared with the cost of the NSW Government's two-year 'Transition to Work' program at over \$17,000 per place.⁶¹

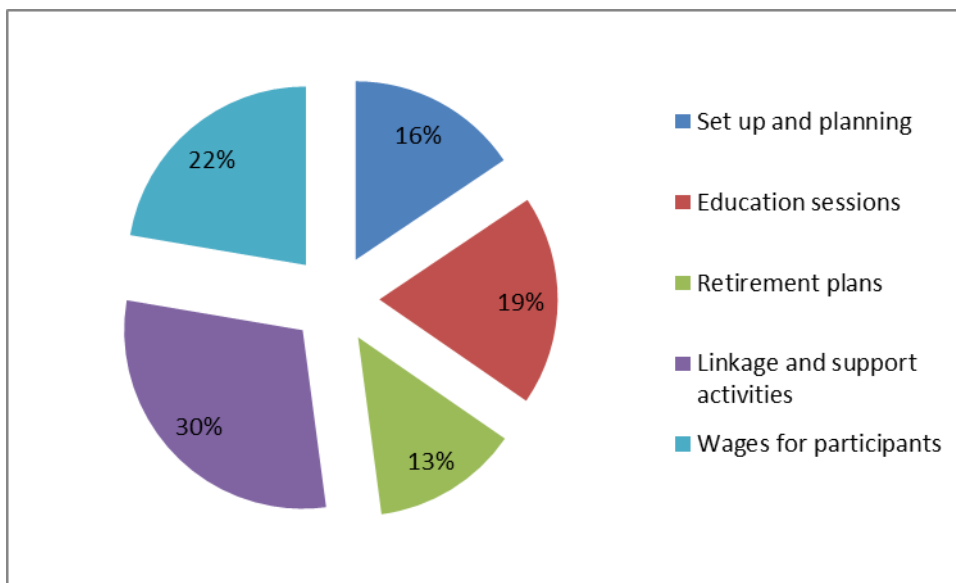
⁶⁰ Calculated by dividing total funding provided by number of pilot participants because ADE reported all funds used and no additional resources.

⁶¹ NDS, 2010, Submission to ADE Vision Process.

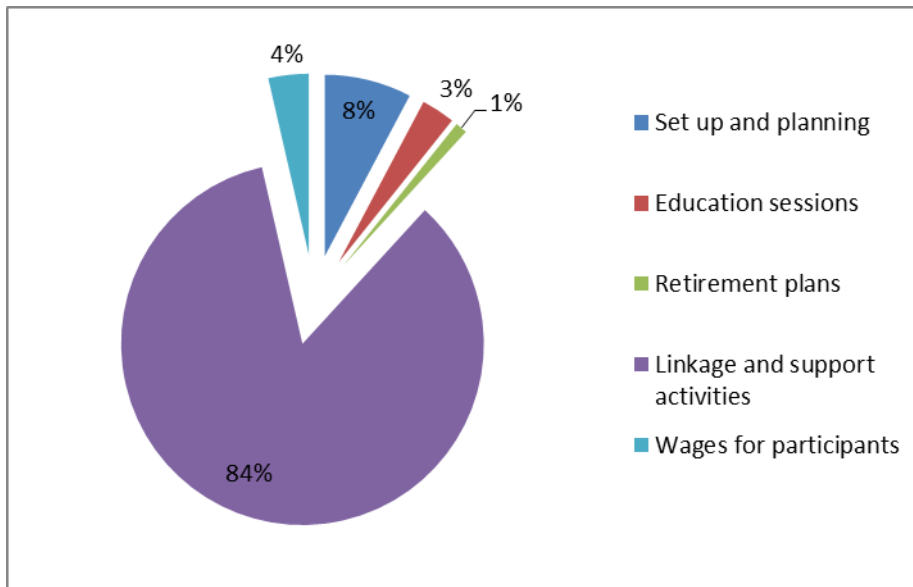
The differences in cost per person at the two pilot sites reflects the differences in how the pilot was implemented (chapter 5), with site 1 bringing a greater focus on education and planning and allowing employees more time off to participate in community activities (one day versus half a day).

The pilot provides information about the relative cost of different activities that make up this TTR program (figure 4.1). The main expenses are staff hours, on-costs (transport/ entry fees) and wages for participants (when trying out community activities)⁶². At site 1, staff time spent organising and supporting employees to access community activities made up a third of the costs and over half when you consider the cost of employees’ wages for these hours. Soon after establishing the pilot the ADE recognised that the initial estimation of time (and cost) to deliver linkage activities was insufficient for the number of employees in the program.

Figure 4.1: Distribution of costs for pilot activities (estimated) (site 1)



⁶² Employees were paid usual wages on days/ time spent.

Figure 4.2: Distribution of costs for pilot activities (estimated) (site 2)

4.3 ADEs' knowledge about, and skills to deliver TTR programs

TTR programs for people with disabilities require staff to have certain competencies—community engagement and networking skills, knowledge of retirement options and barriers, knowledge about retirement education needs, knowledge of person-centred practice, skills in communicating with employees and individualised, person-centred planning approaches, and the ability to provide active support and/or training. Staff supporting ageing workers with disability to retire should have these skills.⁶³

We have only limited evidence about the availability of these skills and requisite knowledge among ADE staff in general. At least two TTR models are coordinated by community access branches of the disability organisations rather than ADE staff, partly because these staff members have the requisite community networking skills. To meet the perceived knowledge deficits, the sector has developed information materials for disability services and ADEs about transition to retirement. FaHCSIA has developed an education resource (*'When I'm at work: Retirement planning'*) for ADEs and provided training to the sector about how to use the resource. ADE staff in the pilot attended training (CRS facilitated) on how to use this resource, which also covered facts about retirement and issues faced for

⁶³ List derived from discussions at the June 2011 forum.

employees transitioning to retirement. ADEs were also offered a consultancy service from which they could get further advice as required.

4.3.1 Lessons from the pilot

Although highly experienced in disability services, the pilot teams had to acquire new skills and knowledge about what was needed to implement the pilot. In particular, the teams had to develop expertise in linkage activities and knowledge about what community options are available and how to support each individual appropriately. They also had to develop an understanding about the boundaries of their role because it involved them working with people outside the workplace. ADE staff already had skills in planning, providing active support and communicating with employees.

Both sites reported that their key staff were familiar with the issues employees faced in transitioning to retirement, before embarking on the pilot, but somewhat uncertain about the overall process.

'Totally confident about our staff educating clients about retirement—I was a little nervous as I didn't know what was expected'. (ADE staff member)

'But I feel more confident now (about education and planning transition activities [sic]); we have a workable document'. (ADE staff member)

Although highly experienced, the ADE pilot teams reported an initial steep learning curve, particularly about how to implement the community linkage activities and about what options might be available in the community. At one site, a key team member had experience and skills in community development and networking and mentored the linkage coordinators (ADE staff) to develop this knowledge and skills. These staff members were initially uncertain about how to approach community organisations and then about ways to allay community group members' fears about how to speak to and act with people with a disability.

'Networking skills was a gap—I addressed this by asking, talking, going to relevant meetings, going to relevant organisations and meeting face-to-face re who is the relevant person. The coordinator has been a great mentor as well in this respect. I am not bad re communication but I learnt the different ways needed to communicate with different organisations, e.g. allaying fears of community organisations re how to speak/ act around and with the employees'. (ADE staff member)

By the end of the pilot, staff undertaking linkage coordination roles were comfortable with all aspects of the role. One ADE got advice from CRS about the difficulties they faced linking employees to community organisations.

These data corroborate other evidence that skills to link community organisations with employees would not be expected to be competencies for support worker

positions. ADEs undertaking TTR programs may need to import these skills or build the capacity of existing staff.

'I went from a supervisor's role to organising people's lives [as a linkage coordinator]. I needed a few more skills in that area; I found it hard to sometimes know what was my role, e.g. did I deal with the employees' families, or was that the coordinator's role. It's a learn as you go [position], very good learning experience [for me]—liaising with people you'd never liaise with normally'. (ADE staff member)

Because each person's needs varied, one of the key skills was to be able to identify and actualise ways to support the person to achieve their retirement aims; essentially, person-centred practice.

'But it's very individual—we did a lot of stuff as a group but feel we should do it more 1-to-1 as everybody's situation and needs are different'. (ADE staff member)

The CRS training for ADE pilot staff focused on the use of the Retirement Flip Chart and Retirement Workbook. Such a focus did not reflect the complexity of the task or recognise the training needs or interests of the ADE staff delivering the pilot. Especially when these resources proved only suitable for a minority of the employees, and there was limited opportunity to apply the training. Even so, staff to whom transition to retirement was a totally new area of knowledge found the information covered was useful.

ADEs would have liked the training to have been more tailored to their needs and interests and take into account their prior knowledge. Training on working with community organisations and developing retirement plans would have been more useful. One ADE has previously researched transition to retirement planning, and one person had already completed FaHCSIA-led training about the use of the 'When I'm at work: Retirement planning' resource.

'We'd already started a lot of pre-training. The flip charts didn't work for us as our employees are higher need—the employees just didn't "get" the chart, we used it a little bit'. (ADE staff member)

On the other hand, discussions about tailoring the resource were useful for a couple of staff members, and another thought that designing the training around the resource meant that most information about employees' retirement transition needs was adequately covered.

Part of the story of the ADEs' capability to deliver retirement transition is around how staff not directly involved in implementing the TTR pilot understood the issues around retiring and the importance of the person-centred approaches used. This issue was also raised in the FaHCSIA TTR June 2011 forum, where it was observed that community inclusion can be hindered by service providers' lack of understanding about retirement options. Supervisors, support workers or staff providing job training for employees in the pilot ADEs had little experience or

knowledge about transition to retirement processes. Both pilot teams reported initially experiencing a lack of understanding of employees' right to retire and some internal resistance to the pilot's aims among other ADE staff.

'Able to communicate with employees, families, other agencies; also communicate with the rest of the organisation so it knows where you're going—some of the initial barriers were internal because you were taking people out of employment'. (ADE staff member)

'The pilot has educated staff re there are other ways of doing things...being able to distinguish between work and the pilot is an issue'. (ADE staff member)

'We will encourage our staff to see retirement as part of employees' rights, and help them to connect them with an opportunity'. (ADE staff member)

Some of the disability support workers at one site did not necessarily think it was appropriate for the person to retire completely and felt responsible to ensure that the workers were looked after. At both sites, some staff members were reported to have difficulties changing the way they think about the interests of the employee versus those of the business. Again, this demonstrates why it is important to take a person-centred approach to transition to retirement.

'ADE staff [sic] need to be "de-employment briefed"—need to forget the "work side", e.g. [a staff member] said how are we going to replace the clients [who want to retire] and I said it's about the employee, not the workplace. It's about language—sometimes it's a negativity about things outside the employment area, "work-focused"'. (ADE staff member)

4.4 ADE systems and tools to support retirement planning

Recent literature reviews and feedback from the sector indicate that lifelong succession and retirement planning should start early and there should be regular and systematic checks of people's health, cognitive and behavioural status to better recognise when they might be ready to retire (see section 3.5).

Although providing information on retirement, superannuation and Centrelink services is part of the Employment Assistance Plan checklist (ADE Funding Agreement Annexure E), the pilot ADEs had no existing retirement planning templates. One ADE in the pilot had included discussions about retirement in Employment Assistance Planning processes (but only one person had ever retired).

The lack of a template for retirement planning was a barrier for one ADE and the planning component was kept very low key and informal, which impacted on employees' satisfaction with community options available to them.⁶⁴ The other ADE developed an individual retirement plan template and prepared picture plans

⁶⁴ In part, because of the lack of a retirement plan template but also because of the high needs of the employees. Changes in personnel involved in the pilot due to staff resignations, absences for sickness and leave may also have impacted on the ADE's ability to deliver this aspect of the pilot.

for all employees, based on a tool developed by an organisation in Western Australia that was freely available on the World Wide Web MY PLAN (see chapter 5).⁶⁵ This ADE is planning to incorporate retirement planning into their human resources policy as part of the exit and entry into work process (at August 2011). The retirement process will be explained to people on their entry to the ADE ('what is next after work') and reviewed at an appropriate age. The MY PLAN template will become part of Employment Assistance Plans.

'Will continue the picture plans, MY PLAN. And will see how we can continue to link people in with the community in an informed, low cost way. We do MY PLAN as part of the employees' EAPs—covers people's dreams, etc; by doing this at a younger age, we can find people's dreams, etc and needs and if we e.g. identify [government] support early it can be put in place when people retire'. (ADE staff member)

4.5 Conclusion

The pilot confirms other evidence that there is an urgent need for the Commonwealth Government and the state and territory governments to continue to work together developing policy for planning and transition to retirement for older people with disabilities in the workforce. At present, access to retirement options is ad hoc and unstructured. And access to transition to retirement planning is currently dependent on the goodwill of the ADE or other disability services and their ability to source funding from government or other sources. The Disability Policy and Research Working Group provides one mechanism for giving advice about how policy gaps and issues can be addressed.

ADEs are employment providers for people with disabilities and sustaining this role depends on the strength of their business operations. Although somewhat outside their main role, ADEs and associated disability services have begun developing programs to fill the gap in support for transition to retirement for their employees. There is no consensus in the sector about whether such a role is rightly the responsibility of ADEs because the role is outside core business and because of possible conflicts between business considerations and the person's interests. Some argue the role is more suited to an independent disability service provider or support person because of the nature of the skills and linkages with the community. We have no evidence about the efficacy of this model to inform the evaluation, as all pilot sites were ADEs.

Others argue that ADEs are in a good position to provide TTR because of the long-term trusted relationships between staff members and employees, and because there are opportunities to address planning for retirement over the whole of a

⁶⁵ Pilot coordinator says, with due acknowledgement, this tool has been used during retirement planning also, and is very useful in gathering a true picture of a person's life before considering which direction they would like to take for their future whether it be retirement, work or leisure'

person's work life as part of the individual employment planning processes already in place. While the pilot suggests that trusted relationships are important to allay employees' fears of retirement and help them identify potential community options for their retirement (chapter 6), it also identifies the need for other skills that are vital in bridging the gap between employment and post-work activities. These are the ability to implement person-centred planning and to see the whole person rather than the person in their work role, and skills in working with the community and other stakeholders to achieve the post-work goals of the person with disability.

The pilot investigated whether ADEs have the capabilities, skills and knowledge and systems in place to effectively prepare employees for transition to retirement, and the lessons from the pilot for wider application. The experience at the two pilot sites suggests that capabilities will vary among ADEs because the key competencies in community engagement and networking are not required for ADE training and support worker positions. Another likely barrier for many ADEs is a lack of understanding of rights to retire and the processes involved in transition to retirement. These were explicitly addressed in the pilot, and this should form part of any wider application of the model.

The pilot ADEs (and other ADEs) did not have human resource systems and resources in place to support TTR—retirement planning was not part of Employment Assistance Plans (EAP), there were no systematic processes to recognise when an employee might be ready to retire, and there was no template for retirement planning available. The lack of a retirement planning template was a barrier for one ADE, but the other pilot ADE developed templates they will continue to use. Both ADEs developed a process for identifying employees, which took into account productivity and employees' enjoyment of work. One ADE has plans to integrate planning for retirement as part of exit and entry and EAP processes. This evidence suggests that ADEs can build system capacity for retirement planning but that some might need guidance and assistance. In addition, because lifelong planning and skilling had not taken place for some workers within the pilot, the person with disability had not previously articulated when they were ready to slow down or to reduce their working hours and investigate alternate options.

After the pilot, the ADEs involved in the pilot were ambivalent about whether all aspects of TTR programs should remain the sole responsibility of ADEs, particularly if additional funds are not committed to facilitate the role.

Regardless of whether ADEs have the main carriage of transition to retirement programs, the evidence suggests that ADEs are in a good position to recognise when an employee is slowing down and to make an early start to their education about retirement. However, people with disability need to be equipped with an

understanding of what retirement is, and that there are options other than work, so they can be the primary instigator of a transition to their next life stage.

The pilot model assumed that ADEs would need improved knowledge about issues and approaches to TTR and, in practice, support workers were provided with training and education resources. The experience of the pilot confirmed the need for this training, but indicated that it could be better targeted to take into account specific information needs and skill and knowledge deficits. If ADEs were to take on responsibility for TTR, training for staff should have more focus on

- networking and community engagement skills
- person-centred practice that shifted seeing employees as workers to seeing them as individuals preparing for their own retirement, with rights to choose how they spend their time
- planning and social skills training that starts at the beginning of a person's working life—rather than at the end
- strategies for linking employees into community organisations
- the new linkage coordination role and its boundaries
- preparing formal retirement plans (content and method) and tailoring resources to meet individual needs.

5. Education and planning for retirement

Education and planning for retirement were key components of the pilot, designed to address a common lack of understanding and preparedness to retire among ADE employees. This chapter explores what the pilot suggests works to educate and plan for retirement.

5.1 Policy issue

'Ageing', for older people with lifelong intellectual disability, is a relatively new phenomenon and a greater number of adults with lifelong intellectual disability are reaching old age.⁶⁶ Older people with lifelong intellectual disability represent a small but growing cohort of our ageing population and today many are living independently in the community, or are cared for at home or in supported living accommodation. As a consequence, retirement has become a logical outcome of working, for employees of ADEs. But employees of ADEs are not retiring at the expected rate and at the optimum time for them.

Most working Australians are fully aware that they will eventually retire and many prepare for the eventuality by seeking out financial and other advice. Governments offer information and advice services for their employees (e.g. Sage Centre NSW). By contrast, recent research found that people with disabilities working in supported employment have a profound lack of knowledge of life after employment and the options available to them. Further, people with disabilities do not have a clear pathway to retirement and some have a negative view about life after work.

The literature on retirement indicates that people want to have a choice and have control over the retirement process. Older people with disabilities have similar wants and aspirations.⁶⁷

5.2 Approaches to educating and planning for retirement

We have no information about the extent to which the ADE sector gives employees with disabilities education about retirement or does retirement planning.

⁶⁶ Buys L., Boulton-Lewis G.M., Tedman-Jones J.S., Edwards H.E., Knox M.F., and Bigby C., 2008, Issues of active ageing : perceptions of older people with lifelong intellectual disability. *Australasian Journal On Ageing*, 27(2), pp. 67–71.

⁶⁷ Buys L., Boulton-Lewis G.M., Tedman-Jones J.S., Edwards H.E., Knox M.F., and Bigby C., 2008, Issues of active ageing : perceptions of older people with lifelong intellectual disability. *Australasian Journal On Ageing*, 27(2), pp. 67–71.

Disability services with TTR options all include some form of education and retirement planning in their design, but these are all delivered differently. Some frameworks or programs conceptualise education about retirement as a first step, after which retirement planning follows (as is the case in the pilot). Other programs appear to combine education and retirement planning processes. Holding planning meetings with the family and employee is a common approach. In practice, education and planning are likely to be iterative processes, as was the case in the pilot. It is not known how much focus on retirement education versus planning is effective. What is needed will depend on the individual's needs, and person-centred planning is essential.

Table 5.1: Comparison of TTR models and approaches to education and planning

Initiative	Model	Retirement education	Retirement Planning
TTR pilot	Education, person-centred formal planning, individual support to assist person to try out options, address retirement issues.	Yes, using FaHCSIA resource + informal discussion.	Planning meetings with family/ employees. Individual formal plans prepared.
Koomarri Gateway Retirement Program	Individual support, focus on independence and skill development, friendship networks, financial and legal planning.	Yes, own resource + informal discussion.	Planning meetings with family and employees.
AFFORD/ University of Sydney/ La Trobe University	Person-centred planning and case management, coordination of community activities, mentor based in community organisation assists to participate.		Planning meetings with family and employees.
Minda Retirement Lifestyle Services	Person-centred formal planning. Offers combination of home, centre-based and individual activities.		Formal planning.
Greenacres Retirement Options	Centre-based day service supported by an in-house case management service. Mix of structured and unstructured activities.		Individual plan on joining the program.

FaHCSIA has made a retirement education resource, '*When I'm at work: Retirement planning*' (Retirement Flip Chart and Retirement Workbook) available to the sector. The resource was developed specifically for ADEs in 2008 to assist them to educate ADE employees about transition to retirement. FaHCSIA has provided training to the sector to encourage use of this resource.

The Retirement Flip Chart was designed to be used in one-to-one sessions with an ADE staff member, along with the Retirement Workbook as a personal record of retirement planning for the employees. The resources cover: *What is retirement?*; *Why should I plan for my retirement?*; *How much money will I need when I retire?*; *Where will I live when I retire?*; *Important documents*; and a *Planning for retirement checklist*.

5.3 Educating pilot participants about retirement

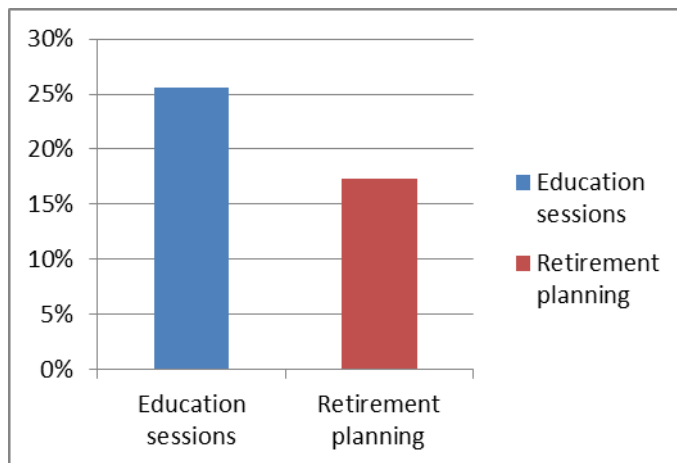
Education about retirement was necessarily an iterative process, starting with formal education sessions, including interested family members, and based on the Retirement Flip Chart. The formal sessions appear to have been useful as a starting point but not sufficient on their own to improve employees' understanding about retirement.

Only a few employees could recall the education sessions, or mentioned the Workbook when we talked to them in August 2011. The part of the Retirement Flip Chart that the employees most related to, and that helped them understand the different issues, was the section with case studies about people like them. Two employees told us they had talked to someone who had retired (a relative), which was one of the homework activities, and they found that helpful. Employees commonly said they learnt most from the ADE pilot staff. The formal education sessions were followed up by informal conversations with individual employees as part of the retirement planning sessions and opportunistically in other interactions. Site 1 spent an estimated 76 hours per person educating employees, or devoted around one-quarter of staff hours dedicated to the pilot on this aspect⁶⁸. Considerable and persistent effort was needed to help employees understand retirement, and the mix of dedicated education and opportunistic discussion worked well.

Over time, employees were less engaged in discussions about retirement, preferring to go out and do activities—a natural progression, which shows the importance of experiential learning for this group. Two employees with high needs were difficult to engage in discussions about retirement at all, but did find activities they enjoyed being involved in.

⁶⁸ Large gaps in information for site 2 mean these data are unreliable and likely to underestimate the time spent.

Figure 5.1: Estimated % of total staff hours on education and retirement planning (site 1)



The ADEs adapted their use of the Retirement Flip Chart because of the constraints of the pilot; it was time-limited, and a group of employees were transitioning to retirement together. As such, it was impractical to offer the individual education sessions for which the resource was designed on an on-going basis. Rather, the education was done as a group, at least for some of the sessions. One ADE followed up the group session with individual education meetings with each employee and their support person. We do not know how much, if at all, using a group education approach impacted on the sessions' effectiveness, except that individuals' information needs vary, as does their ability to understand, so it seems likely this approach would be less effective.

The ADEs also tailored the education messages to better suit the abilities of the employees participating. One ADE chose to frame their discussion around community options for when the person is not working, rather than referring to retirement. The Flip Chart and Workbook are text-based, and as such, were unsuitable for those employees who cannot read or process text easily.

Adaptations made were

- offering abridged versions of the education sessions for employees with a severe intellectual disability who were unable to read or process text
- adjusting education to be relevant to the employee's situation and level of support received from family members or other support persons, for example, where the employee's living arrangements were stable, e.g. they lived in supported accommodation and their money was looked after by relatives, then less education was provided about finances and living arrangements when retired, and providing travel training for those employees who needed it
- replacing the Workbook with picture diaries for employees unable to read or process text.

Part of the formal education included the use of homework and a Workbook, which is meant to reinforce messages. The Workbook does not appear to have been used much and only by those employees with lower needs who were able to read it and process the text. Because of the other formal retirement planning processes in place it did not function as a retirement plan, as intended by the designers. Family members and support workers discussed retirement with the employees at home, reinforcing the messages about life after work and what employees might do with their time. They also tried to allay worries and fears.

ADE staff talked to family members regularly about the pilot—staff at one ADE estimated they spent an average of 8–10 hours per week talking to families about issues ad hoc to do with retirement, via email, phone and face-to-face contact. But some family members who had less contact with the pilot would have liked more contact and worried about whether the employee’s social needs were being met and how they would ultimately spend their time when they retired. Others were content to stand back and see the pilot unfold, seeing the process as the personal business of the employee.

5.4 Retirement planning in the pilot

Only one site used a formal planning process; the other site held a planning meeting with the family or support person and the employee (see box 5.1).

The formal planning process appears to have been effective, particularly in helping the employees make sure they have new friends or keep old friends; making sure they have new activities to do instead of work; and in making sure they can get to where they want to go (table 5.2).

The retirement planning process was effective because it was focused on each individual’s interests and aspirations and gave employees sufficient time to understand the concepts. ADE staff had formal weekly meetings about planning for three months. As shown in box 5.2, all the employees agreed a plan was a good idea, most said they understood their plans and that what was in the plan was important to them. As discussed in chapter 6, the employees were able to experience and try out some of the activities they wanted to do and get help in getting around or with other issues they identified.

Box 5.1: Formal retirement planning in the pilot—intensive, person-centred and pictorial

- Each employee had their own retirement plan, average 51 hours per person, 13% of all staff hours.
- Step 1: Gathering information about the person’s aspirations and the issues they might face and how these matched available community options and services; from the employee and family members.
- Step 2: Writing this up as a record for the ADE staff.
- Step 3: Developing picture plans, *MY PLAN*, which were hung on the wall, with a picture of the employee in the middle and photos, drawings and comments surrounding this about their own vision of retirement.
- *MY PLAN* folder with pictures of the employee doing activities, contact telephone numbers and addresses of places they have been to and other things they might like to try.

The plans took into account family support or support from key workers and included, to varying extents, actions about living arrangements, social participation/ community activities, social networks, financial advice/ planning, transport planning and health advice. For those who had family members or other key workers who were very involved in their support, planning areas such as financial advice or living arrangements were less extensive. A few employees were able to describe the support they were getting to begin the process of changing from a large to a small supported accommodation setting, or support to access bus travel training.

Box 5.2: Employees' feedback on the planning process (July 2011)

- All employees agreed it is a good idea to have a plan for when you retire.
- 5 employees agreed they understand their entire plan, 2 understand part of it.
- 5 employees agreed the ADE staff listened to them a lot, 2 a little bit.
- 5 employees agreed everything in the plan is important to them, 2 some things are.

Table 5.2: Employees' views on how well the plan helps them think about things when they retire (site 1 only)⁶⁹

Making sure you have new friends or keep your old friends	7	0	0	0
Making sure you have new activities to do instead of work, either on your own or in a group	6	1	0	0
Making sure you can get to places you need to go	6	0	0	1
Making sure you have a good place to live	3	1	0	3
Making sure you know how to use your money or that someone can help you with this	3	2	0	2
Helping you to stay healthy	3	2	0	2
Helping you to think about what will happen even later on in your life or when you die	2	2	1	2

Note: Missing data = 1 person.

The combination of education and retirement planning improved many of the employees' understanding about retirement and got them thinking about ways they might spend their retirement. Where employees have developed a better understanding, ADE staff and support workers or family members commented that employees' mindset and fear of stopping work had also changed; they were more confident and positive about retiring. Generally, employees were able to say a little bit about what retirement means, for example, stopping work, the need to consider money and health, and the need to not sit at home all day but to find things to do.

'He's the one that got me started up, saving up--see, I would have been in problem if I kept going through my money. So I've been putting money aside each time, and I make sure I

⁶⁹ Site 2 employees did not have formal plans.

have enough even if I did give up my job, that I make sure I'm not going to be broke, and know how to pay all my bills and that'. (Employee)

'I just know you retire and you can do what you want, but I don't want to retire for the whole time, just two days is enough...You need to think how it passes away and got to think of the budgets and how you pay your bills and bring in the money and all that sort of thing'. (Employee)

'I'll be able to go on trips—trips, and I can go up to the community house'. (Employee)

The experience of employees from site 2 who were not involved in intensive retirement planning provides some clues about the usefulness of the process. Family members and support workers felt that these employees would have benefited from more goal setting and a process to identify other interests or opportunities. There was a feeling that without a formal planning process the person might have lost opportunities to follow their interests.

Employees at the site that used the informal and much less intensive planning process were less prepared for retirement, and had no or only a basic understanding of what retirement means. This suggests that the more informal planning approach may be less effective. However, the ADE did not explicitly discuss retirement with the participants and appeared to have more modest aims for its high-needs employees.

Box 5.3: Employees' experiences of planning for retirement

'Mary'

[The linkage coordinator] helped Mary with her retirement picture plan, talking about the people in Mary's life, who she trusts and what volunteer activities she wanted to do. Mary also spoke with [the linkage coordinator] about money and friends. Mary said that doing the picture plan was very helpful, 'Because it's just the way he did it and all the things he had written down about the plan that was good, it really was'.

'Tom'

Tom said that [the linkage coordinator] and [the pilot coordinator] 'got a bit of paper and said "what would you do if you retired?"'. Tom then worked on a picture plan, 'It's just about what you want to do when you retire and say if I want to learn, he's going to learn me how to get the buses and all that sort...'. Tom said the plan was also about, 'Look after yourself and when you look tidy and when you go down the street you put your best clothes on and not wear your working ones'. Tom said the plan was very helpful, '...I need that. If you don't have that, you wouldn't know, you don't know what you're doing and all of that'.

[The pilot coordinator] and [the linkage coordinator] have talked to Tom about where he lives. They have also talked to him about making new friends, catching public transport, and about keeping healthy and getting medical checks. Tom said that [the pilot coordinator] and [the linkage coordinator] are 'trying to help me get out around the town and know everyone and go to these cafes and all sort of things...[The linkage coordinator] got us going where (they) used to go and [they] did first and now we go on our own and [the pilot coordinator] has been checking us out to see if we're doing everything that we like to do'.

5.5 Conclusion

By contrast to the broader community, the expectation that employees in supported employment may retire is a relatively new idea for older employees and their family members. As found in previous studies, most of the pilot participants had not been actively engaged in activities to connect socially in the broader community or planned for, or considered retirement prior to the pilot. As a result, they lack social skills to participate and are at risk of remaining segregated from the general community and becoming isolated when they are forced to stop work because of ill health. This suggests that education about retirement and planning should start early, as should greater skills development to enable participation.

The pilot confirms that older employees with disabilities can be successfully educated and prepared for retirement and that, once educated about retirement, many employees want what other Australians do in their old age: the chance to decide how they spend their time, to be connected to friends and others in the community, and to pursue their interests.

The findings suggest that intensive and personalised lifestyle planning that commences early and reflects the person's own needs and aspirations is effective in helping people with disabilities understand the challenges they face in retirement and the opportunities available. The process used in one pilot site, with pictorial plans and regular planning and education meetings, may be a good model for other ADEs; particularly for employees with intellectual disabilities.

The findings also suggest that education can be effective, particularly if the messages are repeated over a long time and the education process is iterative. Further, the pilot suggests that different education and planning strategies will be needed for employees with different needs. The Retirement Flip Chart and Workbook provide a good start, covering all the main issues. However, being text-based these resources are not well suited to people who cannot read or process text. Additional resources are needed for those with low literacy levels: written material using simple English, pictorial materials that use a life story approach, and DVDs showing employees thinking about and involved in activities in the community.

6. Ability of mainstream community services to accommodate older workers with disabilities

Linking older people with disabilities in supported employment to mainstream retirement options is a key strategy to fostering community inclusion after retirement. This chapter looks at ways disability services work to engage community services and how they work with individuals transitioning to retirement. It provides evidence from the pilot about what works in TTR programs.

6.1 Policy issues

Australia is moving away from segregated models of support for people with disabilities to social inclusion. Personal and community support is one of the six priorities of the National Disability Strategy 2010–2020. Under this Strategy, Australian Governments have committed to strive for inclusion and participation, person-centred care and support provided by specialist disability services and mainstream services, informal care and support.

The National Disability Strategy is aligned with the United Nations Convention on the Rights of Persons with Disabilities (2008) and the relevant principles—accessibility and full and effective participation and inclusion.

But employees in supported employment are reported to commonly have limited social connections with broader community groups. Disability services may provide only limited opportunities for social engagement and community participation. Safety concerns compound this problem. ADEs report that carers worry about safety and discourage people from being involved in activities because of this concern.⁷⁰ Community inclusion needs to start early and within the family but also be the concern of all community services. As discussed below, the mainstream retirement services may be unused to having older people with intellectual disabilities around and/or be unaware of disability access issues and/or lack understanding of how to include older people with disabilities in their activities.

⁷⁰ TTR June 2011 forum discussion group notes.

6.2 Community services' awareness of disability access issues, acceptance of people with disabilities and need for education

The ability of mainstream community services to include older workers with disabilities can be hindered by lack of disability awareness among mainstream community services/ groups (TTR June 2011 forum discussions). Wilson et al (2010) quoted research that there are many community groups that currently include retirees with ageing-related health conditions (Neighbourhood Centres, Men's Sheds, community gardens, women's groups), but that such groups are thought to lack specialist skills to support people with lifelong disabilities.⁷¹

The mainstream community services involved in the pilot had diverse abilities to include older people with disabilities in their activities. The pilot provides more evidence that services used by other retired Australians may lack experience in working with people with disabilities and lack understanding of access issues for people with lifelong disabilities, particularly those with intellectual disabilities (table 6.1). The lack of education and understanding may hinder inclusion. Two community services had attempted to include older people with disabilities in the past but had failed to do so successfully because of lack of skills. But evidence from the pilot also suggests that many community organisations are accepting of, and willing and able to learn about, how they can include older people with disabilities in their groups.

The level of understanding and attitudes to including people with disabilities varied considerably between services and groups. Of the seven community services we spoke to, just two had disability access policies (both groups funded by government) (table 6.1). A craft group, senior citizens club, church and cafe all said they had no or very limited experience of accommodating older people with disabilities previously. The senior citizens group had never really thought about older people with disabilities before and they are now providing a chance for this group of people to be involved in the community.

71 Wilson N.J., Stancliffe R.J., Bigby C., Balandin S. and Craig D., 2010, 'The potential for active mentoring to support the transition into retirement for older adults with a lifelong disability', *Journal of Intellectual and Developmental Disability*, 35 (3):211-14.

Table 6.1: Feedback from community providers involved or approached (TTR pilot)

Community service/ group	Has disability access policy	Staff experienced in disability access issues	Agreed needed more training to support older people with disabilities
Tourist site	Council disability access policy covers organisation.	Limited—have had people with disabilities volunteer at the site before.	No, on the whole it was a smooth process.
Cafe	No disability access policy but welcomes all customers.	No.	Not applicable, but younger waiters' first experience with people with disabilities.
Men's Shed	No disability policy but welcomes all; inclusive approach.	Have had a few other people with disabilities attend the Shed. Men's Shed coordinator has a background in social welfare.	At the monthly organisational meetings they discuss issues such as how they will work with someone with a mental illness or physical disability and how can they make it easier for people.
Senior Citizens (specific activity)	No disability access policy but welcomes all who want to participate in the activity, 'depending on their ability, and if the time suited'.	No.	Yes.
Community house	Disability access policy.	Yes, coordinator has background in welfare; most of the regular volunteers who work there have experience in working with people with disabilities.	Not needed—very experienced in this area.
Church group	No disability access policy but welcomes all customers.	Have had a number of people with disabilities attend the organisation—run by volunteers so experience in disability access issues varies.	Possibly some individuals.
Quilting group	No disability access policy.	No. Had one person with a disability involved with the activity (had carer with them).	Unsure—felt that others in the group would be willing to 'give a hand' if the person with a disability required support.

Instances that illustrate how a lack of awareness of disability access and inclusion can hinder participation are outlined below.

- An organisation relying on volunteers found that providing supervision and support for the employees to do volunteer tasks was difficult and they worried about safety.
- An organisation providing community activities for disadvantaged people and who did not take on any of the pilot participants had a prior experience where there was conflict between a person with disability and other volunteers who couldn't understand the person's disability. They indicated they would need clear guidelines regarding the person's capabilities and what the activity

involves. They were concerned that volunteers might ask a person with a disability to do something outside their capacities, because they are not trained to provide support.

- Negative attitudes of other people using the service or participating in activities with people with disabilities—two organisations described instances where other members did not feel comfortable when the older employees joined the group, and they subsequently left the group.

'Still have some conflict, e.g. one person attended for a while and then said he didn't feel comfortable with people with disabilities there so he stopped coming; learnt quite a lot in the last two years but perhaps a little to do before we get rid of some issues'. (Community organisation)

On the other hand, the pilot provides many examples of organisations that welcome and embrace older people with disabilities and, with support from the ADE, were able to assist employees to participate. Some of those that were able to easily include the employees were already sympathetic to social inclusion principles and either had existing policies and/or staff experienced in doing so (table 6.1). These organisations included those with older people as members, community centres, recreational organisations, cafes, private businesses and a nationally funded community initiative (Men's Shed).

'We are open to volunteers from all walks of life'. (Community organisation)

'We have some expertise...80% of our members are over 50 and so it was a match made in heaven for us'. (Community organisation)

'I'm the only employee. The volunteers we have understand [about the support needs of people with disabilities and what it would take for them to be part of this organisation]'. (Community organisation)

'At our monthly organisational meetings we discuss issues such as how we will work with someone with a mental illness or physical disability—how can we make it easier for people. If we come up with a barrier we sit down and think about how do we do this. We have a lot of maturity— we don't get frustrated, we look for solutions'. (Community organisation)

One solution to a lack of disability awareness is educating mainstream groups and services about social inclusion for older people with disabilities and about ways to accommodate and foster their inclusion. The TTR June 2011 forum recommended education of mainstream services, as does a recently released United Kingdom literature review of intellectual disability and ageing, and evidence from the TTR pilot.⁷² The pilot indicates that groups run by volunteers or where members share hobbies might be more in need of education and training.

⁷² Slevin E., Taggart L., McConkey R., Cousins W., Truesdale-Kennedy, Dowling S. 2011, 'Supporting people with intellectual disability who challenge or who were ageing. A rapid review of evidence', University of Ulster.

Most of the TTR programs we know of include some sort of strategy to work with mainstream services to engage, educate and encourage community groups to include people with a disability in their activities, and these encompass a combination of partnerships, education, training and community development⁷³. These are discussed in sections 6.3 to 6.5 below.

6.3 Community or interagency partnerships

One strategy for engaging mainstream community services is to establish partnerships with community organisations. We are aware of three disability services that have established partnerships with mainstream services as part of a TTR program. These differ in the kinds of partners involved, from community groups to local government; and the nature of the partnership, from coordination of activities to collaboration on the design and delivery of a program. Although we have only limited evidence about the success of the partnership approach, the evidence available suggests that this approach can be effective as part of other community engagement strategies.

Koomarri developed their community partnership program with local community services/ groups, choosing partners that might offer activities or services of interest to older people—local TAFE college, community church, fitness centre, arts group. Older people with disabilities continue to access activities run by these community partners, for example, the Koomarri retirees we spoke to were involved in cooking classes run by the church group, exercise classes at the fitness centre and doing computer courses through the local TAFE College.

Minda Retirement Lifestyles Services program was developed in partnership with ACROD (SA), Disability SA, ACH Group and the City of Holdfast Bay. The partners were involved in steering the pilot program design and some remain involved in delivering the program. Retired ADE employees are able to access mainstream community or day care activities through this program.

In the pilot, one ADE participated in an existing interagency partnership initiative funded by the Victorian Department of Human Services, the *Options for Older Adults* pilot project. The project is using case studies of individuals who are ageing with disability, and mapping pathways to retirement and developing a tools and resource kit for people who wish to consider ‘whatever is next’ for them as they age. The pilot coordinator established relationships with this group and, as a result, the ADE is planning to be actively involved in the interagency initiative. Older adults at the ADE are learning to become trainers to deliver training with the support of the *Options for Older Adults* project manager and ADE managers.

⁷³ Note: we have limited information about the details of many of these programs.

6.4 Disability awareness training for community organisations

We know of two Australian examples of disability awareness training for community organisations aimed specifically at fostering the participation of older people with disabilities retiring from the workforce in community activities, including the pilot community education workshops. It is possible there are more examples. The training encompasses awareness raising about social inclusion issues and providing specific skills for individuals to accommodate and assist people with disabilities to participate in activities. These examples suggest that no one approach will suit all occasions, and that both community awareness raising and specific training for staff to support participation have a place in fostering social inclusion of older people.

6.4.1 Active support training for volunteer community mentors

The first example, the AFFORD/ University of Sydney/ La Trobe University TTR project, focuses on creating access for individuals to community groups through linkage activities and by co-opting members of these community groups to act as mentors and provide support⁷⁴. Employees transitioning to retirement are matched with a volunteer mentor who is already a member of a community group. The community mentors are conceptualised as ‘co-workers’ and offered training in active support. The project is yet to publish a formal evaluation, but DVDs showing snippets from volunteer mentors show that the training has assisted the community mentors who appear in the DVDs to support the TTR participants in their chosen activities.

The pilot suggests that even without formal training, members of community groups are willing to act as mentors. In at least two groups involved in the pilot, members took on mentoring roles, assisting and looking after the employees. A men’s group arranged for an ‘able-bodied’ person to work alongside each employee. Members of this group explain the activities to the employees and then ‘gently introduced them to what we do’; they commented that for some of the

Box 6.1: Types of disability awareness training for community groups, offered by TTR programs

Active support training aims to increase staff time spent directly supporting participation by people with disability, increase the range of available options and increase the support skills of staff (Wilson et al, 2010).

Social Role Valorization (SRV) is the analysis of human relationships and human services. Koomarri utilises SRV theory to assist people with disability to participate and contribute to community life. SRV is a social theory, which, when properly applied, provides a valuable framework for supporting vulnerable and devalued people within society.

Advanced Instructional Methods uses the proven clinical theories of positive psychology to assist clients with real life skills acquisition and behavioural intervention programmes. Based on collaboration with the individual, their family, natural networks and service providers, realistic and achievable programmes are developed for the person to allow them to achieve new skills and in turn access greater opportunities for a fulfilling life. (Source: Koomarri Annual Report 2010–11)

74 Wilson N.J., Stancliffe R.J., Bigby C., Balandin S. and Craig D., 2010, ‘The potential for active mentoring to support the transition into retirement for older adults with a lifelong disability’, *Journal of Intellectual and Developmental Disability*, 35 (3):211-14.

employees, the activities were easier when they did the activity with a volunteer they knew. The volunteer coordinator of another group observed that the volunteers 'look out' for the employees and have been very supportive.

'Our gardening man helps the employee who volunteers in the garden—we've given him an area to be in charge of. Another of the participants wants to be a specific role [sic] so another volunteer opens the supply cupboard for him. Although I [the volunteer coordinator] did the role of settling the participants in, the other volunteers have stepped up [to support the participants] without being asked'. (Community organisation)

6.4.2 Delivery of community education in the TTR pilot

The second example, the Koomarri project, facilitated five workshops; 17 people from 4 organisations attended, including managers, workers, volunteers and students (table 6.2). The workshops were designed to meet the diverse needs of the community organisations and their staff.

It appears that the community education workshops (and the partnership program) attracted community organisations in which the management already had some awareness of disability inclusion issues. Most of the seven organisations who attended the workshops and who we interviewed had programs or policies in place about inclusion of people with a disability or sympathy for the social inclusion agenda, before becoming involved in the TTR program and workshops.⁷⁵ The church group was familiar with accommodating older frail people with varying levels of ability. The community partners who attended the workshop are listed below.

- **mpowerdome:** a local indoor recreational centre and funded as a Sports CONNECT Hub, where staff received training in supporting programs for people with high needs. This centre has a program for people with disabilities and has been working towards inclusion since 1998. They have long-term programs to help people develop motor skills so they can participate in sport and activities in daily life.
- **NationsHeart Christian Community:** a community church group which provides community services, including a cooking class. NationsHeart also offers a Food Hut service, a program called *Rough Diamonds* for elderly people with disabilities, and a disability inclusion policy.
- **Canberra Institute of Technology (CIT):** specifically the faculty that trains personal trainers. The CIT had access and disability policies in place.

⁷⁵ Findings based on feedback from seven participants, who attended one of the four workshops; either by responding to the survey or being interviewed. Workshop participants appear to be satisfied with the format and facilitation of both types of workshops. All seven participants who gave us feedback agreed the workshop they attended met their information needs and was well facilitated.

- ArtsAbility: part of ACT Community Arts Office, with specialist officers tasked to promote participation in the arts for disadvantaged people and people with special needs.

Koomarri offered education based on the Social Role Valorization (SRV) framework to help participants better understand the needs of people with disabilities and to provide them with ideas about how to include them and other marginalised groups in their activities. They also offered Advanced Instructional Methods training workshops (x 2) to train service staff in teaching people with intellectual disabilities to learn new skills. Advanced Instructional Methods training was offered at the request of the partner organisations to assist their staff to further develop their competencies. These workshops are owned by and were delivered by The Centre for Applied Behaviour Analysis.

Table 6.2: Attendance at the Koomarri community education workshops

SRV Workshop Aug 2010	4	mpowerdome, ArtsAbility, NationsHeart Christian Community
SRV Workshop Oct 2010	8	mpowerdome, ArtsAbility, Canberra Institute of Technology, NationsHeart Christian Community
SRV Workshop March 2010	1	Canberra Institute of Technology
Advanced Instructional Methods Workshop Oct 2010	1	NationsHeart Christian Community
Advanced Instructional Methods Workshop Feb 2011	3	Canberra Institute of Technology and mpowerdome
Total	17	

6.4.3 Impact of the pilot community education workshops

The evidence suggests that the Koomarri community education workshops provided conceptual and instrumental learnings for participants. Even though the workshop participants had varying levels of prior understanding and awareness about social inclusion and disability, the participants indicated the workshops had added to their knowledge about disability and the challenges that older people with disabilities face (table 6.3). All four respondents to the survey agreed they were more confident about their ability to support people with disabilities and had applied the principles learnt in the way they relate to them; as did the three people we interviewed. But we do not have any data from the other ten participants, many of whom were volunteers or students, and difficult to follow-up, and we do not know if they would have different views.

Table 6.3: Koomarri education workshop participants' feedback (n=4)

The workshop gave me ideas about how my organisation could better support people with disabilities to take part in our activities	0	4	0	0	4
I was able to get my questions answered	0	4	0	0	4
I am more confident about my ability to support people with disabilities to be involved in my organisation	1	3	0	0	4
The workshop gave me a greater understanding of the challenges people with disabilities face in taking part in social activities	0	3	1	0	4
I have applied what was taught about equal and ethical partnering in the way I relate to people with disabilities	1	3	0	0	4
My organisation has changed the way it operates to make it easier for people with disabilities to take part in activities	0	3	1	0	4
I would recommend the workshop to other community agencies or groups	0	4	0	0	0

Two managers we talked to already had some knowledge of how to include people with disabilities, and had applied these in their work for many years.

'We have been working with people with disabilities for many years. It is part of what we do'. (Community service manager)

For these participants, the workshop added to their conceptual knowledge and affirmed what they were already doing or aiming to do within the organisation. These organisations asked for and were offered specific training for their staff about supporting people with disabilities.

'It broadened my understanding of the complexity of the issue and recognition of how much change is needed for us to be a fully inclusive society'. (Community service manager)

'Affirmed where I wanted to go; this was the most valuable thing for me'. (Community service manager)

One of the interviewees was a community volunteer who worked with people marginalised from society and with low self-esteem. He said that he understood very little about the issues prior to the workshop and indicated that the SRV workshop has helped him *'hugely'* to know how to deal with people with self-esteem issues. He can now *'relate to people a lot better than I used to'*. He also works with volunteers with disabilities and said the workshop has helped him include them in the community work of the organisation.

'People tell me they feel appreciated and there is a caring attitude here that you don't always find. If people feel that people care about them they feel valued. I was a little judgemental and that has changed because of the workshop'. (Community service volunteer)

All organisations continue to include older people with disabilities in their activities. One unexpected impact was reported: mpowerdome changed one of their programs after the workshop, causing two existing clients to leave saying the program no longer met their needs. This shows the need for disability awareness education in the broader community so that other service users understand the reason for changes made to accommodate people with disabilities.

6.5 Using a community development approach

Community development means to develop the capacity of a targeted group through establishing close relationships and working together.

Stakeholders at the TTR June 2011 forum emphasised the value of highly skilled community development work done in advance to engage community groups, as used by one ADE in the TTR pilot. Such an approach means that groups that appeal to older people can be targeted and key members educated about how to accommodate people with disabilities. A community development approach recognises that changing attitudes and practices is challenging and takes time, and that relationships at the community group level matter. Stakeholders at the TTR June 2011 forum argued that without sufficient preparation a community service is less likely to be receptive or able to easily include an older person with a disability. The experiences of the pilot corroborate this statement.

Participants at the TTR June 2011 forum also identified a need for broader community education about disability and inclusion. In public health practice, community development approaches are often part of a multi-strategy approach and are complemented by broader promotional campaigns that reinforce the messages being given on the ground.

6.5.1 Lessons from the pilot

The pilot provides further evidence that a community development approach can be an effective way to engage community services and facilitate access to community options for older workers with disabilities, though it is resource intensive and necessarily takes time. Further, by working closely with community organisations, a coordinator or linkage person can successfully increase these organisations' capacity. But more evidence would be needed to confirm this finding, because three organisations (a tourist site run by the local council, a community house and a Men's Shed) engaged in the pilot were either familiar with disability issues and/or had existing disability inclusion policies, and it is likely less effort would be needed to engage sympathetic and knowledgeable community services.

Although the pilot linkage coordinator positions were expected to identify options and liaise with and negotiate access to community services, the original framework for the pilot did not identify community development as an approach to be tested. Even so, one ADE pilot site adopted this approach when it became apparent that they needed to build on and/or establish relationships with community services to gain entry for their employees. This pilot ADE was very successful in engaging community organisations, compared with the other site that did not use a community development approach. The ADE used a highly active approach, including personal visits, persuasion and education and networking.

As a result, most community services accommodated the employees in their activities (at one site) and we found a lot of goodwill towards the pilot staff and employees when we interviewed providers. Key staff said they had developed strong relationships with the ADE linkage coordinators over time and commented on the value of their work. They also indicated that their awareness and understanding of disability access issues and the difficulties faced by older workers with disabilities had improved, as had how they might support individuals to participate in their groups. The organisations also recognised that with varying levels of support the employees were able to participate in activities.

Adapting to the employee's needs

The following examples illustrate how organisations' capacity and capabilities improved over the course of the pilot and with the advice of the linkage coordinator position.

- Staff members in one community service (tourist site) were hesitant about including the employees. The volunteer spokesperson reassured them that the employees would be fine. This proved to be the case and existing volunteers' confidence improved after the employees joined activities and they were given guidance by the ADE coach about how to assist the employees and what roles were suitable. Some examples are below.

'An employee needed more support than we were used to providing, so [the linkage coordinator] suggested that we get the person to repeat the task a few times and he'd then be fine to do it by himself— this has worked out.'

'We adapted one participant's role to suit her—she was nervous about being dressed as a nurse as she was not sure she could answer people's questions, so we said she could be a housekeeper and she could sit and knit if she wanted. She was also nervous about what to talk to people about, we spent time giving her information re what to talk about and told her she could also just talk to people about their holidays and show them where appropriate resources about [the tourist site] could be found. We also wanted to locate her in a central area in the organisation so she's easily accessible if she has any problems.'

'We had to provide more support than we generally would with a volunteer, particularly with literacy. Knowing the literacy issues and nervousness of the employees I spent more

time explaining things to them and had our first meeting in person rather than over the phone as usual.'

The value of a community development approach is also demonstrated by the experience at the pilot site that did not use this approach. No mainstream community groups had accepted employees into their group by the time the evaluation ended. The pilot staff at this site had made initial enquiries to the few suitable community groups available in the local (rural) area (including a church group, a craft group, a seniors club), but had not been successful in negotiating ways the groups might be able to include the employees. The barriers—a lack of confidence and skills in supporting people with disabilities and lack of community service options—are discussed in section 6.2 above. As a consequence, the ADE used social outings as the main strategy for fostering community participation.

Given the original six-month timeframe of the pilot, FaHCSIA encouraged the pilot ADEs to employ a person from outside the organisation who had existing links and relationships in the community. The lack of success in one of the pilot sites in making links with community organisations leads us to speculate that it may have been desirable to employ the linkage coordinator from outside the organisation; the reason being this would give the ADE a head-start in developing key relationships in the community and identifying retirement options. The other site was able to develop their internal capacity in community development but did face an initial steep learning curve in identifying suitable options, and overcame this in part by leveraging existing relationships the disability service had in the community (see chapter 4).

Both ADEs chose to fill the linkage coordinator positions from within their organisations because they felt that it was important the linkage person be known to the employees and familiar with their personal situations and have relationships of trust. The ADEs reasoned that working with familiar people would make it easier for the employees to engage in the pilot and with the concept of retirement. And this proved the case in one pilot site, where those relationships were vital in assuring the employees and ensuring the educating and planning components of the pilot were successfully implemented (chapter 5).

6.6 Linking individuals into mainstream activities—case management and person-centred support

TTR approaches in Australia commonly (including the TTR pilot) have dedicated linkage coordinator positions to identify and liaise with suitable community services and family members/ support workers, and possibly also to support employees to take part in community activities (at least initially). The idea being that the support can be gradually withdrawn as the person gets familiar with and comfortable in, the group/ doing the activities and as the community service develops skills to support the person. In the AFFORD TTR project the linkage or coordination role is taken on by the disability service but the support role at the

community service is done by community volunteer mentors. The ACROD/ Minda Planning for Retirement project recommended that *Recreation Link-Up* (a South Australian service that links people with a disability to recreational activities of their choice) or similar service establish formal relationships with ADEs. It is likely no one approach will suit everyone or every context and different approaches for different individuals and situations may be required.

6.6.1 How coordination and individual support was delivered in the pilot

The ADEs coordinated and provided support for the employees—organising opportunities to participate, providing transport and then supporting the person or persons in community activities or in social (unstructured) activities. But this role was implemented with different levels of intensity at the two sites, reflecting the different level of resources applied and the differing approach used to link the employees with activities (table 6.4), with different results for employees (see chapter 3 and 6.6.2 below).

- Site 1 (estimated 112 hours per employee or 38% of total ADE staff hours spent delivering the pilot): Framed as a retirement program, which gave participants the opportunity to try out their preferred activities in a group or individually on a designated day off but they could also attend activities at other times. Employees could choose what they wanted to attend. Group activities were designed to strengthen friendships among participants. ADE linkage coordinators provided guidance and moral support for individuals to participate in community group activities and provided transport to and from the activities. Support was gradually withdrawn over time, where possible. Off-site meeting venues were established, where the employees could meet one day per week. This approach was intended to engender change in attitudes and thinking and open up opportunities for learning new skills and forming friendships.
- Site 2 (estimated 47 hours per employee or 86% of total ADE staff hours spent delivering the pilot): Framed as doing something other than working. Individuals were paired for the whole pilot and had a set three hours (one afternoon) off a week to try out community options, mostly social outings. Employees were to decide between themselves (with ADE staff input) what to try, but there was no systematic approach used. Support levels remained consistent for the whole pilot, reflecting the high support needs of the employees. The ADE provided transport and assistance with fees. Due to changes in staffing arrangements, the linkage coordination role was shared by support workers from Training Education Services and in-home support workers.

Figure 6.1: % total staff hours spent on coordination retirement activities compared with other pilot activities (site 1)⁷⁶

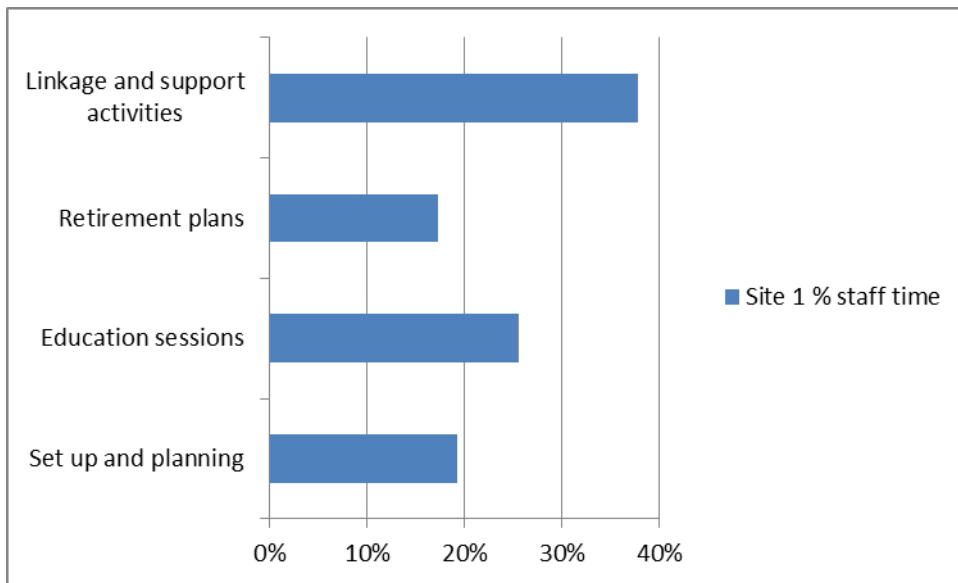


Table 6.4: Approaches to providing coordination and support in the TTR pilot

ADE	How time structured	Linkage position	Community meeting place	Payment of wages when trying out community activities	Support to attend activities	Out of business hours support to participate in activities
Site 1	Set day off a week + can attend activities on other days of the week.	2 part-time positions; linkage coordinators. Internal appointment.	Yes, one in each business location.	Yes.	Yes, transport, moral support, assistance, mentoring.	No.
Site 2	Two employees paired for 3 hours a week.	1 part-time position. Internal appointment.	No.	Yes.	Yes, transport, moral support, assistance.	No.

Where the employees had the option to take part in community groups, the level and type of support provided varied according to their individual abilities. But support always included the organisation of entry to the group (in the first place) and transport to and from groups. The amount of assistance provided to participate in group activities varied for each person and changed over time as

⁷⁶ Data for site 2 not reliable as large amount of missing data, so no equivalent graph provided.

either the community group took on a greater role in providing assistance or as the person became more familiar and able to participate. The linkage coordinators did not fully withdraw support where this needed to be maintained. This assistance is a very important part of giving the person and the community group confidence that the person with a disability can be accommodated.

'We wouldn't want to take on a large number of people with disabilities and not be able to give them adequate support so they feel emotionally or mentally confident in their volunteer role'. (Community service)

6.6.2 Employees' experiences of trying out community options

Experiencing new activities as a way of learning is very important for people with intellectual disabilities and is an important part of a TTR program.⁷⁷

The opportunity to be involved in community activities was the most valued aspect of the pilot by the employees and their families. This aspect is what employees talked about most in interviews and what they gained benefits from (personal satisfaction, social connectedness, and improved wellbeing, as discussed in chapter 3). These benefits are the same as other Australians get when they enjoy an active retirement. Some employees also identified activities they might like to continue on with when they retire.

All employees expressed their enjoyment in having an opportunity to take part in mainstream community activities and take time off work to enjoy social outings and try new things. Some described being supported by the linkage coordinator and the great help this had been for them. The employees, particularly those based in the larger population centre, tried out a broad range of activities from social outings to volunteering, skills training and participating in recreational activities. In the two smaller towns, where there were fewer community groups suitable for older people, the activities were more often, but not limited to, social outings.

The employees were most satisfied when they were able to pursue their own interests (a finding corroborated by family members and other support persons). Employees also enjoyed doing some activities as a group, for example, one group of employees met regularly for coffee and also played indoor bowls. The coffee meeting has morphed into a regular weekly event and now occurs without the regular attendance of ADE staff.

Conversely, where employees felt they had less choice (as occurred for the paired employees) they expressed frustration and disappointment with this situation to our interviewer. The pairing of the individuals meant that compromises were made about what activities were done and these did not always suit the interests of both employees; and employees could think of other things they would have

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liked to do. In addition, employees in one of the pairings had different interests and were not close. Their family members also said they would have liked the employees to have tried a broader range of activities, and made suggestions about what these might be, for example, craft or cooking classes. It is unclear if such opportunities were available.

Table 6.5: Examples of community activities that employees sampled

Type of activity	Examples	
Skills training	Computer course Learn to read and write	Transport training
Recreational	Craft, painting Ten pin bowling Croquet Swimming Bike riding	Library Billiards Bingo Gym classes Indoor bowls
Social outings	Meeting for coffee, eating out Local wild life sanctuary Visits to farm, beach/ park	Art galleries Movies Bus tours
Community groups	Men's Shed Senior Citizens group	Neighbourhood Centre Local church functions
Volunteering	Volunteer local tourism attraction	Animal shelter Gardening

Box 6.2: 'Mary's' experience of community options

Since the pilot began Mary has become involved in many different activities. Mary has enjoyed going to coffee on Mondays, '[the linkage coordinator] doesn't come with us, he is trying to get us to be independent and go on our own and we all get together and talk about what we did on the weekend and we might see where we are going to meet'. Mary has gone to the library, played croquet, gone ten pin bowling, been part of a walking group, and been swimming. She has gone on bus trips; had lunch at the church, and volunteered at the animal shelter. Mary does some of these activities with others involved in the pilot, and sometimes there are people from other supported accommodation places there too. Mary would like to try indoor bowls. Mary's support person said Mary has been telling her about the activities she's doing, 'every time I've talked to her she tells me what she's been doing and she's very happy and upbeat about it'. Mary's support person said the pilot staff have 'helped her come out of herself a bit, get her involved doing thing she would normally always be too shy to do on her own, and they've sort of been behind her and just helped her into doing the croquet or the animal walking...and they seemed to have been beside her all the way and helped her, as I say, because she is very shy and wouldn't do it on her own.'

Mary looks forward to 'getting up and doing things, different, meeting people...just getting out and doing something different that would give you a good feeling you know. You're not at work all the time and, you know, just you don't get so tired you know'.

Mary indicated that just getting out and mixing with people and having a good time was the best part of the pilot; the only thing she would like to change about the pilot is for the "meeting place" to be open longer on the Tuesdays. She said that since the pilot she is happier. Mary's support person also said that since Mary has been involved with the pilot she has been noticeably happier, 'it's been marvellous that she's been a happier person because she's been a lot more social...I haven't been as worrying about her because she rings me up and...she's "tomorrow's the day off and we do this and we do that", and I think it's just had such a positive effect on both of us actually'.

Box 6.3: 'Tom's' experience of the community options

Tom has done lots of activities as part of the pilot. He's tried ten pin bowling and croquet, gone to the library and art programs and to different cafes, and 'talking to strangers, saying my name and then talking to them, yes'. Tom likes talking to people, 'Since I've been going I've been talking to other people...It's good to get around and talk to different people'. Tom likes doing the different activities, '...it's good, it gets you out of the house and you can go around the streets talk to people and [the linkage coordinator] got you going everywhere. Yes, it's good. It's been good since they've done that'. Tom participates in the activities with other people in the pilot. Tom would like to do more activities, maybe golf.

Tom's support person described the pilot's benefits to him as, 'this has given him, you know, a whole new world of activities and he's been to places he wouldn't have had the opportunity to go to before. So he's got this newfound confidence, I suppose...the opportunities to do things that probably wouldn't have been available to him otherwise.' And 'he's just been out and about more than he's probably ever been before, and without his [support person].' And 'It's good that he's doing things on his own and making decisions on his own, which again he probably hasn't had a great deal of opportunity to do in the past. A lot of decisions would have been made for him, I assume, so it's good. He's just blossomed...'

Box 6.4: 'Valerie's' experience of the pilot

Valerie has been to the library, to a wildlife sanctuary, and visited op shops—she enjoyed looking at the clothes and books there. Valerie enjoys the activities as it is time away from work, and she likes the fresh air.

Valerie said that the pilot participant who she does most of the pilot activities with often wants to do different things to what she wants to do. Valerie suggested that the two of them could take it in turns to choose activities that they would like to do. She said, though, that she would prefer to do the pilot activities with another person.

Valerie's support person was asked by the pilot coordinator if there were activities she thought Valerie might like to do as part of the pilot, and she suggested some activities; she also said that Valerie was asked what sorts of activities she would like to do. The support person said that some of the activities Valerie suggested occurred and some didn't. The support person commented that there was one activity that she was not happy that the participants were doing, 'it wasn't what I called getting ready for retirement' and so she asked if they could change the activity and this happened.

Valerie's support person commented that Valerie's health issues would probably preclude her from attending activities independently in the community because she always needs someone to help her.

The community organisations, ADE staff and family members confirmed that being able to experience activities increased the ability and confidence of employees to become involved. Community organisations where the employees had tried out their options talked about how much easier it is for the employees now to participate, as did family members.

'I see one of the participants around town and he always says hello...One of them is self-sufficient in the task he does here now'. (Community organisation)

'The guys pick up tasks quickly, they are tending to be self-managed nowadays'. (Community organisation)

'I do notice changes in them – they are freer in their talk, they didn't say much at the beginning but once they got to know me they talked more'. (Community organisation)

'Well, one would hope that he would keep up quite a few of these activities. I can't say that he would probably keep up all of them, but it would be nice for him to keep up... some of it probably would not continue because of the difficulty in getting him there and getting him

home, that sort of thing. I think certainly this program has made him a little bit more independent, because quite often—like I said, he looks to, you know, someone for reassurance - and so I think it's been good for him that it's made him a bit more independent'. (Family member)

6.6.3 Lessons about what works: intensive person-centred support (case management) and coordination

At the TRR June 2011 forum, it was suggested that a person-centred, intensive case management approach is needed to help employees successfully transition to retirement, because of the complexity of the service system.

The pilot confirms that a key person is needed to take on a coordination role between the individual with a disability, their family and community services to enable a successful transition to retirement. The role may also involve being there to introduce and support the person when trying out activities, but this is not always the case⁷⁸. Case management may also help the person address financial and accommodation issues and navigate the health and disability service systems. The evidence from the pilot confirms that intensive personal support (case management) can successfully assist employees to prepare for retirement and that it is critical the support be person-centred and facilitate the employee's interests and wishes.

In the pilot, a person-centred approach meant employees had the chance to make their own choices about how they spent their time and pursued their own interests and got help (when required) to deal with other issues, such as financial and living arrangements (discussed in chapter 3). The ADEs kept the interests of the employees at the forefront. Consistent and intensive support over almost 12 months by one ADE also provided some employees with the opportunity and enough time to begin to develop greater autonomy and confidence to take part in mainstream community activities and choose how they spend their time. For example, the ADE provided transport training so employees can use community or public transport, and these employees are travelling independently. Some employees have identified activities in the community they intend to continue to take part in and have a better idea of what they can do when they finish work. For example, one employee intends to do some of the community activities she has tried through the pilot, maybe get a voluntary job, and go to activities at the community centre. Another nominated a raft of options—walking, computers, volunteering, ten pin bowling, spending time with friends and having a holiday.

'No, you got to get out, you got to get out and about and talk and get some exercise and that, you can't stay home all day, you'd be bored'. (Employee)

⁷⁸ TRR June 2011 forum

'Well, I can just go out and have not just cups of tea and food, just go and talk to everybody and maybe even go to the pictures with them or go and see them and they can come and see me and things like that. Maybe even go away on a weekend holiday or things'. (Employee)

Where employees had less choice in their activities, family members felt it unlikely they would find activities to enjoy in their retirement or develop a degree of autonomy. Some of these employees, though, had high needs and would find it very difficult to independently continue any of the activities without one-to-one support.

Almost all employees will continue to need assistance with things such as transport, finance, health and diet. So a case management approach during the transition to retirement cannot solve all issues regarding retirement. The NDIS model may be a solution to this issue in the long-term, especially as it will mean lifelong planning for individuals and, as such, early planning for retirement.

Apart from the value of case management, and intensive one-to-one support, the ADEs identified lessons from the pilot about how to provide support and coordinate activities. Most of these align with the key success factors identified by the TTR Forum, apart from the need to fund transport and the risks in withdrawing support too early. These lessons include the following.

- Older people with intellectual disabilities need to experience what life could be like in retirement to understand their opportunities and feel comfortable to continue these.
- Fund a linkage position—as the role could not be done adequately as part of a supervisor role. The responsibility for coordinating and linking a person to community services and activities could be done outside of an ADE by an independent person or disability service. If no funding was available, having these positions would add costs for the business.
- Support should be person-centred and allow employees to pursue their own interests and address knowledge and skills deficits—without this the program is unlikely to succeed in adequately preparing the person for retirement. Transition to retirement should be gradual to allow time to understand and adjust to change.
- Don't withdraw support too early. There is no ideal set time for withdrawing—it depends on the individual and the community group. This has implications for ADEs' business sustainability.
- Provide support to employees at the community level to participate, to allow them to develop confidence and become familiar with activities and for other members of the group to accommodate them.
- Provide a mix of group and individual experiences as this helps facilitate friendships but also allows for individual choice and enables the person to

develop links with community members (also identified as good practice in the SPRC paper).

- Recognise that funding will be needed for transport and fees; again a business cost not currently catered for by ADEs.

6.7 Conclusion

The Australian Government is committed to making changes to our systems, practices and community attitudes to ensure that people with disabilities can participate in the same activities as other Australians.

For the community service system to be able to accommodate older workers with disabilities, two measures are needed. The first is that community services accept older people with disabilities and also understand what is needed to enable them to participate. The second is that the older person with a disability be linked with their preferred activities and supported to participate.

The experience of the pilot confirms the diverse awareness within community services of disability and of the challenges faced by individuals with disabilities to participate in mainstream activities. Even so, community groups were generally welcoming of the ADE employees. We saw instances where an organisation had experience and skills to include people with disabilities and employees fitted easily into these groups. We also saw instances where the coordinator or members had no experience and little understanding, which meant that an opportunity to participate was closed. But the pilot showed examples where attitudes were changed and opportunities were opened up through encouragement and education from the ADE, and the organisation of opportunities for members to meet and socialise with people with disabilities.

Numerous studies recommend that mainstream groups be educated about disability, and the situation of the pilot was no different. But it was clear from the pilot that appropriate approaches will depend on existing levels of understanding and the focus of the education—be it disability awareness raising, behaviour change or skills development. It is anticipated that broad community education to raise awareness about disability and social inclusion may be needed. In two groups, a couple of group members left because they were uncomfortable about sharing activities with a person with a disability, a situation which might be avoided if the community was more aware of the challenges faced by people with disabilities and more used to seeing older people with disabilities.

To change attitudes and raise awareness within community services, evidence from the pilot suggests that both community education and community development can be effective. Community awareness workshops are likely to be an appropriate approach once relationships are formed. Experience from other community education fields tells us that getting people to attend workshops can be

difficult. In the pilot, all the organisations attending had existing relationships with Koomarri.

Community development, as used in the pilot, was very effective in engaging and preparing community services to take on the employees and in increasing the capacity of organisations to assist employees. Over time, one pilot ADE formed close relationships with a number of organisations and passed on advice about how to assist people—they saw the advice implemented and a growth in members of the community services' capabilities to assist the pilot participants.

Person-centred case management has previously been identified as an effective way of helping an employee successfully transition to retirement. The evidence from the pilot provides further evidence that such an approach works well, as employees got to pursue individual interests and address their concerns about money, using public transport and where they are living. Case management in this context includes making the link between the employee, community services and the employee's family, and supporting the person at the group, at least initially. Consistent and intensive support over almost 12 months provided employees from one site with enough time and opportunity to begin to develop the greater autonomy and confidence needed to take part in mainstream community activities, and to choose how they spend their time. With the pilot, the support was gradually withdrawn, but some employees will continue to need some level of ongoing support to access community services and to participate.

For a case management approach to be taken up by the sector it would need to be funded. As discussed in chapter 4, this is not currently funded or a designated role of any one organisation. Any wider roll-out of TTR programs should include person-centred case management and community education.

Having a chance to try out an activity is a very important way of learning for people with intellectual disabilities and was highly valued by the pilot participants. It was what employees talked about in their interviews, and where they gained the most social and emotional benefits. It was not uncommon for a family member to describe the person as having 'blossomed'.

Appendix 1: Program logics for the pilot

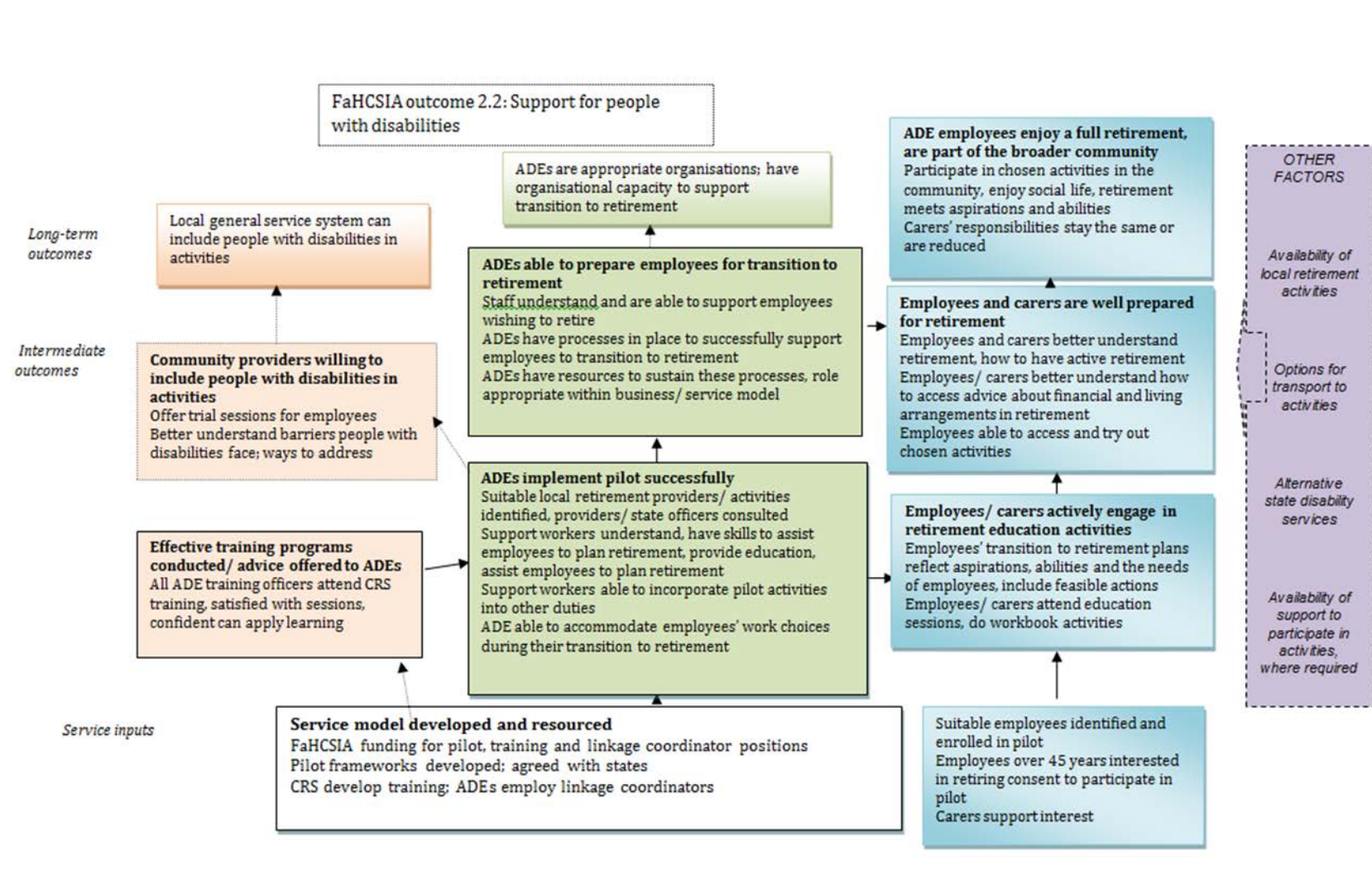
The program logic represents the pilot outcomes and the underlying causal links between them. In practice, the pilot is testing whether the transition to retirement service can help ADE employees successfully prepare for retirement; if the service can be effectively delivered with the current community service system; and whether ADEs have the organisational capacity and skills to deliver such a service.

Through the pilot, CRS Australia trained key ADE staff to, in turn, provide education and advice to their support staff, enabling them to assist employees wishing to retire. Help was available to develop individual retirement plans that reflect employees' wishes and needs, and employees were provided with education about what retirement means. The ADEs were also provided with resources to identify community-based activities suitable for employees when they retire (e.g. community linkage coordinator).

The intervention with service providers in NSW and Victoria focused on consultation between the linkage coordinator and providers to identify possible/suitable activities. It also looked at the experiences of those that offer the employees the opportunity to trial activities. In the ACT, the Gateway to Retirement—Community Education workshop (ACT) targets community providers to address misconceptions about people with disabilities and improve their understanding about ways to include them. The evaluation will compare the impact of the ACT approach with the less direct intervention in NSW and Victoria.

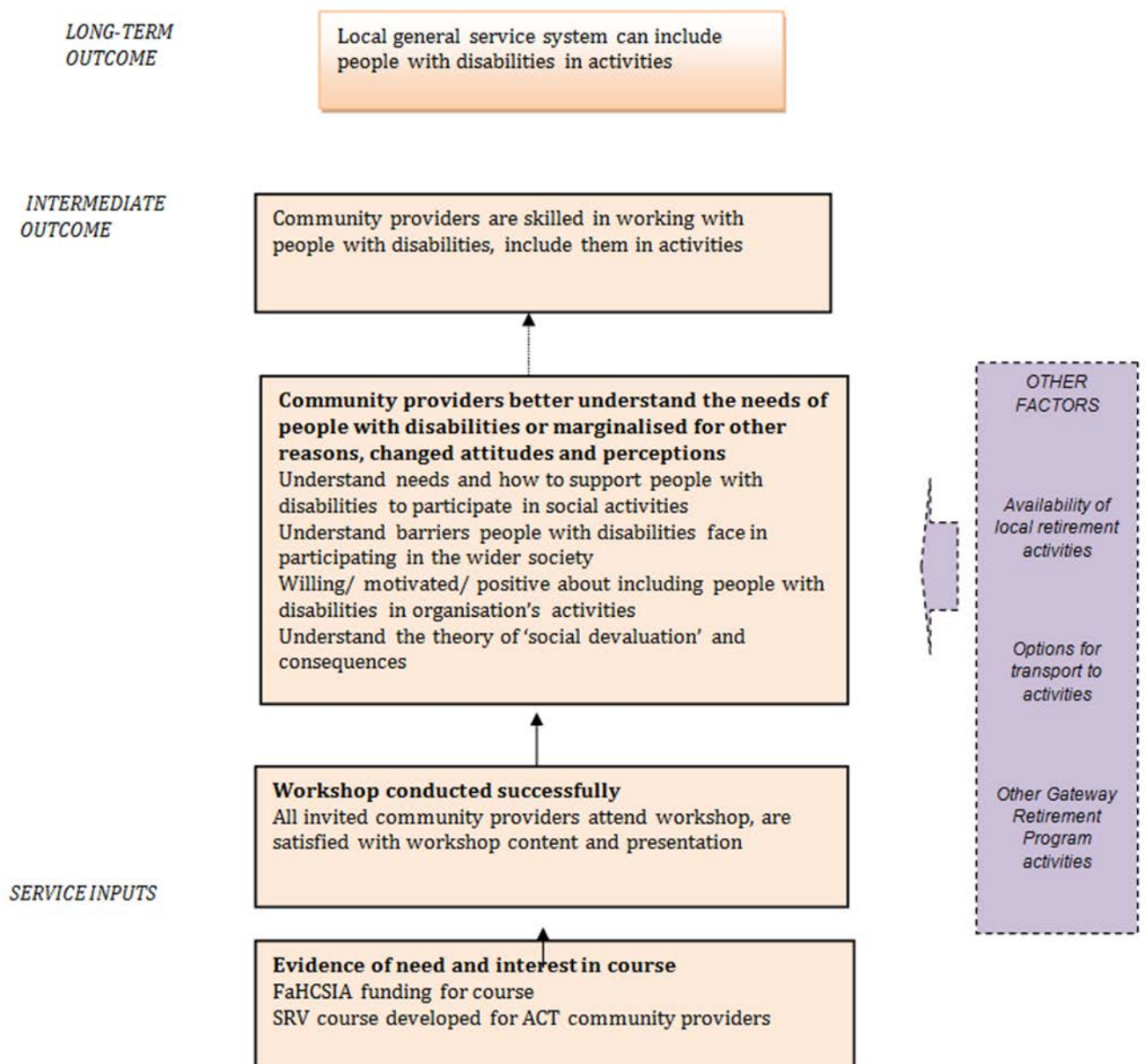
Significant external factors can influence access to retirement activities and services, including availability of: transport; support to participate in activities; specialist disabilities services and policies to access these; financial means and accommodation.

Figure A1.1: Program logic for ADE Transition to Retirement pilot - NSW and Victoria



The Gateway Retirement Program - Community Education workshop is an education course that relies on changes in understanding to influence attitudes and teaching skills and therefore effect behaviour change among service providers. Although the course is part of Koomarri’s broader retirement program, this is outside the scope of the evaluation.

Figure A1.2: Program logic for the Gateway Retirement Program - Community Education workshop



Appendix 2: Summary of methodology

Table A2.1: Summary of method

Data collection method	Sample size	Timing	Comment
Interviews with ADE staff	8	Interviews conducted over the life of the pilot and at the end	
Interviews with community groups/ organisations in Victoria and NSW	7	October 11	Mix of face-to-face and telephone
Interviews with employees participating in the pilot: NSW and Victorian pilot sites	12	July 11 October 11	Face-to-face. 11/12 interviews - support person present at interview
Interviews with support persons: NSW and Victorian pilot sites	12	July 11 October 11	Face-to-face
Interviews with retirees' support workers: Koomarri	4	July 11	Face-to-face and small number by telephone
Interviews with support person/ support workers: Koomarri	3	July 11	Face-to-face
Group interviews with state officers	8	March 11 August 11	3 interviews
Meeting with key policy officers in FaHSCIA and DoHA to discuss broad system and policy issues	2 meetings	August 11 October 11	
Review of relevant key policy documents—disability and ageing sectors			
Survey of community members attending Koomarri workshops	4	March 11	Response rate=4/9 returned. No email or mail addresses available for 12 people
Interviews with Koomarri workshop participants	3	April 11	Few direct contact details available and difficult to contact students and volunteer church members via organisations
Analysis of ADE monitoring of resources (staff time and costs) data			
Review of Vantage progress reports			

Appendix 3: Other transition to retirement models

Koomarri Gateway Retirement Program

The Koomarri Gateway Retirement Program aims to assist people with disability to transition to retirement. It provides support for people with disability and the family by working to improve their independence and skills development. This is achieved by identifying ways in which the person with disability can pursue their personal hobbies and interests, supporting them in maintaining and enhancing the friendship networks, and providing assistance to support independent living (where appropriate). The Gateway Retirement Program supports the person to be included in mainstream community activities, where possible, to sustain community participation.

Koomarri also provides support to transition to retirement through financial and legal planning sessions, where professional speakers give advice in the areas of wills, guardianship, power of attorney, trusts, statement of wishes and developing individualised living solutions.

Australian Foundation for Disability (AFFORD), The University of Sydney and La Trobe University Transition to Retirement (TTR) program

This pilot transition to retirement program was developed in partnership with the NSW Department of Ageing, Disability and Home Care and the Australian Research Council.

The AFFORD, The University of Sydney and La Trobe University project focuses on creating access for individuals to mainstream community groups through linkage activities and by recruiting members of these community groups to act as mentors and provide support⁷⁹. AFFORD offers the retiring worker opportunities that most older Australians have, which is to volunteer their services to assist others. Almost 50% of the participants are volunteering their time to support community organisations. The others in the program are pursuing their own personal interests.

Employees transitioning to retirement are matched with a local community group whose members share interests with the employee with a disability. Early indications are that the matching process is vital.⁸⁰ There is only one older worker with a disability in each community group.

⁷⁹ Wilson N.J., Stancliffe R.J., Bigby C., Balandin S. and Craig D., 2010, 'The potential for active mentoring to support the transition into retirement for older adults with a lifelong disability', *Journal of Intellectual and Developmental Disability*, 35 (3):211-14.

⁸⁰ Retiring from an Australian Disability Employment Forum 2011.

The mechanism is 'active mentoring' where mentors are provided training to develop skills and resources to support the retirees with a disability to participate in the community group's activities.⁸¹ The project is also applying the notion of active support, where a support person is trained to provide just enough support to allow the person with disability to participate in an activity.

People with disability are supported to access community activities and clubs, such as bowling or gardening groups, and to volunteer for the Salvation Army, St Vincent de Paul Society and local gardening nurseries. A transition to retirement coordinator works with each worker to identify community opportunities and to overcome barriers to participation in these activities. For example, one supported worker was anxious about meeting new people in his new volunteer placement, and travelling to and from his placement. This worker was provided with a mentor in his voluntary placement to help him feel settled, and his coordinator provided travel training so he felt comfortable travelling.

The program also works with community organisations to help them actively include people with a disability. Within this program, older workers first participate in program activities one day a week, which helps them to become accustomed to the program while still at work and to get used to the idea of not working full-time.

Minda Incorporated Planning for Retirement service model for transition to retirement and retirement Lifestyle Services

A pilot project, *Planning for Retirement*, funded by ACROD (South Australia) in 2005–06 in partnership with Minda Incorporated, ACH Group, the Intellectual Disability Services Council and the City of Holdfast, developed a model for service delivery for people with disability retiring from ADEs.

The model combines a six-step planning process with suggested service initiatives to actualise each step.

- **Step 1: Lifelong Planning for Retirement:** This includes financial planning, health maintenance and lifestyle planning elements. Suggested service initiatives include establishing a superannuation cooperative, worksite fitness programs and community linkages agencies.
- **Step 2: Retirement Recognition:** The pilot recommended a Better Practice Project to drive change in the sector, including establishing a one-stop-shop for employees and carers seeking advice and information on retirement planning, a retirement recognition checklist, and retirement workshops.

⁸¹ Wilson N.J., Stancliffe R.J., Bigby C., Balandin S. and Craig D., 2010, 'The potential for active mentoring to support the transition into retirement for older adults with a lifelong disability', *Journal of Intellectual and Developmental Disability*, 35 (3):211–14.

- **Step 3: Retirement Reason:** The *Planning for Retirement* project recommended a Retirement Reason Assessment be undertaken annually from age 50 when factors indicate that retirement is a viable option for the worker.
- **Step 4: Retirement Planning:** Planning to identify alternative service providers, links to alternative lifestyle options and support requirements for after retirement. The service initiative is state government-funded retirement lifestyle packages, which are individually planned and tailored to each retiree. These are now being offered by Minda Incorporated.
- **Step 5: Retirement Transition:** Different and flexible transition arrangements, taking an employee from work to retirement.
- **Step 6: Retirement Lifestyle:** This can be achieved where a support infrastructure exists to respond to changing support needs, for example, local partner groups.

This pilot program has now ended and Minda has adopted the model, incorporating retirement planning, transition and retirement lifestyle packages for employees into its normal operations. Minda provides centre-based, community and in-home post-retirement options for people with disability. This includes creating fishing groups and pub groups, and having reading and massage activities in the home. Employees are able to work part-time while they are part of Lifestyle Services as a way of easing people's transition to retirement.

Minda has recently received funding from the SA Government's Positive Ageing Development Grants Program to develop and implement two Retirement Assistance Ventures (short-term, close to retirement service interventions) that prepare and support older people with disability to successfully transition to retirement:

- **Venture 1: Retirement Coaching** - train and link volunteers (retirees not living with disability) in mentoring the target group with practical steps in adjusting to a non-work daily routine, and coach in navigating their way through service options.
- **Venture 2: Ageing Well Workshops** - short-term courses (Healthy Body, Diet and Nutrition for Positive Ageing) that support the target group to self-manage their health and wellbeing, with a learning environment incorporating their requirements (including Fitness Centre access).

Greenacres Retirement Options program (New South Wales)

The Greenacres Retirement Options program (GRO), based in Wollongong, provides a centre-based day program for older people with a disability who have retired from Greenacres Disability Services' supported employment. The program is funded by the NSW Government for 100 places a week.

The program provides a mix of structured and unstructured activities for retired workers, including recreational activities, activities that enhance social and living skills, community access, local cultural and community events and opportunities for volunteering. The program offers individual planning to maximise choice in the activities the older person can participate in as part of their program.

The program aims to support older workers post retirement and to give them an option for continued social and community participation post retirement. It also supports the carers and family of these workers by giving their worker somewhere to go post retirement and giving the carer a break.