



Quality of life after retirement from Australian Disability Enterprises

Never Stand Still

Art & Social Sciences

Social Policy Research Centre

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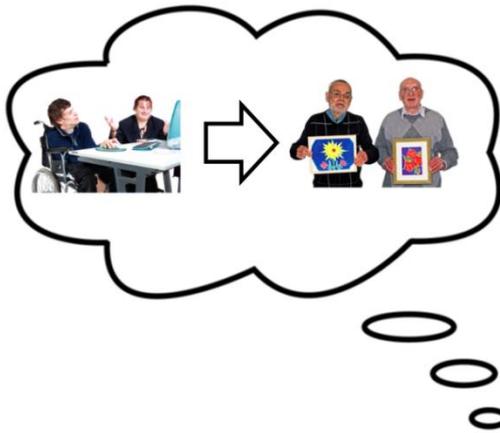
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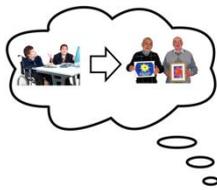
Glossary

ADE	Australian Disability Enterprise
ADHC	Ageing, Disability and Home Care
DSS	Department of Social Services
QoL	Quality of Life
NDIA	National Disability Insurance Agency
NDIS	National Disability Insurance Scheme
DSP	Disability Support Package
NSW	New South Wales
SPRC	Social Policy Research Centre
TTR	Transition to Retirement
TTRCM	Transition to Retirement Case Management
UNSW	University of New South Wales

What do people working in ADEs (Australian Disability Enterprises) think about retiring?



What is this report about?



ADEs (Australian Disability Enterprises) employ people with disability in supported employment.

The government helped people to get ready to retire from ADEs.

This report is about what people working in ADEs think about retiring. It includes some people who were getting ready to retire and some people who had already retired.



Retiring means stopping work because you are getting old or feeling sick or tired. When people retire they have more time to do what they want instead of working. They don't earn money anymore. Instead they use money they saved up or that the government gives them.

Who did the research?

The Department of Social Services asked for the research to be done. They are part of the government.



The Social Policy Research Centre did the research.

Who took part?

Lots of people took part in the research:



- 45 people with disability. Some people were getting ready to retire and some people had already retired.



- 3 family members – they were brothers and sisters of people with disability



- 5 service providers and people in government

How did they take part?

There were two ways people could take part:



- In an interview – this is talking with a researcher



- In a survey – this is answering questions on paper

What did the research find?

People got help to think about retiring.

They got help from:



- Family members



- ADE staff



- Support workers

People wanted more help to think about retiring.



Sometimes family members, ADE staff and support workers didn't know a lot about retiring.

This meant that some people wanted more help to think about retiring.

Many people thought it would be good to have help from a worker who knew a lot about retiring.

Most people felt like they had made their own choice to retire, but some people had retired for other reasons.

Some people said they retired because:



- They didn't like their boss or workmates



- They weren't doing well at work anymore and other people said it would be good for them to retire

A lot of people liked being retired.

People who found retiring good:



- Were more independent. They were able to do things on their own.



- Had lots of help from family and ADE staff



- Spent more time with family and friends



- Had other activities to do instead of working



- Had lots of different activities to choose from



- Had money to pay for activities

Some people found retiring difficult.

People who found retiring difficult:



- Had high support needs – they needed a lot of help because of their disability



- Didn't have enough money to pay for activities

People who had high support needs often had less money for activities because they had to pay more to get the extra help they needed



- Often lived in group homes.

Some family members also found things changed when a person with disability retired.



Often the family members were a brother and sister of a person with disability.



- Sometimes they found it difficult to help the person plan for retiring.



- Sometimes they also had to retire so they could support their family member with disability.

There were things people liked about retiring.

People liked:



- Doing new activities



- Meeting new people



- Having more choice about what they did during the week

There were things people didn't like about retiring.

People didn't like:



- Not having enough to do
- Not having enough different activities to do



- Not seeing their friends from work anymore



- Not having enough money to do the things they enjoy



- Having some friends and family members get old and die

What happens next?

This information can be used to help make retiring better for people with disability.



It shows that people with disability want:

- To retire in a way that suits them
- To do activities they are interested in
- To have enough activities to do
- To have information about activities
- To have money to pay for activities



It shows people with disability need:

- Help to get information
- More money to spend on activities
- More activities to do
- Different types of activities to do

This includes:

- People with high support needs
- People living in group homes



It shows family members, support workers and ADE staff need:

- Information about retiring
- Long-term support to help people with disability plan for retirement

This is an Easy Read copy of the following main report:

Jones, A., Katz, I., Giuntoli, G., Bates, S., & Johnson, K. (2016). *Quality of life after retirement from Australian Disability Enterprises (SPRC Report 17/16)*. Sydney: Social Policy Research Centre, UNSW Australia.

This Easy Read report was written by Ariella Meltzer, Shona Bates and Anna Jones.

Executive summary

Aims

The aim of the research was to examine the effectiveness of case management in supporting people with disability working in Australian Disability Enterprises (ADEs) to make retirement decisions. This included a specific focus on the outcomes for people who had received individualised transition to retirement planning through the Department of Social Services (DSS) funded Transition to Retirement Case Management (TTRCM) program.

Methods

The methods included a survey of 24 ADE employees who had retired during the TTRCM program and interviews with 21 ADE employees who were either transitioning to retirement or who had retired following their involvement in the TTRCM program. Three family members and five stakeholders were also interviewed as part of the research.

Experiences and perceptions of the retirement process

The research found that there were a number of factors influencing the decision to retire. These included:

- the influence of their employer and/or support network
- reaching a certain milestone, either length of service at the ADE or age-related
- their own need to work less and enjoy other leisure activities.

A critical aspect of TTRCM support in planning for retirement was that the program provided information as to what activities and funding options were available locally and actively supported participants to trial new activities. ADE employees also received planning support from a range of different sources, including family members and ADE employers; however, these two groups often felt under-resourced in this role and saw the value in having an independent, dedicated service providing pre and post-retirement case management support tailored to the needs of each individual. There was uncertainty voiced by interviewees about the rollout of the National Disability Insurance Scheme (NDIS) and what impact this would have on retirement planning options for ADE employees not eligible for NDIS funding.

The ADE employees interviewed had different experiences of the retirement process, often based on their level of independence, the level of support they received from their employer and/or support network, the knowledge they had about what options were available (both in terms of activities as well as financial supports), and their ability to pay for activities. Important factors were the availability of suitable activities, both disability-specific and mainstream, and the availability of funding. Not having access to funding, or not knowing what funding was available, restricted participation in activities outside their home for some people.

Those with higher support needs, generally people living in group homes, faced the biggest constraints when transitioning to retirement. This appeared to be a result of a combination of factors including: whether their home environment was able to accommodate change in routine of a retiree; their eligibility for available funding support packages, such as the 'Active Ageing' package; and the amount of personal funds the individual had at their disposal after accommodation and support costs were deducted.

Outcomes for ADE employees following retirement

The majority of retired ADE employees who took part in the research felt that they had benefited from retiring and were happier in retirement than they had been when they were working. They spoke of participating in a range of different activities throughout their week, including both structured activities and unstructured or ad hoc activities. Participating in meaningful activities after retirement was important for the wellbeing of retirees, as was social contact with family, friends and others in the community. This is consistent with findings from mainstream literature on retirement.

The types of activities people engaged in depended on the person's preferences and interests, the level of support they required to engage in community-based activities, and the availability of organised activities in their local area. Retirement activities of ADE employees interviewed included voluntary work, social activities and specific disability programs. Participating in activities in retirement enabled social participation, which was identified as important to wellbeing for this group.

The research highlighted the major changes to individuals' social connections as they transition in to retirement. Some liked to retain friendships and connections they had made while working at the ADE, and would return and visit or volunteer to maintain these social connections. Others made new connections through engaging in other activities, including voluntary work, joining sports clubs, and participating in activities, and enjoy spending more time with family. Some people commented on the grief and difficulty of dealing with the death of family members or of close friends. Inevitably such deaths reduce the social networks of retirees. While this study has focused on outcomes for people in the early stages of retirement, in the longer term there may be other supports required for retirees to reduce the risk of social isolation.

Financial circumstances limited the activities retirees could engage in, and this was particularly the case for people with higher support needs, which were generally those living in supported accommodation. Retirees with higher support needs were more likely to participate in disability-specific leisure programs. Participation in disability-specific leisure programs tended to be for two or three days a week, as this was the maximum number of days that the available funding packages enabled. People living in supported accommodation appeared to experience greater difficulty in retirement because much of their pension went towards paying the cost of supported accommodation, leaving less money available to participate in leisure activities. In addition, people in this group also tended to need a higher level of support to access leisure activities. Having fewer available funds but higher support needs resulted in people being less able to participate in the activities they enjoyed in retirement.

Experience of family members

The number of interviews conducted with family members was small. However, the findings highlighted the complexities of retirement planning and that a person's decision to retire can have direct implications for family members and supporters. This was more marked for people with higher support needs.

The interviews also highlighted the need for support to be provided not only at the point of transition but also into retirement and throughout retirement, as circumstances continue to change as a person ages.

Quality of life survey of retirees

The majority of survey participants who chose to retire were satisfied with the support they received during the retirement process. They felt that stopping work was better than they thought it would be and that retiring had improved the activities they were engaged in. However, a quarter of the participants stated that they did not receive any support when retiring, or that the support that they received was not good.

The survey participants indicated that choice about what to do instead of working can be an important element in determining retirees' quality of life. Women were less likely to feel more in control after retirement than men. Around a quarter of participants reported that they were unhappy about the amount of time they spent on their own and/or the amount of money they had to do the things they wanted.

Discussion

Overall the majority of participants in this study, both in the qualitative interviews and those who responded to the survey, were positive about their experiences of retirement. Although they had made the decision to retire themselves, most participants had retired for negative reasons, such as being marginalised by employers, conflict with work colleagues, or reduced work performance.

The research found that retirement did not appear to cause additional financial hardship for retirees as most remained on the Disability Support Pension (DSP). No longer receiving an income through working at an ADE appeared to make only a small difference. While retirees did not report feeling comfortably off in retirement, they were used to living on a limited income and largely knew how to manage their finances. However, living on a pension and having less discretionary income created barriers to participation for many retirees and limited their capacity to engage in community-based activities, personal development and travel. Many participants lacked access to suitable post-retirement activities, and some of the activities themselves faced funding difficulties.

Most participants indicated that they had benefited to some extent from preparation for retirement. The main sources of support during the transition to retirement came from employers, relatives and/or accommodation support services.

Retirement had a significant impact on many of the supporters of people with disability, some of whom had to give up their own employment in order to care for their relative.

Overall, the experiences of retirees and those contemplating retirement were more positive than participants in previous research. This is likely to be because retirement is now a recognised part of ADE life, and most ADEs now provide information or other forms of preparation for retirement. Nevertheless, it is of concern that 'push' factors accounted for many of the decisions to retire.

Policy implications

Support should be tailored to the needs of the individual ADE employee. While some retirees were happily engaged in mainstream retirement activities others felt more comfortable returning to the ADE or engaging in disability-specific activities. Therefore, a range of activities should be available for ADE employees in retirement that can accommodate different preferences and interests, as well as differing support needs.

Policies therefore need to be directed at providing a range of post-retirement options for people with different needs, and these options need to be adequately funded, especially for those people who require high levels of support to engage in activities.

Information about local activities and funding options should be provided to ADE employees who are transitioning to retirement, as well as to ADEs, family members and/or accommodation providers. In the absence of a dedicated transition to retirement case management program, the participant's informal support network was required to take on this role and participants reported feeling under-resourced.

Support programs should allow for support to be provided over the course of retirement as the needs and circumstances of the client change. One-off programs appear to have limited long-term impact.

Barriers to retirement for those living in group homes should be addressed by policy – in particular the requirement in some establishments that residents have to be out of the accommodation during the day.

During the transition to the NDIS, it is important to consider the needs of those people currently retiring, or considering retiring. This cohort should not lose out on access to adequate retirement activities or funding

1 Introduction

The Australian Government Department of Social Services (DSS), Disability and Employment Sector Reform Branch, commissioned a research team from the Social Policy Research Centre (SPRC) at UNSW Australia to undertake a study to assess the quality of life of people with disability who had retired from an Australian Disability Enterprise (ADE). The focus of the research was to examine the outcomes for people who had received individualised transition to retirement planning through the DSS-funded Transition to Retirement Case Management (TTRCM) program, as well as the effectiveness of case management in supporting people with disability to make retirement decisions.

1.1 Background literature

Australian Disability Enterprises (ADEs) are not-for-profit organisations which provide supported employment for people with moderate to severe disability. Similar to the mainstream Australian population, the ADE workforce is getting older; the number of people over the age of 50 is projected to increase to almost 50% of the ADE workforce by 2025. These forecasted age trends have significant implications for the sector; ADEs must balance the need to maintain a competitive business model alongside providing appropriate supports to an ageing workforce. Given the increasing number of people with disability facing the prospect of retirement, it has been argued that person-centred specialist disability services are required to assist older people working in the ADE sector to transition successfully into retirement (McDermott, Edwards, Abello, & Katz, 2010).

While retirement is a commonly used term in policy and in the general community, particularly when applied to older people, there is no commonly accepted definition of what it means (Cohen-Mansfield & Regev, 2016; Denton & Spencer, 2009). Retirement has been defined simply as a 'withdrawal from paid working life' (Denton & Spencer, 2009 p. 64), but has also been conceptualised as a multifaceted, non-linear process that people will experience differently as their circumstances change over time (Hershenson, 2016).

Mainstream literature on the factors that contribute to the experience of a successful retirement suggests that people need the opportunity to engage in retirement activities which they value and find meaningful. Reichstadt et al. (2006) identified four interrelated themes when they asked older people what they considered important for successful ageing. These included: having a positive attitude and being adaptable; experiencing security and stability in terms of one's living environment, finances and social supports; maintaining good health and wellbeing; and being able to engage in stimulating and meaningful activities (Reichstadt, Depp, Palinkas, Folsom, & Jeste, 2007).

Adjusting to life in retirement is not necessarily a straightforward process, and research has found that, particularly in the first couple of years, people tend to experience fluctuations in their attitude towards being retired. These highs and lows can impact on an individual's sense of wellbeing (Moen, 1996; Reitzes & Mutran, 2004). Retirement is recognised as a significant life event which impacts on an individual's routines, roles and relationships and affects how retiree's view themselves and their status within society (Moen, 1996; Reitzes & Mutran, 2004; Steffens, Cruwys, Haslam, Jetten, & Haslam, 2016).

Research has shown that the transitions to, and experiences of, retirement of older employees with disability can be very stressful, particularly for older employees with intellectual disability who rely on routine and require additional time and planning support (Bigby, Wilson, Balandin, & Stancliffe, 2011; McDermott & Edwards, 2012). In a qualitative study involving employment and support providers, family members, and ADE employees, Bigby et al. (2011) identified a number of perceived barriers to retirement for people with disability. The study found that participants perceived retirement as a risk to the wellbeing of the older employee, with many expressing a wish that the person continue in organised disability-specific programs in retirement, a desire at odds with the current policy shift to increased social inclusion for people with disability. Older ADE employees in the study expressed concern that there would be a lack of meaningful activities and social interaction in retirement and hence they could not fully envision a fulfilling life in retirement (Bigby et al., 2011).

McDermott and Edwards (2012) identified similar barriers in a qualitative study examining people's decision to retire, which included 33 older people with intellectual disability and 10 retirees. ADE employees who took part in the study expressed the concern that they would be bored in retirement, no longer feel the sense of satisfaction gained by contributing to society through work, and experience a reduction in meaningful social interactions. Other barriers identified in the study included people's living arrangements and associated support requirements, as well as financial limitations. It was argued that ADE employees were not adequately prepared to make self-directed or informed decisions, and required further information and real-life experiences to envisage a satisfying life post-retirement (McDermott & Edwards, 2012).

These studies identified that few policies have been put in place in Australia to address some of the key barriers to retirement experienced by people with disability. It is argued that the service system remains poorly resourced to provide the required support to prepare people with disability for retirement and enable them to remain actively engaged in retirement. One of the key difficulties identified within the service system is that while ADEs receive funding from the Federal Government, retirement programs for people with disability are funded by state governments, with provisions for these varying from state to state. The availability of retirement programs was viewed as an important factor in enabling people with disability to successfully retire, along with supporting mainstream community services to better accommodate people with disability (McDermott et al., 2010; Stancliffe, Bigby, Balandin, & Wilson, 2013). It is not clear whether the advent of the National Disability Insurance Scheme (NDIS) will exacerbate this issue, at least for the current cohort of potential retirees who may be too old to access NDIS resources, or whether the NDIS will be able to ensure continuity of services for ADE employees.

1.2 Policy background

Until 2010, there were no formal mechanisms in place to help older people with disability working in ADEs to transition to retirement. In 2010, the Australian Government Department of Social Services (DSS) piloted a Transition to Retirement Case Management (TTRCM) program in three regional locations. The program, facilitated by CRS Australia¹, aimed to support the retirement planning of older people working in ADEs by educating them about retirement, facilitating retirement planning, and assisting in identifying and linking people into community-based activities. Values such as individual choice and inclusion were inherent in the program design, with case management support intended to focus on the individual, their needs, wishes and goals (ARTD Consultants, 2012).

1 Formerly known as the Commonwealth Rehabilitation Service and has since been disbanded.

An evaluation of the TTRCM pilot program conducted by ARTD Consultants (2012) found that older employees could be successfully prepared for retirement; however, this required ongoing person-centred retirement planning and people needed to be successfully matched and linked with community-based services and activities to find meaningful engagement post-work (ARTD Consultants, 2012). The evaluation also highlighted that although ADE staff had trusted relationships with employees and could assist in identifying potential community or options post-retirement, they may not have specific skills or resources to work with community organisations and link employees into general community activities. The authors suggested that a successful transition to retirement process required 'additional and specific' staff skills to bridge the gap between supported employment and retirement activities (ARTD Consultants, 2012).

Following the trial, the TTRCM program was offered nationwide with CRS Australia providing the case management service. The program was initially offered to ADE employees aged 65 years or older but later extended to employees aged between 55 and 65, as it was recognised that age was not the primary determinant when considering retirement; factors relating to health and disability played a more significant role. The program guidelines specified that TTRCM participants were to receive six months of case management assistance to initiate and implement retirement plans. Throughout the duration of the program, which operated between March 2013 and December 2014, a total of 1239 ADE employees attended an information session, 429 employees were supported to develop a retirement plan, and 75 employees retired.

At the conclusion of the TTRCM program, a number of key recommendations were made. These included: the need for ongoing education for ADE employees about retirement and encouraging employees to view retirement as a positive outcome; ongoing education to mainstream community-based services around supporting the participation of people with disability in programs; and the importance of individualised, adequately funded case management services to facilitate the transition to successful retirement for people with disability (Department of Human Services, CRS, Summary of Outcomes (unpublished)).

DSS encouraged ADEs to continue to support employees to plan for and transition into retirement. This included discussing retirement and incorporating retirement planning into the annual review process with employees, researching retirement options that might appeal to the employee, and referring employees to other agencies for assistance and support as appropriate.

2 Methodology

The current research used a multi-method approach, including quantitative and qualitative methodologies. The quantitative components involved an analysis of results from a survey distributed to ADE employees who had retired during the TTRCM program. The qualitative component included interviews with ADE employees who were either transitioning to retirement or who had retired following their involvement in the TTRCM program; family members; and stakeholders. The analysis involved combining the qualitative and quantitative analyses to form a more holistic picture of the successes and challenges of the transition to retirement process and any associated changes in quality of life that people experienced in retirement.

This section describes each component of the research methodology in detail. Table 1 provides a summary of the data sources and sample size for the research.

Table 1 Sample

Data source	Total
Survey	
QoL survey of ADE employees who have retired	24
Face-to-face interviews	
ADE employees transitioning to retirement	10
Retired ADE employees	11
Family members of ADE employees	3
Key stakeholders	5

2.1 Quality of life survey

ADE employees who retired during the course of the TTRCM program were invited to complete a short quality of life survey (Appendix A). A total of 72 surveys were mailed by DSS to potential participants: 24 people completed the survey and seven surveys were returned to sender due to the postal address no longer being current. The response rate was 37% (24 completed questionnaires / 65 sent questionnaires).

The quality of life survey was an adaptation of a questionnaire developed by SPRC to explore changes in the quality of life of people with disability when they changed their accommodation support packages (Fisher et al., 2014). The survey, which consisted of 23 questions, aimed to capture potential change in the experiences of retired ADE employees in a number of key life domains pre- and post-retirement, including socio-economic participation, social and community connectedness.

The survey instrument was in Easy English, combining text and images to ensure that the questions were simple and accessible for a person with disability. The survey instrument was piloted during initial interviews and modified accordingly. It included a question on whether the questionnaire was independently completed by the person with disability, completed with the help of a trusted person, or completed by a proxy on the person's behalf.

2.2 Interviews

Interviews were conducted with ADE employees who had taken part in the TTRCM program and had either retired or were still transitioning to retirement; family members; and key stakeholders involved in the transition to retirement process for ADE employees. Interviews were conducted with people connected to nine different ADEs within the Sydney, Illawarra, Hunter and Northern River regions of NSW.

2.2.1 Recruitment

Participation in the study was voluntary and recruitment was undertaken using two separate strategies, both based on an arm's length approach:

1. DSS sent an invitation letter to ADE employees who were known to have retired, or who were due to retire by the end of 2015
2. DSS sent an invitation letter to a sample of ADEs to invite them to engage in the research and to provide recruitment information to relevant employees. ADE employees and key stakeholders who were willing to participate were then contacted by researchers.

Family members were recruited either through the ADE employee (n=2) or through the ADEs who participated in the research (n=1).

2.2.2 Interviews with ADE employees

The SPRC research team interviewed ADE employees who had taken part in the TTRCM program and had either retired (n=11) or were transitioning to retirement (n=10). Interviews focused on the experiences and outcomes of transitioning to retirement, including:

- background information about the participant, including where they lived and where they worked or were still working
- their experience of the retirement process
- how they felt about the prospect of retirement and the impact this will have or did have on their life.

The interview guide is outlined in Appendix B . Interviews were conducted by the SPRC research team and were completed face-to-face in locations of the participants' choosing.

Accessibility

The interviews were designed to be flexible and rely on the skills and judgement of the interviewers who have experience interviewing people with disability. The interviews were tailored to the communication support needs of the participant where required. Participants were also encouraged to have a trusted supporter attend the interview with them if needed. A supporter is someone who sits in on an interview with the person with disability to help that person communicate in the best way possible with the researcher. A third of the participants chose to be interviewed with a supporter present.

Demographics

The majority of ADE employees interviewed for this research had an intellectual disability (n=18), followed by physical disability (n=2) and psychiatric disability (n=1). More men (n=13) than women (n=8) participated, which is generally representative of the population in the ADE workforce. The majority of the participants were in the 60–69 age group, which was expected given this was the target group for the TTRCM program. In terms of living arrangements, participants lived in a private dwelling or social housing on their own (n=7), with their partner (n=4) or with a flatmate (n=4), in group homes (n=4), or with siblings (n=2).

2.2.3 Interviews with family members

Interviews with ADE employees' family members (n=3) focused on gaining supplementary information about the retirement planning process and what the outcomes were for ADE employees. This included:

- background information about the ADE employee, including where they live and where they worked or are still working
- their perception of the retirement process
- their perception of the impact retirement has had, or will have, on their family member's quality of life

The interview guide is outlined in Appendix C. Interviews were conducted by the SPRC research team and were completed by telephone. Few family members participated in the interviews. Many ADE employees lived by themselves or in supported accommodation and did not identify a family member who could talk about the transition to retirement process.

2.2.4 Interview with key stakeholders

Interviews with stakeholders focused on gaining supplementary information on the retirement planning process and what the outcomes have been for ADE employees, family members or friends, and staff within the ADEs. Stakeholders included participants employed through ADEs (n=2), who were able to provide a workplace perspective; and participants providing accommodation support (n=2) or disability-specific retirement programs (n=1), who were able to provide information on the impact of retirement on the lives of ADE employees beyond the workplace.

The interview guide is outlined in Appendix D. Interviews were conducted by the SPRC research team and were completed either face-to-face or via telephone.

2.3 Analysis

2.3.1 Quantitative analysis

Exploratory analyses were conducted on the participants' answers to the items in the questionnaire. The participants' answers and scores were summarised through descriptive statistics, such as frequencies and percentages, and relevant relationships were explored using bivariate statistical analyses.

Chi-square tests of independence were completed to check the relationship between relevant questions and the participants' backgrounds, such as demographic characteristics or other key indicators in the questionnaire. The alpha level was 0.05.

For cross tabulations, adjusted standardised residuals were calculated to determine what factors specifically contributed to group differences (Agresti, 1996). Adjusted standardised residuals were interpreted as a normally distributed variable, so any such residual with an absolute value that was equal to or greater than 1.96 was significant (Sheskin, 1997). For the cells that had a significant residual it can be concluded that the observed frequency differed significantly from the expected frequency. The sign of the standardised residual indicates whether the value is above (+ sign) or below (– sign) what is expected under the null hypothesis. Adjusted standardised residuals are to be preferred to standardised residuals because they have a sampling distribution closer to standard normal distribution (Bewick, Cheek, & Ball, 2004).

2.3.2 Qualitative analysis

The interviews with ADE employees, family members and stakeholders were audio recorded and transcribed, and then coded and analysed using the analysis framework outlined in Table 2. The analysis framework was developed based on quality of life markers used in previous SPRC research (Fisher et al., 2014).

Table 2 Analysis framework

Support provided to transition to retirement
Support to think about retirement
Support when choosing to retire
Support following retirement
Individual experience and perceptions of retirement process
Adequacy of support provided
Facilitators and barriers to the retirement process
Outcomes for ADE employees
Participation
Relationships
Material wellbeing
Personal wellbeing
Personal development
Self-determination
Rights, respect and equity

2.4 Ethical considerations

Human research activities are governed by the principles outlined in the National Statement on Ethical Conduct in Research Involving Humans (National Health and Medical Research Council, 2007). The Research Code of Conduct sets out the obligations on all UNSW researchers, staff and students to be aware of the ethical framework governing research at the University and to comply with institutional and regulatory requirements. Ethics approval for this project was provided by UNSW Australia Human Research Ethics Committee (Ref no. HC15588).

2.5 Limitations

The research was designed to gather information on the long-term impact and effectiveness of the transition to retirement process from key groups, including ADE employees, their family members and the broader service network. Participation in the study was voluntary and hence participants may not be representative of all people in each of the key groups. For practical reasons, only ADE employees who lived in one of the four study sites within NSW were invited to participate in the qualitative component of the study. Attempts were made to minimise selection bias by recruiting ADE employees by mail-out but this was not a random selection.

It is also acknowledged that the sample size for interviews with family members was small. The original intention was to engage up to 10 family members in the research; however, only three interviews were conducted. Many of the ADE employees who participated in the research were not able to identify a family member potentially willing to contribute to the research.

3 Individual experience and perceptions of retirement process

This section summarises the experience and perception of the retirement process from the perspective of 11 ADE employees who had retired, as well as 10 who were still transitioning to retirement, having participated in the TTRCM program. The findings are based on qualitative interviews with ADE employees, as well as three interviews with family members and five with key stakeholders working in the disability sector.

3.1 Deciding to retire

In the qualitative sample, almost all of the people with disability had an understanding of retirement and shared their perspective on either making the decision to retire, for those who had retired, or their future intentions to retire. For those who had retired, the majority spoke of feeling ready to retire, either because they were finding the work too physically demanding and/or because work was no longer enjoyable. However, people spoke of having reached the decision for varying reasons. Just over half of the retirees interviewed described the culture of their workplace as having changed and many felt increasingly sidelined as a result. For some, this was experienced as subtle, or not so subtle, changes to their work role which made them question whether they wished to keep working.

Something had happened, I can still remember it and I thought at the time that's not fair, I don't like that, and I remember thinking what am I doing? [...] I just said to my supervisor "I just want to let you know I'm ready to – I've just made a decision", just like that, and she said "okay". (Retired ADE employee)

He wasn't happy there anymore, there'd been a lot of changes, change of management, change of clients, expectations from him were much higher. So they ended up cutting his hours, cutting his days, cutting his money and it just went on and on. The new manager that came in, he seemed to think of it as a moneymaking business rather than supporting employees with disability. (Family member)

Others spoke of being explicitly encouraged by the ADE to retire, usually as a result in a decrease in their work performance. Only a couple of participants described the decision to retire as having been made by someone else on their behalf, the majority spoke of having come to the decision themselves, although usually with strong encouragement. Negative interactions with other colleagues also appeared to influence a couple of people's decisions to retire, although only in the context of other changes in the workplace resulting in work being less enjoyable and retirement seeming more desirable. A few retirees spoke of stopping work as soon as they made the decision, but most either transitioned over a period of time or waited until they reached a certain milestone.

For those interviewed who had not yet retired, just over half spoke of intending to retire once they had reached a certain milestone. This could be either length of service at the ADE or age-related.

Well 67 I believe is the retirement age [...] I will try to, it's all permitting because you never know because it depends on your health [...] definitely get out at 67, I don't think I'll work longer than 67 because there's other parts of life too [...] So I think you've made a good contribution when you get there so it's pretty good. (ADE employee transitioning to retirement)

Several people acknowledged that the decision to wait until they reached a milestone before retiring would be dependent on maintaining good health and work productivity. No longer being physically able to walk to work, or becoming noticeably slow at work, were cited as signs it would be time to retire.

In the afternoons I get tired, I'm still doing the same jobs though. If I start to get too slow then I might think that might be it [...] I don't want to slow things down too much. And everyone saying 'she's sloooooow!' (ADE employee transitioning to retirement)

A number of those still transitioning to retirement recognised that retirement offered an opportunity to spend more time doing things they enjoyed, including leisure activities, travel and spending time with loved ones.

I look at it this way, I may not be around forever, like I said I'd like to spend more time with my family [...] I've seen quite a few people retired younger than me from here over the last few years, there's been a few retire. Now I think I'm the old man [...]. So you know I just can't be going on and on. (ADE employee transitioning to retirement)

Well the thing is when you retire well then you've got to – your life changes and then you've got to organise that, it could be community groups or walking and travelling and get to enjoy the nature side of life. (ADE employee transitioning to retirement)

Findings from previous studies found that older people working in ADEs were adamant they did not wish to retire and were pessimistic about the prospect of retiring (Bigby et al., 2011; McDermott et al., 2010)]. The findings outlined above indicate that potentially there has been some shift in attitude towards retirement over the past few years for people working in ADEs.

However, half of the people interviewed who were still in the transition phase continued to raise concerns about retirement. These concerns were consistent with many of the barriers to retirement for people with disability noted in previous studies, including concerns about not being able to engage in meaningful activities in retirement and no longer experiencing the social connection and sense of satisfaction that their workplace provided.

I know I'm going to retire sometime [...] Just a little bit longer. What I'm going to do when I retire? Nowhere to go, just staying home ... (ADE employee transitioning to retirement)

For a couple of people, the structure of their existing support services presented additional barriers when deciding to retire. Only a small number of people in the qualitative sample lived in supported accommodation, mainly group homes, but those who did appeared to experience additional structural and financial barriers to retirement. This included the staffing arrangements in their home not being structured to accommodate the different routine of a retiree. For one person, there was no accommodation support available at home during the day and they needed to always have a structured activity to fill in this time. This was not an isolated case, with one of the stakeholders interviewed also noting the same issue.

I mean we've got one [person] here where the group home's not staffed during the day so they have to be doing something [...] they can retire and stay home but they would have to leave the home they're in and move to another house that is staffed during the day. (ADE stakeholder 2)

These barriers and their implications will be discussed further in Section 3.3 and in Section 4.

3.2 Support to plan for retirement

All of the people with disability who participated in the study had taken part in the Transition to Retirement Case Management (TTRCM) program outlined in Section 1.2. As previously mentioned, the TTRCM program was designed to be person-centred and support ADE employees to plan for their retirement through exploring options and linking people in with community-based activities (Department of Human Services, CRS, Summary of Outcomes (unpublished)).

The TTRCM was funded by Department of Social Services (DSS) and operated between March 2013 and December 2014. Interviews for this study commenced in January 2016, 12 months after the TTRCM ceased. Half of the people with disability interviewed could not recall the details of their involvement in the TTRCM program; either the support provided or the community-based activities identified. This included both retired ADE employees and those still transitioning to retirement.

Most people interviewed described receiving retirement planning support from a range of different sources. For those who had a family member as their primary support person, usually a sibling, the family member took on the primary role of facilitating the planning. Similarly, for those in receipt of accommodation support, their support workers tended to be central in the planning process. Others did most of the planning independently or in collaboration with their spouse or partner. People spoke of retirement planning taking place in collaboration with the ADE, although tensions were sometimes present relating to the timing of retirement. As mentioned in Section 3.1, many retirees felt that the ADE had actively encouraged them to retire when they may not have otherwise considered retirement. This tension was also noted by family members and stakeholders.

My manager deals mostly with that type of thing. She lets us know that she's had a meeting with the workplace and if the productivity is not up and maybe their care has increased, they're just not able to support that resident in the workplace [...] I really think it's a shame. I just think it would be nice if people could work as long as they wanted to. (Stakeholder 4)

When the TTRCM program was operating, the case managers collaborated with each of the relevant parties. Family members and stakeholders noted that having a neutral person in this role, someone who was responsible for coordinating the planning process, was beneficial in negotiating some of the planning tensions. As one stakeholder who worked in an ADE noted, having your employer initiate the discussion about retirement was not something that was always well received, particularly for people apprehensive about how life in retirement would look.

People like to know that this is the person that they can talk to about this and it's a comfortable place. Often when workplaces talk about it, people feel pressured. "Don't you want me to work here anymore? What are you doing this for?" If it's an external thing, it's like, "Oh you're trying to sell it to me, okay. That's different. Oh, you're trying to sell me an idea. Oh, fair enough." Yeah, for us it's, "Oh you're pushing me out the door. What are you doing?" (Stakeholder 3)

Hence, one of the benefits of the TTRCM program was that it was an external program with a dedicated role of assisting people to consider their retirement options and start the transition process, completely separate from discussions about the person's work performance.

Participants who could recall their involvement in the TTRCM program generally recalled the planning process as beneficial in terms of having the opportunity to brainstorm potential ideas or activities based on their individual interests, as well as being provided with assistance to investigate what community-based activities were available in their local area.

Well she asked what I want to do, you know what interests, things like that, what I would like to do and that. And you know, gave a bit of a break down, you know the things, and she gave me a list of contacts [...] Yeah if anyone retires I do recommend it [...] basically they're taking a lot of the work off me. (Retired ADE employee)

Another key benefit noted by participants was being provided with support to access the newly identified activities and try them out. People spoke of feeling more confident when case managers were available to support them to attend new activities, rather than being expected to attend the activity on their own. This also provided an opportunity for the ADE employee and case manager to troubleshoot if the activity did not entirely suit.

I said I liked to work at the op shop, so we looked around places. They wanted me to carry big heavy boxes, I said “No way, I can’t do it” I’ll break me bones. But when I got up to [a different op shop] they didn’t ask me to do that. (Retired ADE employee)

For about a month [the case manager] came and collected him and drove him to the cards group, so that he would get familiar with the people in the group, get to know the group and he’s been going now for probably two years. He quite enjoys going to the cards now and he realises also that [the local council] has a lot of other things that he can do. (Family member)

Providing prospective retirees with the opportunity and support to try new activities was seen by family members and stakeholders as a crucial element of successful retirement planning. Consistent with findings from previous studies, family members and stakeholders who participated in the study noted that many ADE employees, specifically people with intellectual disability, experienced difficulty in envisaging a positive life for themselves in retirement. Being provided with the opportunity to go and try new activities was therefore considered to be a facilitating factor in the retirement planning process.

To me, that’s one of the biggest issues [...] the fact that people with a disability have not been able to exercise a lot of control of their lives, so asking them what their options are, you get a blank look [...] They need to go and try it and experience it and be able to come back and say, “Wow, that was really good. That wasn’t”, whatever. They’ve got an opinion then. Until then, somebody’s talking to them and they’re not really engaged because they don’t know. (Stakeholder 3)

As soon as they’re engaged [...] and by that I mean actually engaged, like, coming to the [retirement program], experiencing what we do and participating, then they want to come more. To me the appeal of work is still there, but certain elements of it more so than others – a social outlet, seeing our friends. The value is still there but actually packing boxes for six hours, less appealing when I could be doing something else. (Stakeholder 1)

Coupled with having the opportunity to try new activities was the change in work hours. All of the people with disability interviewed who were still transitioning to retirement worked part-time. Most had reduced their days of work to between two to three days, although some continued to work their usual hours. Shifting the balance between work and leisure activities was seen as an important aspect of the transition for some people, especially for those anxious about the change in routine and the potential loss of familiar supports and social interaction.

Only a small number of stakeholders working within the ADE service system participated in the study. These participants spoke of the ADEs not having the resources to take on a case management role once the TTRCM program ceased. In the absence of the support provided through the TTRCM program, difficulty finding appropriate community-based activities was cited as a barrier in the planning process.

Getting information, having an agency or a group that we could turn to, or a resource that we could turn to where if somebody says, “I’m thinking of retiring or partially retiring” we could go to that resource and get information and referral. That to me would be gold. (Stakeholder 5)

However, the ADE was seen to have a continued role to play in the retirement planning process through facilitating ongoing individual and group discussion with relevant ADE employees regarding retirement, as well as through supporting flexible work conditions as part of employee’s transition to retirement.

That’s a big part that we can play. I guess the point is we smooth the road for people. So if somebody says, “I want to work two days a week” we make that really smooth so that that’s not a boss going, “No, I want them working three days”. (Stakeholder 3)

The sample size was too small to determine whether this flexible approach was consistent across all ADEs. ADEs receive funding from DSS, with the Disability Employment Assistance Operational Guidelines (2015) stipulating that a person needed to work for a minimum of eight hours per week to maintain their employment. A couple of the ADE employees mentioned that they were expected by their ADE to work a minimum of two or three days and would prefer to have worked less.

The few people with disability who described the TTRCM program as having less relevance acknowledged that their designated case manager had generated a few ideas and facilitated one or two activities, but ultimately they felt that they had a good understanding of what they wished to do in their retirement and the capacity to organise themselves independently.

We did have a little bit of help [...] she'd come to see us and she helped us –like we were both went to do swimming down at the heated pool and also she got me out doing the men's shed and the gym.

Nothing that spectacular. But we were our own people; we were able to decide for ourselves, “yes, this is what we want to do”. (Retired ADE employee)

People who fell into this group were all living independently in either their own home or in social housing. They were used to making decisions for themselves about how they spent their time, and therefore, from their perspective, transitioning into retirement was no different. This supports findings from previous studies that people working within ADEs have a range of different support needs, and planning supports need to be tailored based on the individual.

Stakeholders also spoke about the need for retirement planning supports to be tailored to the individual. Some felt that not all ADE employees were suited to the case management model offered through the TTRCM program. These stakeholders noted that the emphasis on linking people in to mainstream community-based retirement activities was suitable for people with higher levels of independence, or those who had strong support networks who were able to facilitate ongoing participation, but for people with fewer resources, ongoing engagement in the activities was harder to maintain. The six-month time limit for the TTRCM program was seen as insufficient to ensure that retirees remained actively engaged in community-based activities.

It was too short a period to really put things in place and follow it through and make sure that – the time to talk to somebody about what they want and then look for a service that's suitable, yes. Then implement it and then make sure that they're going and to cover off all the things that may go wrong that it continues to happen because those things can – it might be a transport issue or it might be – you might set it up with one person in the organisation but that person may leave and then nobody else really wants to take it on. Yes, so there are a lot of reasons why those things don't continue.

(Stakeholder 2)

This is consistent with the findings from an evaluation by Stancliffe et al. (2013) of a separate transition to retirement program where it was noted that as circumstances changed, people often required renewed short-term support, and the authors argued that this support should be available on an ongoing, as needed basis (Stancliffe et al., 2013). Approximately half of the ADE employees interviewed had continued to maintain at least one activity arranged during their participation in the TTRCM program. Due to difficulty with recall for some participants, it was not possible to ascertain why some were no longer accessing the activities, although a couple did mention changes in family circumstances or health, or simply that the activity did not meet their needs and/or interests.

3.3 Support available in retirement

As identified in Section 1, a number of studies have found that the service system in Australia is not sufficiently resourced to provide the required support for people with disability to prepare for retirement and remain actively engaged in retirement (Bigby et al., 2011; McDermott et al., 2010). McDermott et al. (2010) suggested that governments at the national and state/territory level needed to share the responsibility for providing pre and post-retirement programs for older ADE employees.

The TTRCM Final Report (2015) noted that access to funding was a key issue affecting the transition to retirement process. It was observed that funding models were not consistent and varied between states, resulting in differing outcomes for people depending on where they lived. In terms of funding, a small number of the retired ADE employees in the current study spoke of receiving an 'Active Ageing' individual funding

package through NSW Family & Community Services, Ageing Disability & Home Care (ADHC). However, many people spoke of never having received support previously beyond that provided through the ADE, and therefore they had no idea what funding options were available to them in retirement.

It's kind of like starting from a blank square because we've got people who have been in an ADE which is federally funded, never having engaged in ADHC [...] I say we can get support from ADHC, we can get a case manager, and they go, "who are ADHC?". (Stakeholder)

The potential impact of the NDIS remained an unknown, with some retirees expressing concern about the impact of the NDIS roll out on their current funding support. This was of particular concern as the majority of retired ADE employees in the qualitative sample may not be eligible to receive support through the NDIS due to age.

But I don't know how I'm going to get on with this new stuff coming in. (Retired ADE employee)

The upside is that [retirement] is great but the downside is that because of money, money and funding, funding, blah, blah it's likely to get cut out. But that's simply because as you might know the NDIAS whatever – they're looking at getting everybody to be independent, more independent. While we understand that, what we've been doing has been really really good and it might not be able to continue. (Retired ADE employee)

Funding played an important role in providing access to community-based activities, either through the provision of transport, or because people required direct support to attend an activity. Not having access to funding, or not knowing what funding was available, restricted participation in activities outside their home for some people.

The activity group we go to is absolutely fantastic [...] But he can't do that five days a week, because those outings – because they've got to staff them, they cost like \$100 plus. Even to go to something like Vivid Sydney, which you and I would just jump on the train and go down and see that. That would cost a person with a disability \$120–\$130 [...] You can't do that three times a week or you'd have no pension left. (Stakeholder)

Being restricted in retirement due to funding constraints was more commonly reported by people who had higher support needs, generally people who lived in group accommodation. This appeared to be a result of a combination of factors including: whether they were able to travel to and participate in activities independently or required support; their eligibility for available funding support packages, such as the 'Active Ageing' package; and the amount of personal funds the individual had at their disposal after accommodation and support costs were deducted.

As will be discussed further in Section 4.1, people with higher support needs, such as those needing direct support to attend an activity, often participated in disability-specific leisure programs. Participation in these programs tended to be for two or three days a week, as this was all their funding package covered. A couple of the leisure programs were dedicated retirement programs, but generally programs were open to people of all ages. Leisure programs specifically geared to retirees with a disability were uncommon. Two of the ADEs who participated in the study also provided a disability-specific retirement program; one operated through state-based funding and the other on a fee for service basis. These retirement programs aimed to provide opportunities for community participation and social interaction, with a focus on encouraging people to exercise control around how they spend their leisure time in retirement.

Similar to the findings of McDermott and Edwards (2012), stakeholders interviewed in this study noted that in the absence of being able to attend a retirement program or day program, either due to not being eligible or there being no spaces available, people with higher support needs often remained at work because this was a familiar and supportive environment which provided activity and routine.

The service I was talking to you about a minute ago they kept their older employees there because they couldn't get the funding for them in the day services so they kept them there [...] even though they're not productive that they were keeping them at work. We have people here like that as well but they're not here full-time because they can also access [retirement program]. (Stakeholder 2)

Stakeholders spoke of putting processes in place within the workplace to support and accommodate these employees, such as modifying the tasks required of them to account for age-related physical or cognitive changes.

It is important to note that organised disability-specific leisure programs did not suit everyone, and only a couple of the retired ADE employees who took part in an interview were accessing these types of programs. Other retirees utilised their funding package to create individualised retirement programs, sometimes pooling funds with friends to enable this to occur, and many attended mainstream community-based groups. These included sports clubs (such as lawn bowls), men's sheds, or retirement activities run through their local council. A number of interviewees noted that finding the right fit with the available mainstream groups was crucial. Consistent with findings from previous studies, while some mainstream groups were open to people with disability joining, interviewees spoke about this not always being the case.

Some had quite significant negative experiences, there's quite evident sort of bias against people with disability and fear of having somebody with a disability and lack of understanding as to what a disability could mean, especially intellectual disability. "How much support would that person need? Do we have it within our group to support them? What does that mean?" and then just some general bigotry. (Stakeholder 1)

Seeing how the public responds, as well. It can be tricky. I know when we took [ADE employee] to a certain place to do bowling they weren't willing to put in the extra time to explain things. They were not very patient with him. That didn't work out [...] they just didn't seem to want to take the time with him. We have since found a place that he loves and they're really great with him. (Stakeholder 4)

Interviewees also raised the availability of relevant mainstream community-based activities as an issue. A couple of people spoke about there not being a sufficient number of activities to choose from that were affordable and enjoyable.

If there was one more social activity that was stimulating, and not just going through the motions of doing it because that's all that was available in this area, we would certainly explore that. (Stakeholder 5)

It was also noted by some retirees that the local council run programs for retirees were full of 'old people'. This is likely due to retirees without a disability joining the programs when they are older, and often have mobility issues, rather than when they first retire and are still quite active.

3.4 Summary

The research found that there are a number of factors influencing a person's decision to retire, including the external influences of their employer, co-workers and family, as well as recognising their own needs to work less and enjoy other leisure activities. When planning for retirement, being provided with information as to what activities and funding options were available locally and being actively supported to trial new activities was seen as a critical aspect of TTR support. People received planning support from a range of different sources, including family members and ADE employers; however, these two groups often felt under-resourced in this role and saw the value in having an independent dedicated service providing pre and post-retirement case management support tailored to the needs of each individual. There was uncertainty voiced about the rollout of the NDIS and what impact this would have for ADE employees not eligible to receive support through this scheme.

ADE employees interviewed had different experiences of the retirement process, often based on their level of independence, the level of support they received from their employer or family, the knowledge they had about what options there were (both in terms of activities, as well as physical and financial supports), and their ability to pay for activities. Those living in group homes faced the biggest constraints as staffing arrangements in their group home were not always able to accommodate the routine of a retiree, and yet due to the cost associated with living in a group home, they had limited personal resources to spend on activities outside of their home.

4 Outcomes for ADE employees following retirement

This section summarises the quality of life outcomes for 11 ADE employees who had retired after having participated in the TTRCM program. Half of the retirees interviewed had been retired for two to three years, whereas the others had been retired for less than two years, with at least one having only recently retired. Therefore, the findings from the interviews relate to people's experience in the early stage of retirement.

The findings are summarised under the quality of life domains outlined in Section 2.3.2. It is important to note that while each of the quality of life domains are reported on separately, in reality, relationships exist between the domains and these interactions are also important for understanding a person's quality of life in retirement. Most people in the qualitative sample spoke about being happy in retirement, with many mentioning they preferred retirement to working. While everyone had their own unique experience of retirement, having a strong social support network and engaging in activities that were enjoyable and meaningful were commonly reported as being central to experiencing a happy retirement.

4.1 Participation

As outlined in Section 1.1, mainstream literature suggests that in order to experience a successful retirement, people need the opportunity to engage in retirement activities which they value and find meaningful. The retired ADE employees spoke about participating in a range of different activities throughout their week, including structured activities and unstructured or ad hoc activities. Most retirees were happy with the range of activities they were doing in retirement, although a few spoke of wishing they could do more.

Structured activities tended to be group-based and involve a social element. The types of activities people engaged in depended on the person's preferences and interests, the level of support they required to engage in community-based activities, as well as the availability of organised activities in their local area. As mentioned in Section 3.3, people with higher support needs were more likely to participate in disability-specific leisure programs. Participation in disability-specific leisure programs tended to be for two or three days a week, as this was the maximum number of days that the available funding packages enabled. A couple of the disability-specific leisure programs were dedicated retirement programs, but other programs were open to all ages.

Other people spoke of joining mainstream community-based groups, such as men's sheds, mainstream local retirement programs, or 'pensioner groups'. These group-based activities provided opportunities for shared experience and social contact.

Well the men's shed I go out there, you can – some days I just sit around talking, some days get out in the gardens. It all depends where they want – if they want a bit of help out in the garden so I go out and give them a hand [...] and all the fellas out there like to have a bit of a joke with you and all this at the same time. (Retired ADE employee)

Volunteering was another common activity in the weekly routine of retirees. This was usually for charity organisations but also included organisations such as sports associations. One retiree spoke of volunteering

one day a week with his previous employer (ADE). As with taking part in structured community-based groups, volunteering provided opportunities for social contact, along with providing an opportunity for retirees to contribute to their local community.

I joined a rugby club, I played rugby union. A friend of mine worked for LJ Hooker and he got me involved in it and I've been going ever since. I help put all the things around the oval. (Retired ADE employee)

I tag clothes [...] And a woman might come in and she wants, she's looking for a suit for a kid. And we look – "No, sorry, we're sold out". (Retired ADE employee)

Retirees spoke of spending their less structured time in various activities or pursuits, depending on their individual preference. Most spoke of having a day during the week that they spent at home, 'a quiet day', when they might garden, read, draw, listen to the radio or watch TV. Aside from this, people spoke about spending time with family or friends, going on day trips, or visiting their local club to play the pokies or to have a meal.

We go to pubs or clubs, wherever. Now we might go say from here to [the lake] and we might go to the yacht club and while we're there we might have one or two drinks and play the pokie machines or sit outside in the cool air and all this. Just enjoy, enjoy watching the sailboats. (Retired ADE employee)

This club he's a social member now, and he goes up there for dinner with another friend on a Friday night and he goes to watch the races and he's made a lot of friends through the lawn bowls. (Stakeholder 4)

Another important aspect of retirement was having opportunity for travel. Like most retirees, people in the study regularly spoke about the holidays they had been on or were in the process of planning, often joking that if it was not for financial restrictions, they would be travelling all the time.

He's been to Tasmania, he's been to Queensland, he's been to Cairns, he's been to Hawaii, he's been to New Zealand. So he's actually done a lot of travelling in these years that he has been off as well. (Family member)

4.2 Relationships

Mainstream literature on the process of transitioning to retirement has found that friendship networks, and identifying as having a role as a friend, can have a positive effect on a person's experience of retirement. While people let go of their identity as a worker when they retire, other roles that remain, such as a friend role, can provide stability and support during the transition (Reitzes & Mutran, 2004). Indeed, given that people gain a sense of identity from the social groups to which they belong, the number of groups a retiree belongs to has been found to be a predictor of quality of life in retirement (Steffens et al., 2016).

As with any retirees, people in the qualitative sample spoke of the importance of relationships with family members and friends, and the sense of belonging they derived from the social networks they established. All the retirees interviewed either lived with others, whether this was their partner, family members or flatmates, and/or in close proximity to friends.

We usually sort of – it's like a little community if you like. One does something, everybody wants to join in and we're very close as we're all here for each other. (Retired ADE employee)

Well, with the boys I live with. I chat to. We go out and have fun. We have a coffee. We go out. (Retired ADE employee)

Having friends or family members retire at a similar time appeared to be an advantage as people then had longstanding relationships to support them with the transition to retirement, often trying out new activities together. When asked what they missed about work, people primarily mentioned their friends, and a couple of people were considering returning to work. One of the key reasons they cited was to increase their

opportunity for social interaction. This group generally spoke of engaging in fewer community-based activities in retirement and/or having smaller social networks. This is consistent with findings from previous research that indicated people with disability frequently lose social contacts when they retire and fail to develop new connections which leads to an increased risk of social isolation (McDermott & Edwards, 2012).

However, most retirees interviewed described themselves as being happier in retirement and observed that while some of their longstanding social networks had changed since retiring, others had been maintained and they had also developed new social connections.

I still miss the actual interaction with the friends we had but they've moved on too. So some friends have passed away, you know how life goes on and staff move and managers change and supervisors change and so it takes on a whole new format. (Retired ADE employee)

New social connections were generally formed through participation in leisure activities, either disability-specific or mainstream. People did not necessarily report developing any new close relationships at this stage of their retirement, however, feeling welcomed as a member of the group, and being missed when absent, was seen as important.

Yeah aerobics, with a group of elderly people and they say, "Hello, how are you going?", and all that. They're real friendly and I've always liked people. (Retired ADE employee)

I made new friends up at the op shop. (Retired ADE employee)

I couldn't go on the first week after the holidays. And everyone was "where were you?" (Retired ADE employee)

Alongside existing or new social connections, regular encounters with people in the local community also formed part of the retirees' social network. Wiesel and Bigby (2016) referred to these as 'convivial encounters' and noted that encounters between people with and without disability were an important aspect of social inclusion (Wiesel & Bigby, 2016). Retirees regularly spoke of being well known in their local coffee shop or at their local club, these places forming an important part of their weekly social routine.

I go by myself, because [my flatmates] are all at work. But I know all the boys down there. They all know me [...] they say "come, come sit down, here's your cup of coffee and your cake" (Retired ADE employee)

We're members of the leagues club and the ex-services and we just go where we want to go, we're our own people, we can speak and see and hear so – "g'day mate, how are you?". That sort of stuff. So we just blend in and we fit in here. (Retired ADE employee)

It is also important to note that it was common for retirees to talk about the death of a family member, friend or partner. People spoke about the grief they felt at the loss of someone close, and the support they received from others during this time. Mainstream literature on ageing notes that a person's social network often shrinks or changes as they age, which leads to an increased risk of social isolation (Sanderson, Brown, & Bailey, 2015). While this study has focused on outcomes for people in the early stages of retirement, in the longer term there may be other supports required for retirees to reduce the risk of social isolation.

4.3 Material wellbeing

In the qualitative sample, retired ADE employees spoke of minimal changes to their living arrangements following retirement. The majority lived either independently or with their partner in a privately owned dwelling or in social housing, and envisaged that they would continue to do so in the short to medium term. The remaining retirees lived in supported accommodation, one of whom had recently moved in with a group of fellow retirees.

In terms of personal finances, most retired ADE employees who took part in an interview spoke of remaining on the Disability Support Pension, which they had lived on for much of their lives. While they did not report feeling comfortably off in retirement, they were used to living on a limited income and largely knew how to manage their finances.

Every two weeks I go out for dinner – that's pension week. (Retired ADE employee)

No longer receiving an income through working at an ADE appeared to make only a small difference, as people spoke of pensions often increasing slightly when they stopped earning an income. In terms of managing on a slightly reduced amount, participants simply acknowledged the need to save for a little longer to be able to go on holidays or buy new things. However, one person had returned to work at his former workplace and explained that this was partly for the additional income. While he could manage on his pension, he explained that the small amount extra he earned when working he could put towards saving for a holiday and planning for future expenses.

What I get here is pocket money [...] my pension goes on the bills, and what I live on myself comes out of what I get here. So I'm trying to build that up [...] I'm putting money aside each week, I get it put aside in a special account, mainly for the – you know funeral expenses, because you know how dear that can be. (Retired ADE employee who returned to work)

No retirees in the qualitative sample mentioned superannuation, and whether superannuation funds were factored in to their weekly budget in retirement. It should be noted that this was not a question that was directly asked during the interviews. A family member did comment on the small amount of superannuation her brother received on retirement.

I was absolutely flabbergasted after working for 53 years or something he got \$12,000 superannuation. (Family member)

McDermott et al. (2010) found that the majority of older people retiring from an ADEs were likely to retire with no superannuation or limited superannuation, despite having worked for much of their life (McDermott et al., 2010). In the current study, financial support from family, particularly inheritance from parents, was noted to play a role in some people's finances and the choices they could make in retirement.

Well it was up to me to retire. I had the money, my lawyer is my guardian and he takes over the whole lot. I'm on a budget so I don't go any further. I don't have to worry about anything (Retired ADE employee)

He's on a disability pension so he's quite adequately able to support that and he has accounts from my parents that were left to him. (Family member)

The other major contributor to retirement, and the choices people could make, was the availability of community participation funding packages. As outlined in Section 3.3, funding models vary between different states in Australia. Many of the retired ADE employees spoke of receiving an Active Ageing package through NSW Family & Community Services, Ageing Disability & Home Care (ADHC), and some also received a Home Care package. However, not all of those interviewed were eligible for additional funding packages and some were not aware of the funding packages potentially available to them in retirement.

There was actually no awareness of Active Ageing funding which I found quite astounding. One of our retirees had aged out of the possibility of even applying for Active Ageing funding. (Stakeholder 1)

The group for whom retirement appeared to have the greatest impact on their material wellbeing were those living in supported accommodation or group homes. Only a couple of the retirees interviewed lived in supported accommodation and both mentioned that they would choose to do more in retirement if they had the support available to do so. They appeared to experience greater difficulty in retirement because much of their pension went towards paying the cost of supported accommodation, leaving less money available to participate in leisure activities. In addition, people in this group also tended to need a higher level of support to access leisure activities. Having fewer available funds but higher support needs resulted in people being less able to participate in the activities they enjoyed in retirement.

“You should try guitar lessons. You should try joining a drama group and you should try going to theatre more often”. Which is really great but this particular individual would need one-on-one support or at least would need to be part of a group to be able to do those things and then would have to have access to the funds to pay for those different things, plus the transport, plus the support and everything else. He’s living on a disability pension. The majority of his disability pension is probably going towards the group home. (Stakeholder 1)

One of the supported accommodation service providers had made the decision to reconfigure some of their houses, and move residents who were all either retired, or transitioning to retirement, into the same dwelling. This had reportedly helped to overcome some of the structural barriers related to retirement for people living in the group home, such as staffing arrangements and accommodating differences in activity choices.

That was a definite issue we were having in some of our homes we were having so many different age groups that it wasn’t really working. Especially on weekends when some older residents would really just like to stay home and our younger people wanted to go out. (Stakeholder 4)

While, in this instance, this decision had resulted in positive outcomes for people, it was not clear how much choice the individual’s had in determining where and with whom they lived. Having the opportunity to make these choices is recognised as a basic right, as outlined in the Article 19 of the United Nations Convention on the Rights of Persons with Disability (CRPD) (2008). A family member, whose brother had also been moved into a house with other older people with disability, noted that her brother coped better with this move than she thought she would if she was in a similar position.

4.4 Personal wellbeing

Retirement is recognised in mainstream literature as a significant life event which impacts on an individual’s routines, roles and relationships and affects how retiree’s view themselves and their status within society (Moen, 1996; Reitzes & Mutran, 2004; Steffens et al., 2016). The impact of retirement on an individual’s wellbeing has been found to be influenced by the circumstances surrounding their transition to retirement and how they subsequently perceive retirement (Moen, 1996).

In the qualitative sample, two main themes emerged relating to personal wellbeing. For one group, retirement was a relief. This group had experienced work-related stress in the lead up to retirement and they described feeling considerably happier now they had left that behind them.

We love life, we’re happy. (Retired ADE employee)

It’s lovely. Not going to work. I love it. (Retired ADE employee)

Many in this group described negative changes in the workplace culture at the ADE that had triggered their decision to retire, often in combination with unpleasant interactions with others in the workplace. This group tended not to want to return and visit colleagues at their ADE in retirement as this stirred up negative emotions, and while they were happy in retirement, reflecting on their experiences during the transition to retirement brought up a sadness that had not yet dissipated.

He still talks about the bad days there. I say listen, “That’s history, it’s in the past.” I said, “You need to think about the happy people and happy things you do now, not about that”. But it still plays in his mind and it probably will for a long time. (Family member)

For the other group, retirement was a time of adjustment. People spoke of needing time to adjust, to find new things they enjoyed and this process was not necessarily easy. People in this group still usually reported being happily retired, but it had taken time to get to this position. As one stakeholder observed, there was often a period of grief in the beginning stages of retirement when people needed let go of the familiar and meaningful (i.e. their work role and the work routine) and establish something new.

So what we found was particularly for guys with intellectual disability, their whole world has been built up in that supported employment role. Their social connections have been fostered in that environment. Their self-worth and their sense of self in terms of their skills, in terms of sort of their value as an employee and as a friend, all of those things have been fostered in that one environment over the course of maybe 30 plus years. (Stakeholder 1)

They sort of lose themselves a little bit when they retire, and that can happen to anyone as well. But I think it's more likely to happen to someone with a disability who hasn't had a lot of life experience, who has worked in the same place for the last 40 years. They know what holidays are and they can do that, but in terms of thinking about what would I do every week if I wasn't coming to work, I don't think they can get their head around it to be honest. Like I say, I mean, there are again, some similarities with the mainstream workforce again, but I think it's just a little bit more exacerbated. (Stakeholder 3)

This is consistent with the findings in mainstream literature outlined in Section 1.1, that adjusting to retirement can be a process, and people can experience fluctuations in their attitude towards being retired. These fluctuations in turn influence a person's sense of emotional wellbeing (Moen, 1996; Reitzes & Mutran, 2004).

Across both groups, people also spoke about their physical wellbeing but, unlike emotional wellbeing, this tended to be in terms of age-related changes rather than changes resulting from retirement. Some people spoke of being diagnosed with chronic diseases, such as high blood pressure or diabetes, and needing to make sure they kept these well managed. Other spoke of ongoing issues related to their disability, such as seizures or hearing impairments. Most retirees spoke of remaining physically active in retirement, often incorporating exercise classes or sporting activities in to their weekly routine, as well as walking to places or activities within their local community.

Mum would always walk – even when it was raining, she used to walk miles. Dad used to walk miles, and I think I got that rhythm in me and I still walk and if I don't walk I get pains in me leg. You know? I have to do exercise and I'm pretty fit. (Retired ADE employee)

Only one spoke of weight gain from becoming more sedentary in retirement. It is important to note that retirees interviewed in this study were still in the early stages of retirement and were relatively fit and healthy. It would be expected in the longer term, as people age, that physical health will have a greater influence on people's experience of retirement.

4.5 Self-determination, rights and equality

As outlined in Section 3, the majority of retirees in the qualitative sample spoke of making the decision to retire themselves, and that this decision was respected by their family and the ADE. Only a couple of people reported that the decision had been made by someone else on their behalf, although most appeared to have been strongly encouraged by their workplace to retire.

Some retirees spoke of being used to making decisions, either independently or in consultation with their partner or friends, and therefore they viewed the decision to retire, as well as decisions around how they wished to spend their retirement, as no different. For this group, retirement meant having greater control over their time, and the flexibility to decide what they wished to do and with whom they wished to spend time.

Sleeping in. And in the cold morning I don't have to work in that bloody cold [workplace]. (Retired ADE employee)

I mean it is just everyday activity – you do what you do. If you don't want to do it, don't do it. Some people like to look for another job, some people like to get part-time work but we're flat out doing nothing, if you know what I mean? (Retired ADE employee)

However, this was not the experience for all retirees. For some, particularly those who needed greater support in order to participate in activities, or people living in supported accommodation, retirement involved making some compromises around how they spent their time.

Yeah but they don't go out so much, what I used to, but you know, things change. And you've got to – I suppose you've got to toe the line a bit. (Retired ADE employee)

Often this was due to structural restrictions, such as supports not being available due to staffing arrangements in their supported accommodation, or financial limitations, such as not being able to afford to do multiple funded activities in a given week. These retirees were more likely to participate in disability-specific community groups for part of their week. However, despite the need for greater compromise around how they spent their time in retirement, this did not mean that they had no opportunity to express preferences and make decisions. Nor did it mean that retirees did not enjoy the activities they did. In most cases, people spoke about being given opportunities for decision-making whenever possible, and that decision-making was encouraged by both family and support staff.

[Day programs] are good because they offer him different options for things he would like to do and on different days and things like that. But this worked out for us and him. They were all things that he really wanted to do. (Family member)

They have group home meetings and they all sit around and talk about what they want to do. Recently they all decided they wanted to go to Canberra, so the staff really nicely arranged that and they've been down and I think they were going to Cockington Green and I'm not sure where else. (Family member)

Decision-making was viewed as a normal aspect of life for some retirees. Others were further developing their capacity for decision-making in retirement. Outside of the structured environment of their workplace, retirees were encountering greater opportunity to make decisions about how they spent their time. As mentioned earlier, participating in disability-specific community programs did not preclude increased opportunity for making choices. Stakeholders interviewed, who supported people with disability in retirement, noted positive changes over time in the skill and confidence in decision-making for some in retirement.

Being able to make decisions, not always easily or clearly, but understanding that they have the right and control and ability and entitlement, entitlement to make those decisions, entitlement to control their own environment and to shape it and to achieve what they want to achieve and to achieve nothing at all if they'd prefer not to. (Stakeholder 1)

We have a day program that's a lot of arts and crafts and that sort of thing. One thing I'm liking now, the residents are speaking up and saying, "I don't like doing that. I've done that for years, I really don't want to do it." It's great that they don't need to be told that they have choice; they don't have to do what you've always done. (Stakeholder 4)

Overall retirement appeared to facilitate increasing autonomy and decision-making by retirees.

4.6 Personal development

Personal development seldom featured in interviews with retirees. Some retirees spoke of engaging in organised activities, typically disability-specific programs, which enabled them to develop their artistic skills or improve their literacy. Others could identify courses, such as introductory computing courses, that they may wish to participate in at some point in the future.

They teach me – I'm doing painting of painting, writing letters and doing handy crafts. (Retired ADE employee)

I want to do some computer. And to read and write. (Retired ADE employee)

A number of retirees had commenced voluntary work, typically in charity-run opportunity shops, and had needed to develop skills in customer service, as this had not been part of their role while working at the ADE. One person wished to become a volunteer bus driver, something he had done previously, but was yet to apply for his bus driver license as he was yet to save the necessary funds.

I could have gone back doing that one day a week this year but at the time, you know finance just didn't allow – because you've got to expect – even though they'll give you the money back, just that initial outlay – so that's put me on hold there (Retired ADE employee)

Stakeholders who supported people with disability in retirement noted that for some retirees, developing skills, such as decision-making and social skills that enabled them to participate successfully in community-based activities in retirement, was central to facilitating a positive retirement experience.

How to make decisions, when it's okay to say no, when it's okay to say yes. Really authentic communication. That's a huge amount of work. That's really big. So the idea that we can just take somebody out of the workforce and say you want to learn guitar, great, you're going to go to a guitar class, you want to do line dancing and you want to do swimming, we'll insert you into those environments and then allow it to occur automatically is a wonderful idea but in practice you have to do a lot more backend work on the social interactions and everything else that will facilitate the guys to flourish in that environment. (Stakeholder)

4.7 Summary

The research has highlighted the different outcomes individuals have when retiring from an ADE. As previously mentioned, most people in the qualitative sample spoke about being happy in retirement, with many mentioning they preferred retirement to working. While everyone had their own unique experience of retirement, common findings from the interviews highlighted the importance of participating in meaningful activities after retirement and the importance of social contact. This is consistent with findings from mainstream literature on retirement. Retirement activities of ADE employees interviewed include voluntary work, social activities and specific disability programs. Participating in activities in retirement enabled social participation which was identified as important to wellbeing for this group.

The research highlighted the major changes to individuals' social connections as they transition out of retirement. Some liked to retain friendships and connections made at ADE's to the extent they would return and visit or volunteer to maintain social connections. Others made new connections through engaging in other activities, including voluntary work, joining sports clubs, and participating in activities, and enjoy spending more time with family. Some people commented on the grief and difficulty of dealing with the death of family members or of close friends. Inevitably such deaths will reduce the social networks of retirees.

Financial circumstances limited the activities people could engage in, and this was particularly the case for people living in supported accommodation.

5 Experience of family members

As outlined in Section 2.5, the number of interviews conducted with family members for this study was small. The original intention was to engage up to ten family members in the research; however, only three interviews were conducted. Many of the ADE employees who participated in the research were not able to identify a family member potentially willing or able to contribute to the research. However, the interviews completed with family members raised some potentially important considerations when determining the pre and post-retirement support required by ADE employees and hence have been included in this study.

5.1 Retirement implications for carers

Two of the family members interviewed were the primary carers for their siblings with disability. While previous studies have noted the implications when ADE employees live with ageing parents and wish to retire, in this study it was siblings who were the primary carers. Given that siblings are generally of a similar age to the person with disability, and often still in paid employment themselves, the implications of the ADE employee deciding to retire or needing to retire differ from those of parents.

Both of the family members interviewed recognised the need for their sibling to start planning for retirement as changes in their physical health and/or emotional wellbeing were evident. However, as the primary carer, these changes also had an impact on the family member's ability to continue in paid employment. For one family member, her brother had experienced a number of health issues which had required periods of hospitalisation and recuperation, and the family member had taken leave from work to support him. She recognised that it was likely that her own plans for retirement would be brought forward to enable her to continue providing this level of support.

It's been a big change for him and it's also been a change for me, because it means that – whereas I was pretty much working full-time, now I've used up all my long service leave and now I'm definitely looking at closer retire – I mean I was always thinking I would retire probably middle of next year, but now I'm thinking, if I get to July I'll be happy [...] If he's not well, it's just easier for me to not be working, I can sort of self-support myself, just means less holidays. (Family member)

The other family member had found that consideration of how retirement impacted family members was not adequately taken in to account during the planning and transition phase, with her sibling's work days being reduced or changed by the ADE without consultation.

I did mention to her, "look I don't think the manager is really considering families and carers, or you know how our routines are working or how these changes might affect us". So I really think there should have been more communication [...] But I had no input at all. She would just come home with a letter to say that this is happening. (Family member)

The family member was supportive of her sister's decision to retire, however, due to safety concerns she could not remain at home on her own. Hence during the transition period, the family member and her husband needed to structure their own work shifts to fit with the reduced hours her sister worked at the ADE. Given her work hours kept changing, this had not always been easy. By the time of the interview, the ADE employee and the family member had both retired.

5.2 Post-retirement planning

The other issue raised by family members was the need to plan for the next stage; to support their sibling with disability to make decisions regarding potential aged care supports and end-of-life preferences. Family members noted that these were decisions they were conscious of needing to make for themselves, given they were of retirement age and aware that things would start to change as they age. The concern family members expressed was, if something were to happen to them, who would provide this decision-making support to their family member with disability.

We're all in our 60s. Everyone needs to plan for the future and if I'm any sort of sister and carer, I'll be planning [ADE employee's] [...] I'd hate to see him all of a sudden [...] chucked in a nursing home, do you know what I mean? [...] And I don't want him to be in an institution – I don't want him sitting around with very old people, just getting old. (Family member)

A decision will be made for him by other people, because once you can't live in the situation where you are now, then someone's going to say, "You have to go somewhere else". We would have a choice of saying, "I want to stay at home and have someone come and care for me", but I'm not sure if that's what will happen. (Family member)

While post-retirement planning was not within the scope of the TTRCM program, the need for this type of decision-making support in retirement is consistent with the argument outlined in Section 3.2 that as circumstances change, people may require renewed short-term formal support.

5.3 Summary

As mentioned, the number of interviews conducted with family members was small. However, the findings do further highlight the complexities of retirement planning, and that a person's decision to retire can have direct implications for those closest to them. While this is likely to be true for all retirees, it is possibly more marked for people with disability, especially those with higher support needs. The interviews also highlighted the need for support to be provided, not only at the point of transition into retirement, but also throughout retirement, as a person ages and their circumstances continue to change.

6 Quality of life survey

This section reports on the results of the survey, including the main demographic characteristics of survey participants, as well as the analysis of their experience of retirement and their perceived quality of life pre- and post-retirement (the survey is outlined in Appendix A).

6.1 Demographic characteristics

Just over half of the survey respondents were men (54%, n=13), however, compared to the population of all ADE workers, women were over-represented in the survey sample (46% compared to 35%). A total of 13 men (62%) and eight women (38%) participated in individual interviews, which compares with the percentage of men and women in the population of all ADEs' workers.

The majority of the participants in both the survey and the individual interview were in the 60-69 age group. None of the survey participants identified themselves as Aboriginal. About a quarter (26%) spoke a language other than English at home, which is taken as an indicator of having a minority ethnic background. The majority of the study participants received help to complete the survey (Table 3).

Table 3 Help received by the participants to complete the survey (n=23)

Help received	n	%
I did the survey on my own	6	26
I got help to do the survey	15	65
Someone else did the survey for me	2	9

Table 4 shows that about 40% lived on their own, whereas about 60% lived with others. Table 5 shows the state of residence of the participants, with NSW accounting for over a third of participants.

Table 4 Participants' living arrangements (n=24)

Living arrangements	n	%
On my own	9	38
With family	3	13
With flatmates	6	25
Partner/spouse	4	17
Residential services	2	8

Table 5 Participants' State of residence (n=24)

State	n	%
New South Wales	9	38
Queensland	5	21
South Australia	3	13
Victoria	4	17
Western Australia	3	13

6.2 Survey results

Ninety-two per cent (n=22) of participants chose to retire; only two participants stated that they did not choose to retire (Table 6). The majority of the participants (63%, n=15) felt good about retiring (Table 6) and stated that stopping work was better than they thought it would be (52%, n=12, Table 7). None of the study participants went back to paid work after retiring. The two participants who did not choose to retire (both in the 70–79 age group) reported that sometimes they felt good about retirement and sometimes they felt bad about it; overall they thought that stopping work was just what they thought. There were no statistically significant differences in terms of satisfaction with retirement and what stopping work had been like for the participants with respect to gender, speaking a language other than English, living arrangements, jurisdiction, or whether they chose to retire or not.

Table 6 Participants' satisfaction with retirement (n=24)

Value	n	%
I feel good	15	63
Sometimes I feel good and sometimes I feel bad	7	29
Retiring is bad	2	8

Table 7 Participants' satisfaction with their retirement (n=23)

Value	n	%
Better than I thought	12	52
Just what I thought	5	22
Not as good as I thought	6	26

Table 8 shows that participants received help with planning their retirement from different sources. About three in four participants reported that the support that they received was either good or OK (Table 9). However, four participants (17%) stated that they did not receive any help, and two (9%) thought that the support that they received was not good (Table 9). The two participants who did not choose to retire stated that the support that they received was just OK. There were no differences in the participants' responses based on their gender, age, speaking a language other than English, living arrangements, and jurisdiction.

Table 8 Participants' sources of support with planning their retirement (n=24)

Value	n	%
My old workplace	8	33
My family	4	17
My support workers	6	25
Someone else	6	25

Table 9 Participants' satisfaction with support received with planning their retirement (n=24)

Value	n	%
It was good	11	48
It was just OK	6	26
It was not good	2	9
I didn't have help	4	17

The majority of the participants reported that they had a lot of choice regarding what they would do instead of working (Table 10). The relationship between choice about what to do instead of working and the participants' satisfaction with their retirement was found to be statistically significant. Participants who stated that they had no choice were more likely to think that retirement was not as good as they thought² (Table 11). There were no differences in the participants' responses based on their gender, age, speaking a language other than English, living arrangements, and jurisdiction.

Table 10 Participants' perception of choice in relation to what they would do instead of working (n=24)

Value	n	%
A lot of choice	14	61
A little choice	5	22
No choice	4	17

2 χ^2 (4, N=23) =12.06, p =.013. Two sided Fisher's exact test is reported because more than 20% of cells had expected frequencies lower than 5. The minimum expected count was 0.87. This association needs to be considered cautiously because of the violation of the Chi Square assumptions.

The Fisher exact test was repeated on a binomial version of the two variables (one variable was 'a little or no choice' vs 'a lot of choice' and the other was 'better or same as I thought' vs 'Not as good as I thought'), which gave similar results: χ^2 (1, N=23) =6.66, p =.018. More than 20% of cells had expected frequencies lower than 5; the minimum expected count was 2.35.

Table 11 Participants' judgement about what stopping work has been like by their choice on what they would do instead of working (n=23)

What has stopping work been like for you				
Choice about what to do instead of working	Better than I thought	Just as I thought	Not as good as I thought	Total
No choice	0 (0)*-	1 (20)	3 (50)**	4 (17)
A little choice	1 (8)	2 (40)	2 (33)	5 (22)
A lot of choice	11 (92)**	2 (40)	1 (17)*-	14 (61)

Note. Column percentage in parenthesis. * The asterisk means that the adjusted standardised residual (ASR) was greater than 1.96. The + sign next to the asterisk indicates that the value was above what was expected under the null hypothesis; the - sign indicates that the value was below what is expected.

Table 12 shows that the majority of the participants stated that the activities that they did were better than when they were working. The majority of the participants reported that their accommodation, the amount of time they saw their family and friends, their health, the control they had on what they did, the amount of help they received to make decisions, and the amount of money they had to do the things they wanted was about the same as before retiring (Table 12). However, one in four participants (26%) reported that the amount of money they had to do the things that they wanted to do was less than when they were working, and one participant in four (22%) reported that the amount of time they spent on their own was not as good as when they were working.

The association between the quality of life dimensions in Table 12 and the participants' gender, age, speaking a language other than English, living arrangements, jurisdiction, help received when choosing to stop work, and satisfaction with living paid work were tested. The only association that was found statistically significant was that between gender and sense of control³; there were fewer women who reported feeling a lot more in control and more women who reported feeling about the same level of control as when they were working than would be expected if the sexes were equal.

³ $\chi^2(2, N=23) = 12.71, p = .001$. Two sided Fisher's exact test is reported because more than 20% of cells had expected frequencies lower than 5. The minimum expected count was 0.48. This association needs to be considered cautiously because of the violation of the Chi Square assumptions.

Table 12 Participants' judgement on how their current accommodation, activities, social relationships, time spent on their own, health, control over what to do, and help received compare with when they were in paid work (n=23)

	Better/A lot more than before	About the same as when was working	Less/Not as good as when was working
Where I live now is	8 (35)	14 (61)	1 (4)
The activities I do now are	14 (61)	8 (35)	1 (4)
The amount I see my family and friends now is	8 (35)	12 (52)	3 (13)
The amount of time I spend on my own now is	7 (30)	11 (48)	5 (22)
My health now is	6 (26)	14 (61)	3 (13)
I feel in control of what I do	10 (44)	12 (52)	1 (4)
The amount of help I get now to make decisions is	7 (30)	14 (61)	2 (9)
The money I have now to do the things I want is	5 (22)	12 (52)	6 (26)

Note. Row percentage in parenthesis.

6.3 Summary

The data suggests that the majority of survey participants chose to retire were satisfied with the support they received during the retirement process, and felt that stopping work was better than they thought it would be. However, a quarter of the participants (n=6) stated either that they did not receive any support (four participants) or that the support that they received was not good (two participants).

The analysis found a positive relationship between the participants' choice about what to do instead of working and their satisfaction with their retirement. Participants who stated that they had no choice were more likely to think that retirement was not as good as they thought, suggesting that choice about what to do instead of working can be an important element in determining retirees' quality of life.

For the majority of the participants, the main positive impact of retirement was an improvement in the activities with which they engaged. Overall, retiring did not generate any relevant change in the participants' accommodation, the amount of time they saw their family and friends, their health, the control they had on what they did, and the amount of help they received to make decisions. The analyses showed that the relationship between gender and sense of control was statistically significant, with women being less likely to feel a lot more in control and more likely to feel about the same control as when they were working.

The only two life areas in which about a quarter of the participants reported that things were not as good as before were the amount of time they spent on their own and the amount of money they had to do the things they wanted.

Links with qualitative findings

Overall the quantitative and qualitative findings were similar, and both methods confirmed that most participants who retire from ADEs are satisfied with the process. Interestingly, in both the survey and the interviews, participants indicated that they had chosen to retire, although the interviews showed that this choice was often influenced by negative experiences in the ADE – both from employers and work colleagues. Even though some participants had been pressurised to retire, their experience of retirement was generally positive, especially where the support was experienced as helpful.

7 Discussion and policy implications

Overall the majority of participants in this study, both in the qualitative interviews and those who responded to the survey, were positive about their experiences of retirement. Although they had made the decision to retire themselves, most participants had retired for negative reasons, such as being marginalised by employers or having conflicts with their fellow employees. However, retirement appears to have been experienced positively by most retirees.

There were a range of experiences of retirement and a number of barriers and facilitating factors to positive retirement were identified. Many of these factors related to the characteristics and circumstances of individuals; for example, their level of ability and independence, support from family, and living circumstances. Other important factors related to the availability of suitable activities; both disability-specific and mainstream.

Although retirement did not appear to cause financial hardship for retirees, lack of finance did create barriers to participation for many participants and limited their capacity to engage in community-based activities and personal development, as well as travel. Many participants lacked access to suitable post-retirement activities, and some of the activities themselves faced funding difficulties. Policies therefore need to be directed at providing a range of post-retirement options for people with different needs, and these options need to be adequately funded, especially for those clients who require high levels of support to engage in activities. It is possible that in time the NDIS will be able to address this, as the funding packages are based on need. Nevertheless, irrespective of the funding available, it is important that people with disability have access to different activities and that information about local programs is provided to people with disability and their supporters.

Most participants indicated that they had benefited to some extent from preparation for retirement provided through the TTRCM program, but their main source of support during their transition to retirement came from their employers and relatives or accommodation support services. It is important to note that support should be tailored to the needs of the individual client. For example, some people were keen to engage in mainstream activities whereas others preferred, or were restricted to, disability-focused activities. Also, the time-limited case management approach used in the TTRCM program was not suitable for all clients. The findings indicate that longer term engagement by case managers would be preferable, as the needs of the participants changed over time from when they first commenced retirement planning, throughout their transition to retirement and then in retirement. Support for post-retirement planning, such as making decisions regarding potential aged care supports and end-of-life preferences, also needs to be considered.

In general, the activities that participants were engaged in were perceived as positive. Although many had dropped out of activities, indicating that not all of the activities were appropriate for this population – overall there appears to be a lack of suitable retirement activities for people with disability. Many participants also had a restricted range of activities available to them due to lack of funding. This was particularly the case for those with higher needs, who required more support (and therefore more resources) and hence had less ability to engage in a range of activities. Many participants were concerned about the potential impact of the NDIS on access to post-retirement activities. It is important that DSS and the National Disability Insurance

Agency (NDIA) clarify the policy implications for those currently contemplating retirement who are most likely to be affected by the transition to the NDIS, and that the implications are clearly communicated to people with disability, their supporters, and ADEs. This is likely to be less of a concern for future generations of ADE retirees, as they will already be receiving NDIS packages of care.

Retirement had a significant impact on many of the supporters of people with disability, some of whom had to give up their own employment in order to care for their relative. This is an under-researched area and more research should be conducted on the implications of retirement for family members and supporters of people working in ADEs. Similarly, policies and programs related to retirement planning should be more cognisant of the role of families in retirement and the impact on the families of those ADE workers who are planning retirement.

The findings of this study contrast in some ways with the previous literature in this area. Overall, the experiences of retirees and those contemplating retirement were more positive than participants in previous research. This is likely to be because retirement is now a recognised part of ADE life, and most ADEs now provide information or other forms of preparation for retirement. This was not the case previously. Nevertheless, it is a matter of concern that many people working in ADEs are still retiring because of 'push' rather than 'pull' factors. The findings also confirm that retirement is more challenging for those with higher support needs. This group is disadvantaged because they need more funding and support to engage in activities. Those who live in group homes or other supported accommodation face significant structural barriers to successful retirement. This is an important policy concern which should be a priority for DSS.

Overall this research has found that retirement is experienced positively by the majority of ADE employees. There appears to be far less anxiety and concern about retirement than in the past. However, some groups of employees continue to face significant structural barriers to retirement, and there are urgent policy reforms which need to be put into place to address these barriers.

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Appendix A: Quality of life survey

The Australian Government wants to know what it was like for you to retire, or stop work. They would like you to take part in research about retirement.

The Government asked the Social Policy Research Centre (the researchers), who are part of the University of NSW, to do this research. The researchers have some questions to ask you.

If you are happy to answer these questions, then please fill in this survey and send it back to the Social Policy Research Centre by **20th May 2016**. There is an envelope included to send it back in.

Another option is to fill the survey in on a computer instead. You can email Anna Jones at a.r.jones@unsw.edu.au and she will send you computer link. Anna is one of the researchers at the Social Policy Research Centre.

Just answer the questions that you can. You don't have to answer all the questions.

If you want to, you can also ask someone to help you answer the questions.

If you want a researcher to help you understand the questions, please phone the Anna Jones from the Social Policy Research Centre on 02 9385 782020.

Questions about you



1. Are you a:

Man



Woman



2. How old are you?

Under 40

40-49

50-59

60-69

70-79

80+

3. Are you Aboriginal?



Yes



No



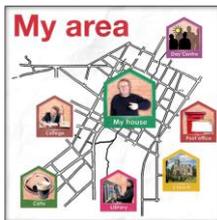
4. Do you speak a language that is not English at home?



Yes ✓

No ✗

5. What suburb do you live in?



(write here) _____

6. Who do you live with?



On my own

With family

With flatmates

Other (Who is it?)

Questions about choosing to stop work and who helped you

7. Did you choose to retire?

- Yes ✓ No ✗

8. How do you feel about stopping work?



- I feel good
- Sometimes I feel good and sometimes I feel bad
- Retiring is bad

9. Who helped you most with planning to stop work? Just choose one.



- My old workplace
- My family
- My support workers
- The people who run my new activities
- Someone else

Who was it?

10. What do you think of the help you got when choosing to stop work?



- It was good
- It was just OK
- It was not good
- I didn't have help

11. How much choice did you get about what you would do instead of working?



- A lot of choice
- A little bit of choice
- No choice

12. What has stopping work been like for you?

- Better than I thought
- Just what I thought
- Not as good as I thought

13. Have you gone back to paid work since retiring?

- Yes No

Questions about how you feel now that you have stopped working (retired)

The next questions are about how different parts of your life are now compared to when you were working.

14. Where I live now is...



- Better than when I was working
- The same as when I was working
- Not as good as when I was working

15. The activities I do now are...



- Better than when I was working
- About the same as when I was working
- Not as good as when I was working

16. The amount I see my family and friends now is...



- Better than when I was working
- About the same as when I was working
- Not as good as when I was working

17. The amount of time I spend on my own now is...



- Better than when I was working
- About the same as when I was working
- Not as good as when I was working

18. My health now is...



- Better than when I was working
- About the same as when I was working
- Not as good as when I was working

19. I feel in control of what I do....



- A lot more than when I was working
- About the same as when I was working
- Less than when I was working

20. The amount of help I get now to make decisions is...



- A lot more than when I was working
- About the same as when I was working
- Less than when I was working

21. The money I have now to do the things I want is ...



- A lot more than when I was working
- About the same as when I was working
- Less than when I was working

22. Do you have anything else you would like to say about what your life is like since stopping work?

23. How much help did you get to do this survey?



- I did the survey on my own
- I got help to do the survey
- Someone else did the survey for me

Appendix B: ADE employee interview guide

This interview schedule is designed to be flexible and to rely on the skills and judgement of the interviewers, who have experience interviewing people with disability.

- Language is pitched at a Plain English level and can be adapted by fieldworkers to be harder or easier depending on the needs of participants.
- Some 'Easy Read faces' are provided in an attachment for the fieldworker to introduce if necessary. If used, these should be used flexibly according to the preferences and needs of the participant.

Background

1. Where do you live?
2. Who do you live with?
3. Can you tell me about your job? Where did you work? What did you do?
4. How much did you work? Every day? Some days?
5. How long did you work there?
6. What did you like about work? What made you happy? What was important to you about your job?
7. What didn't you like about work?
8. What did you like doing when you weren't at work?

Retirement process

9. Why did you start thinking about stopping work/retiring?

Prompts

- Feeling tired or sick a lot of the time
 - Just didn't want to work anymore
 - Got to the age where you could stop work
 - Wanted to spend more time with family and friends
 - Wanted to try doing new things or activities
 - Your workplace told you it would be a good idea
10. Did you make the choice to stop working yourself?

11. Who helped you think about and plan for stopping work/retiring?

Prompts

- People from your workplace
- Your family, friends, carers or key worker

12. What did they do to help you?

Prompts

- Talk to you about what it means to stop work/retire
- Talk to you about things you could do when you stopped working – did you make a plan? Did you talk about the things you wanted and needed?
- Helped you try new activities – what activities did you try?

13. What did you like/not like about this?

Option 1: If the ADE employee has retired

14. Did you feel ready to stop work?

15. What do you do now instead of going to work?

Prompt

- Community activities (mainstream and supported), day program, volunteering, spend more time with family/friends, sport and/or recreation, travel, hobby/craft, watch TV, stay home).

16. What do you like about stopping work/retirement? What things do you do that make you happy? Why?

17. What makes you unhappy? Why? Do you miss work?

18. Have things in your life changed for you since you stopped work?

Prompt

- Where you live
- What activities you do
- Spending time with family and friends
- Having and using your money
- Staying healthy
- Feeling happy
- Having a say about what you do

19. What types of help do you get now?

Prompt

- From your old workplace
- From family, friends, carers or key workers
- People who work with people with disability
- The government

19. Do you have anything else you would like to add?

Option 2: If the ADE employee hasn't yet retired

20. What do you think you will do when you stop going to work?

Prompt

- Community activities (mainstream and supported), day program, volunteering, spend more time with family/friends, sport and/or recreation, travel, hobby/craft, watch TV, stay home.

21. Do you feel ready to stop working?

22. Do you have any worries about stopping work? Are there things you think you might miss about work?

23. How do you anticipate that retirement will affect your family member/friend's life?

Prompt

- Living arrangements
- Social participation/community activities
- Social networks/interpersonal relationships
- Material wellbeing/finances
- Physical and emotional wellbeing
- Ongoing opportunities for personal development
- Making choices about their life

24. Do you have anything else you would like to add?

Appendix C: Family member interview guide

Please note that the primary focus of the research is to examine the experience of people who have already retired from ADEs. However, people planning to retire will also be interviewed and hence the wording of questions in the background and retirement process sections will be changed by the interviewer to present tense, rather than past tense, where appropriate.

Background

1. Can you start by telling me a little bit about your family member/friend's current living arrangements – where are they living and what supports do they receive in order to live there?
2. Why did your family member/friend choose to work for Australian Disability Enterprises? What was their role? Did they work full-time or part-time?
3. What do you think your family member friend liked/disliked about their work/workplace?

Retirement process

4. When did your family member/friend start thinking about retiring? Did they bring up retirement or was it suggested to them?
5. Why did your family member/friend decide to retire?

Prompts

- Personal health reasons (tired, unwell)
- Other personal reasons (didn't want to work anymore; wanted to relax more; wanted to spend more time with family and friends; wanted to do other activities in the community, etc.)
- Reached retirement age
- Encouraged by workplace
- Encouraged by other individual(s)

6. How did your family member/friend plan for their retirement? Who was involved in this process?

Prompts

- Assistance from workplace
- Assistance from family, friend, carer or key worker
- Transition pilot through CRS Australia

7. What type of support did your family member/friend receive to plan or prepare for their retirement?

Prompts

- Education about retirement
- Talking to family member/friend about what they wanted to do/creation of a retirement plan
- Community activities identified and/or trialled (experience, enough, gaps, mainstreamed/or not)

8. What support do you feel was most helpful/least helpful for your family member/friend when planning for retirement?

9. Were you involved in your family member/friends planning for retirement? If so, what type of support did you receive?

10. What support did you find was most helpful/least helpful during the retirement planning process?

Option 1: If the ADE employee has retired

11. What does your family member/friend do now instead of going to work? How often do they do these activities?

Prompt

- Community activities (mainstream and supported), day program, volunteering, spend more time with family/friends, sport and/or recreation, travel, hobby/craft, watch TV, stay home).

12. What do you think your family member/friend likes most about what they do now? Why?

13. What do you think your family member/friend likes least about what they do now? Why?

14. Do you feel your family member/friend felt ready to retire?

15. How has retirement affected your family member/friend's life? What do you think their retirement means to them?

Prompt

- Living arrangements
- Social participation/community activities
- Social networks/interpersonal relationships
- Material wellbeing/finances
- Physical and emotional wellbeing
- Ongoing opportunities for personal development
- Making choices about their life

16. What types of support has your family member/friend received since they retired?

Prompt

- Ongoing assistance from workplace
- Assistance from family, friend, carer or key worker
- Assistance from community organisation
- Assistance from a disability agency or other government department

17. How has your family member/friend's retirement affected your life? What does their retirement mean for you?

Prompt

- Relationship with their family member/friend
- Opportunity to contribute to decisions regarding their family member/friend
- Caring responsibilities
- Service requirements
- Material wellbeing/finances
- Physical and emotional wellbeing

18. What types of support have you received since your family member/friend retired?

- Ongoing assistance from workplace
- Assistance from community organisation
- Assistance from a disability agency or other government department

19. Do you have anything else you would like to add?

Option 2: If the ADE employee hasn't yet retired

11. What does your family member/friend plan to do after they retire?

Prompt

- Community activities (mainstream and supported), day program, volunteering, spend more time with family/friends, sport and/or recreation, travel, hobby/craft, watch TV, stay home.

12. How prepared do you think your family member/friend feels for their retirement? What do you think their retirement means to them?

13. How do you anticipate that retirement will affect your family member/friend's life?

Prompt

- Living arrangements
- Social participation/community activities
- Social networks/interpersonal relationships
- Material wellbeing/finances
- Physical and emotional wellbeing
- Ongoing opportunities for personal development
- Making choices about their life

14. How prepared do you feel for your family member/friend's retirement?

15. How do you anticipate your family member/friend's retirement will affect your life? What will their retirement mean for you?

Prompt

- Relationship with their family member/friend
- Opportunity to contribute to decisions regarding their family member/friend
- Caring responsibilities
- Service requirements
- Material wellbeing/finances
- Physical and emotional wellbeing

Do you have anything else you would like to add?

Appendix D: Stakeholder interview guide

Background

1. What has been your involvement with transition to retirement planning for ADE employees?

Retirement planning process

2. What planning processes have been put in place to assist ADE employees to transition to retirement?
3. What is your overall perception of the effectiveness of transition to retirement planning for ADE employees?
4. Has transition to retirement planning been effectively implemented within ADEs?
5. How active are ADE staff member in the planning process? Do appropriate ADE employees have retirement plans in place? Are ADE employees receiving the retirement planning support they require?
6. Have there been barriers to effective implementation of transition to retirement planning within ADEs?
7. Have there been factors that have facilitated implementation of transition to retirement planning?
8. Do you have any recommendations about how the retirement planning process could be improved?

Outcomes

9. What have been the outcomes for ADE employees? What has retirement/planning to retire meant to them?

Prompt

- Living arrangements
- Social participation/community activities
- Social networks/interpersonal relationships
- Material wellbeing/finances
- Physical and emotional wellbeing
- Ongoing opportunities for personal development
- Making choices about their life

10. What have been the outcomes for family members/friends of ADE employees?

Prompt

- Relationship with their family member/friend
- Opportunity to contribute to decisions regarding their family member/friend
- Caring responsibilities
- Service requirements
- Physical and emotional wellbeing

11. Has transition to retirement planning impacted on staff members within ADEs?

Prompt

- Change in role/changed workloads
- Skill development e.g. referral and linkage management
- Change in relationship with ADE employees

12. What would you say has facilitated positive outcomes?

13. What would you say has hindered positive outcomes?

14. Any other comments