Service providers’ perceptions of active ageing among older adults with lifelong intellectual disabilities

Abstract

Background: Considerable attention is currently being directed towards both active ageing and the revising of standards for disability services within Australia and internationally. Yet, to date, no consideration appears to have been given to ways to promote active ageing among older adults with intellectual disabilities.

Methods: Semi-structured interviews were conducted with 16 Australian professional direct-care support staff (service providers) about their perceptions of ageing among older adults with lifelong intellectual disabilities and what active ageing might entail for an individual from this population who is currently under their care, in both the present and future. Data were analysed against the six core World Health Organization active ageing outcomes for people with intellectual disabilities.

Results: Service providers appeared to be strongly focused on encouraging active ageing among their clients. However, their perceptions of the individual characteristics, circumstances and experiences of older adults with intellectual disabilities for whom they care suggest that active ageing principles need to be applied to this group in a way that considers both their individual and diverse needs, particularly with respect to them transitioning from day services, employment or voluntary work to reduced activity, and finally to aged care facilities. The appropriateness of this group being placed in nursing homes in old age was also questioned.

Conclusion: Direct-care staff of older adults with intellectual disabilities have a vital role to play in encouraging and facilitating active ageing, as well as informing strategies that need to be implemented to ensure appropriate care for this diverse group as they proceed to old age.
Introduction

Internationally, considerable attention is currently being directed towards both improving the quality of disability services and promoting active ageing. While it might be assumed that older adults with a lifelong intellectual disability (ID) will benefit from these initiatives, in Australia neither of the frameworks that have been adopted as a means to guide the development of policy and programs in these areas consider the special needs of this particular group. The objectives outlined in the Interim National Quality Framework (NFQ) for Disability Services (Australian Government 2010) are broad-based and do not consider differences in needs that emerge as a consequence of either age or type of disability, while those outlined in the publication Ageing and Aged Care in Australia (Department of Health and Ageing 2008) give little attention to disabilities at all. Given that people with IDs are now surviving into old age in greater numbers than ever before (Janicki et al. 1999, World Health Organization 2000), it is imperative that programs which meet their specific needs are devised and implemented to enable them to experience ‘active ageing’, along with the rest of the ageing population.

Older adults with IDs are a profoundly diverse group, in terms of both their awareness of the ageing process and their history of engagement in work. For example, qualitative research undertaken in Australia with older adults with lifelong IDs reveals that some have little or no concept of ageing (Boulton-Lewis et al. 2008) and quantitative research shows that around one-third of adults with IDs aged 55 years and over have never thought about retirement or mentioned it to their carers (Ashman et al. 1995). While these findings may be explained in part by the nature of ID itself, it remains that many who form part of the cohort targeted by today’s active ageing policies were institutionalised in their early years and have thus had little or no experience of paid work. It is little wonder then that the term ‘retirement’ appears to have failed to elicit any serious consideration by a substantial proportion of
older adults with IDs. This points to the inadequacy of a generalised ‘active ageing’ framework being used to guide the devising of programs and policies for this older adults with IDs within Australia, since it is underpinned by a traditional notion of retirement as a stage that follows a lifetime of employment or partnership with a person (spouse/de facto) who has been employed prior to retirement. To a certain extent, the current neglect of older adults with IDs within active ageing government and agency policy documents in Australia reflects the longstanding notion that people with disabilities are “weak and helpless” and in need of interventions, instead of them being deemed capable of embracing opportunities for growth and capacity building throughout their lives (Llewellyn et al. 2004). Indeed, Depp and Jeste (2009) who examined operational definitions that have been used for research into ‘successful ageing’, found that of 29 operational definitions used for this concept, 13 involved the absence of ID (measured by either self-reported absence of cognitive impairment or high scores on cognitive screening tests) as one indicator of ‘successful ageing’. Unfortunately, this kind of methodological approach only serves to reinforce the notion that active ageing principles are not applicable to adults with IDs and that ID equates to incapacity, which is in stark contrast to alternative conceptualizations that conceive successful ageing in terms of lifelong development despite the limitations imposed by old age (Burnett-Wolle & Godbey 2005).

A decade ago, the World Health Organization (WHO 2000) released a publication that focused specifically on issues related to ageing among people with IDs (including the myths perpetuated about IDs) and recommended the development of specialty services that could provide a range of outcomes which could promote active ageing for members of this particular population. These six outcomes included: practical, leisure, or life enhancing skills (i.e., making choices between alternative activities and allowing person to access community opportunities for work or retirement); improved or maintained dietary and general health status that prevents physical health factors from hindering typical activity; a varied rhythm of life (i.e., involving preferred activities); recognition that challenge and productivity
must continue throughout old age; an increased and well-established social network; and participation on a regular basis in the general life of the community, with friends or acquaintances of one’s preference. Thus far, despite this publication, little research attention has been focused specifically on the extent that active ageing is or is not being experienced by older adults with IDs. However, although the active ageing framework has not been explicitly utilised, several studies have investigated the experiences of this group in key areas that fall within the general purview of ‘active ageing’, specifically issues of work, retirement, and social and community engagement.

In Australia, Ashman et al. (1995) used data obtained from a large sample of older people with an ID, aged 55 years and over, to examine matters related to work and retirement. They found that the most common experience was for participants to have never worked, with the proportion of those having never worked tending to be higher in the older age groups (for example, 67% of those aged 80 years). Far fewer, approximately two-fifths, were either currently employed or were now retired after having worked at some stage. Among the group who were currently employed, the vast majority had positive attitudes towards work, which serves to highlight the lack of opportunity almost half of the sample had during their lifetime to enjoy the potential benefits that come from participation in the workforce. Subsequently, Ashman and Suttie (1996) determined that older people with IDs also experienced lack of opportunity in relation to community and social engagement. Most of the participants had limited use of community facilities and infrequent contact with family or friends, with the exception of those who lived with a relative. Carers and service providers also identified a range of factors that formed barriers to social and community engagement among the study sample including: limited opportunities for making their own choices and decisions; limitations imposed by regulations and available finances, thereby inhibiting more extensive programs for recreation and leisure; the lack of a means by which older adults with IDs could contact others (such as restricted or no access to a telephone), and various circumstances existing in participants’ residences (which included private
dwellings, supported dwellings, hostels, and institutions) that reduced their opportunity to increase their access to services and amenities (Ashman & Suttie 1996).

Several international research projects have also demonstrated that people with an ID of all ages, but especially the older cohort, are often disadvantaged in terms of having the opportunity to participate in leisure activities and developing critical life management skills, such as accessing transport, money management and general autonomy. In the Netherlands, Zijlstra and Vlaskamp (2005) assessed the duration, frequency and content of weekend leisure activities for 196 adults (with profound intellectual and multiple disabilities, ranging in age from 18 to over 58 years) residing in residential facilities, from data derived from a questionnaire and diary completed by direct support professionals (service providers). They concluded that leisure time meant “more empty hours than quality time” (p.434), after finding that only 3.8 hours of leisure activities were provided for during the weekend and nearly half of that included ‘passive’ activities within the facility, such as watching television or listening to music. Parents, family members and volunteers offered few leisure activities, with these typically being offered by professionals in an ad-hoc manner – most did not plan activities, explaining that clients needed rest on the weekends. Zijlstra and Vlaskamp (2005) also identified a negative consequence of ageing, with older residents experiencing significantly fewer leisure activities, both in total number and variety, which they attributed – at least in part - to the fact that their own ageing parents were no longer able to facilitate outings. In Ireland, McCausland et al. (2010) assessed the health and social care needs of 75 older adults (50 years and older) with mild to severe ID who utilised residential and day services, and identified key met (daytime activities, social relationships, food, looking after the home, transport) and unmet needs (basic education, transport and money budgeting) amongst these older adults. As this cohort is the first substantial group of people with an ID to age and reach ‘old age’, McCausland et al. (2010) argued for the development of continuing lifelong
learning programs and emphasised that more research is needed to better understand the specific health and social care needs of older persons with ID.

The reality is that facilitating meaningful retirement and later life transitions for this growing cohort of older adults with IDs is a major policy challenge that will require understanding of their personal preferences, as well as the support and active participation of their respective families, professionals and caregivers. After examining data gathered from a mail survey of 72 Irish service providers, Lawrence and Roush (2008) documented that very few services currently had formal retirement policies or pre-retirement planning, with the main reasons for retirement among older adults with IDs (where they transitioned from workshop to activation centres, offering more leisure and social activities) being age, an individual’s personal wishes, and declining physical ability. Indeed, from interviews with 16 older adults with ID (41 to 61 years) attending semi-rural Scottish day centres, Judge et al. (2010) found that conceptions of retirement differed. Some had no concept of retirement, whereas others viewed it as an upsetting, negative experience because it would mean stopping attending their current day centre and disrupting current friendships and activities. These adults felt disempowered and did not want this anticipated change; they did not want to ‘retire’ from their current life. The reality of the ageing process means however, that as people with an ID age, their health and functional abilities will decline and their needs, care and service requirements are likely to change as a consequence.

Together, the studies discussed above identify numerous obstacles that need to be overcome by those involved in the provision of services to older adults with IDs, if they are to support active ageing in ways that have been outlined by the WHO (2000). Achieving these WHO active ageing outcomes, specifically those that centre on social engagement, interactions and independence, will require commitment and awareness, particularly from service providers and staff who provide direct care to people with IDs. They are the ones who carry much of the responsibility for supporting their clients in
striving towards culturally normative behaviours (Schuengel et al. 2010), with their level of expertise with a given client resting on their interpersonal relationship and tacit knowledge of that client (Schuengel et al. 2010, Reinders 2010). With direct-care staff known to bring out the ‘best’ and ‘worst’ in their clients (Hall & Hall 2002), their role in both monitoring and promoting active ageing among their clientele will be fundamental to the success of any active ageing policies and programs that might be devised and implemented within the disability services sector. Currently, however, we have little insight into the experience of active ageing among older adults with IDs from the perspective of service providers.

Given this knowledge gap, this research had two main aims: (1) to identify service providers’ experiences, views and perceptions of ageing and achieving active ageing among older adults with lifelong intellectual disabilities and (2) to better understand what active ageing might entail, both now and in the future, and the implications for older people, families, caregivers and service providers. Given the increasing life expectancy of older people with an ID, gaining an understanding of the key barriers and facilitators associated with developing active ageing-supportive service provision for this cohort - who have very disparate life circumstances and work histories - is essential to inform and facilitate best practice.

Method

Research Design

As little was known about the topic, a qualitative research design – specifically in-depth interviews - was adopted to explore facilitators and barriers to active ageing for older people with intellectual disabilities. A non-probability, purposive sampling technique was utilised to recruit and select three specific groups of participants: older people with a disability (service users), key informal network members and service providers. This article focuses specifically on the viewpoints and experiences of one key group, the
professional direct-care support staff termed “service providers” (SPs). The recruitment process was as follows: disability or aged care service providers for people with intellectual disabilities in two Australian states (Queensland & Victoria) were asked to nominate service users who met two key eligibility criteria: aged older than 50 years and able to communicate verbally. Although the specific diagnosis of intellectual disability could vary, service users had to have the cognitive capacity, communication and verbal skills to understand the nature of the questions and effectively communicate their perspectives. As Table 1 illustrates, 16 older adults who had all either been born with an ID or acquired it during childhood participated (including 6 men and 10 women aged between 52 and 80 years - average 63 years; SD 7.3 years). Half of the older adults with IDs were engaged in work, five were still working in supported employment, and three were in voluntary community work. Those not involved in work regularly attended some type of formal day program, such as Adult Training Support Services (ATSS). Each of those recruited then nominated a key informal network member and service provider to be interviewed.

[INSERT TABLE 1 ABOUT HERE]

Participants

The participant sample for the current study comprises all 16 service providers, who provide unique insight into the experiences of older people with an ID. These 16 individuals were staff who had hands-on service delivery or front line management roles within the disability or aged care service sector; most were female, had over a decade’s experience in the industry and had worked with the older adult with an ID who nominated them for interview for at least the past year. The interviews undertaken with service providers explored their perceptions of the experiences and aspirations of older adults with IDs as they age, as well as related issues. Eleven of the nominated service providers were from ATSS programs, four were sheltered workshop staff, and one was a disability case manager (see Table 1 for characteristics of each case i.e. service providers and the individual for whom each provides services). Standard good practice interview and ethical protocols were followed, with ethical clearance
having been obtained from the university ethics research committee and written informed consent gained from all interviewees prior to interview. Separate face-to-face semi-structured interviews were conducted in locations of participants’ choice (typically their workplace/training centre), with the majority lasting between 60 and 90 minutes. Interviews covering the same general issues of active ageing (i.e., getting older, daily activities, future plans, barriers and aspirations) were undertaken with the three key stakeholder groups. The specific questions presented to service providers are displayed in Table 2. These open-ended questions were developed by the project team, with some questions being formulated in response to specific issues raised during the interviews.

[INSERT TABLE 2 ABOUT HERE]

Analysis

All interviews were audio-taped and transcribed verbatim. Transcriptions were uploaded to NVivo8, a software management tool, to assist in managing, exploring and analysing the data. Each interview was read through several times to ensure familiarity and then the process of initial coding commenced. To determine the presence and experience of active ageing among older adults with IDs, the six core WHO (2000) outcomes were utilised to guide the analysis - chunks of data were assigned to these corresponding categories, specifically: (1) practical, leisure, or life enhancing skills; (2) improved or maintained dietary and general health status that prevents physical health factors from hindering typical activity; (3) a varied rhythm of life (i.e., involving preferred activities); (4) recognition that challenge and productivity must continue throughout old age; (5) an increased and well-established social network; and (6) participation on a regular basis in the general life of the community, with friends or acquaintances of one’s preference. Our other research (Buys et al. in press, Buys et al. 2008, Boulton-Lewis et al. 2008) has explored emergent themes, whereas the focus here is on analysing data for their consistency or lack of consistency with these six WHO outcomes: thus identifying the facilitators of and
barriers to these outcomes for older adults with IDs according to knowledge held by those delivering services to them. All authors separately engaged in the analysis process, with consensus being reached through discussion. The themes are summarised below, illustrated with verbatim extracts from the interviews so readers can evaluate the thematic structures and groupings. Where possible, multiple extracts reflecting different perspectives on a particular aspect have been grouped together in tables, according to their corresponding theme or sub-theme.

Results

Whilst the six WHO themes below illustrate service providers’ perceptions of the specific and unique experiences associated with active ageing for this cohort of older people with an ID, it is important to emphasize the overarching fact that most service providers were extremely proud of the fact that disability was not defining their ageing clients – as one service provider proudly explained, “she could be any 80 year old woman in many ways, couldn’t she?” (SP6). There were, of course, challenges associated with the ageing process, as well as individual life histories and circumstances that impeded active ageing; these challenges and opportunities from a service provider perspective, are described below.

Theme 1: WHO outcome of developing practical, leisure or life enhancing skills

The ongoing development of different skills was found be supported by both family by both family and non-family members. Since on the whole, non-family members appeared to play a greater role than family members in this particular regard, maintaining activities without family support was identified as a core sub-theme.

Although the ages of the older adults with an ID in this study varied considerably, nearly all were described by their respective service providers as being keen to be active and to learn new things. A
minority appeared to need some direction in this regard, while most were motivated and self-directed by their own desire to remain active. Comments such as the following were typical: “I think given half a chance, she will just keep going and going and going for as long as she can” (SP11). Service providers emphasised the need for their clients to continue their engagement in meaningful activities in line with their particular interests and preferences, describing how they saw supporting and facilitating such choices, activities and preferences as a key part of their role. A wide array of leisure activities, personal interests and life enhancing skills - including voluntary work for charitable organisations, reading, arts and crafts activities, caring for pets, social outings (especially bowling) and fulfilling personal obsessions with a specific sport or the royal family - were identified as being enjoyed by older adults with IDs. For example, SP10 revealed that the individual to whom she provided support had opted to do voluntary work for a charitable organisation as part of her weekly routine, which encompassed activities as diverse as visiting the library, dancing, music, going to the movies and social outings: “She wants to do things. She doesn’t want to be idle” (SP10). Although issues of work and retirement are discussed in Theme 4, it is important to note that adult literacy, numeracy (especially money management) and basic education classes were particularly valued, as were conversations with service providers about ageing issues. For example, after a discussion about planning for the future and pre-paid funerals, SP11 remarked that her female client decided she wanted a pre-paid funeral for herself and is now currently making funeral plan payments.

Maintaining activities without family support

Many of the older adults with IDs in this study were without any contact with family, because their parents had pre-deceased them and, for those with siblings, some siblings were not interested in maintaining any meaningful relationship or contact with them. Thus, family members did not necessarily act as facilitators of the ongoing development of these older adults’ practical, leisure or life skills.
Rather, this role was largely performed by service providers on weekdays and on weekends, by carers in group homes and other members of the community, such as those belonging to religious organisations. In one case, family appeared to act as a constraint on the development of practical skills; SP1 described how living at home meant that SU1 lacked the opportunity to pursue leisure activities outside the house, such as eating out and shopping, due to the age of her parents and their inability to participate in these types of activities:

I think she’s just been protected...I think if [SU1] was 30 years younger, her world would have been opened up a whole lot more for her and that’s not a criticism of her parents. As an example, [SU1] doesn’t handle boiling water or handle the stove at her mother’s request. They [the parents] try so hard to protect and do everything... but then that leaves that person without a lot of resources of their own (SP1).

A positive service provider relationship appeared critical to facilitating participation in these activities, with one (SP11) describing how the individual under her care had experienced problems in the past whereby a previous service provider had purposely blocked some of her activities and isolated her. Describing these instances as tantamount to mental abuse, SP11 described how the positive relationship that she and SU11 had formed over the past 12 months had enabled SU11 to increase both her engagement with others and involvement in social activities.

Theme 2: WHO outcome of improved or maintained dietary and general health

Despite maintenance of skills and activities being a primary goal for service providers, the majority reported that they had witnessed some age-related changes in their clientele, such as them getting slower or becoming tired more easily. As Table 3 illustrates, service providers had differing perspectives on this. On the one hand, many health changes (such as getting slower, increased eyesight and hearing difficulties) were viewed as a natural part of the ageing process. There was a sense that most were coping reasonably well with these changes, and were maintaining generally good health – and those with lifelong health issues, such as asthma and diabetes, were continuing to appropriately
self-manage their health. On the other hand, for approximately a fifth, age-related physical problems (especially a major health scare) was having a very real and negative impact, limiting mobility and disrupting both daily home routines and social participation. In one situation, pain was attributed to “getting older” by SU13, with this reason being accepted by support staff, when in fact, he needed a hip replacement (SP13); in another, a male had changed from being enthusiastic about participating in centre-based program to becoming uninterested after an episode of urinary incontinence at a community organisation meeting and an (unrelated) assault by a fellow resident. His service provider perceived that this had undermined his confidence, sense of pride and self-esteem, resulting in him becoming withdrawn and depressed:

...just because he wet himself, he’s been humiliated. He’s stopped in the last two years, he’s taken to sitting in their relaxation room, which is air-conditioned...and he’s taken to hiding in there now, but he still participates in some activities like going to the movies (SP9).

After action was taken to determine what was troubling SU9 and gaining the necessary treatment (anti-depressants) however, he was beginning to show signs of improvement and returning to his ‘old self again’.

[INSERT TABLE 3 ABOUT HERE]

**Theme 3: WHO outcome of a varied rhythm of life**

Regardless of age, service providers saw having a ‘varied rhythm of life’ as involving preferred activities as critical to quality of life, and endeavored to facilitate this with the older adults for whom they provide care. This was about reducing boredom and enhancing independence, choice and the ability to participate in desired activities – whether that was indulging in a regular ‘sleep-in’, trialling and rejecting disliked activities (e.g., cooking) or maintaining lifelong passions. As SP10 explained, it was a point of great pride for the individual under her care to be able to say to people that “I go out every day now”. However, as well as the ongoing challenges of limited service availability, flexibility and
maintaining individualised programs within budgetary constraints, health was identified as the main age-related barrier to maintaining a varied rhythm of life. For example, declining health meant one older adult with an ID was unable to easily get to the football and racecourse independently anymore and this translated into a general decline in interest: “He’s not as interested anymore. When I started here five years ago, because I like horses as well, we would have a conversation about it. Now he couldn’t care less...he liked to bet, but he’s not interested in having a bet anymore (SP13).

**Theme 4: WHO outcome of recognising challenge and productivity must continue throughout old age**

Service providers demonstrated a strong awareness of the need for their respective clients to experience ongoing challenge and productivity into old age, but expressed concern in a number of cases about how this could be facilitated into the future. Three core sub-themes were identified: understanding and preparing for retirement, remaining ‘active’ and the transition to aged care.

**Conceptualising and preparing for retirement**

Although a few described how their respective clients had now “chose[n] not to work full time because they were getting too tired” (SP15), most commented on the absence of any thought being given to retirement by the older adults for whom they provided care, who never mentioned it. As one service provider explained, “I don’t think that she has a concept of getting old. I think SU5 still operates and believes she’s a teenager” (SP5); similarly, when asked whether his client ever mentioned retirement, another replied:

> Nobody has – not since I’ve been here. So it’s a bit hard, but from what I see, they’re just a jovial bunch of guys who just don’t care what’s ahead. They’re very happy to come to work and be among this group of people and grow old and think they’ve achieved something. That’s how they are. I’m always learning from them (SP4).

Service providers were most concerned about what ageing and retirement would mean for those who were living at home, with SP1 holding serious concerns about how the female to whom she provided
care would cope with the inevitable death of her aged parents. SP1 explained that SU1 was totally unprepared, since she had never lived away from home. SP1 also commented that if it was up to her, she would have made sure that SU1 experienced “sleep-over” respite and supported holidays over the years because “…it has never been expected of her, she’s probably become very inflexible and this has become a bit of the problem”.

**Challenges of remaining ‘active’**

When asked what they considered the ideal retirement would be for their respective clients, all service providers spoke about the need for them to remain “active”. What this actually entailed varied considerably however from case to case, with service providers nominating different kinds of activities that were in line with those activities that individuals were currently enjoying. For one man aged 60 years, currently working at a sheltered workshop, the ‘ideal’ would involve practical things with his hand, but his service provider was concerned that when he retired he would miss the work environment and his friends there. SP4 commented that if SU4 was forced to retire he would “take it very badly”. Similarly, a service provider to a woman aged 54 years, also currently working at a sheltered workshop, remarked that for this woman work was “pretty much her whole life”, and when asked if this particular female would need to keep busy upon retirement, replied: “She would have to - even if she went to an ATSS or something during the day – just to give her something to do during the day otherwise she’d probably get pretty bored by herself…. she’d have people to talk to” (SP3).

**Accommodation post-retirement and the transition to aged care**

A number of service providers voiced their concerns about the future of the older adults with IDs in this study, in regard to being placed in facilities that were appropriate to their needs post-retirement. Nursing homes would be the sole option for many as they aged and service providers worried that staff at these establishments might not understand the needs of their clients as they age,
due to their limited experience and knowledge of people with IDs. One service provider’s concerns for her client were prompted by previous experience with another client who was placed in a nursing home for six week’s respite after a hospital stay, and her perception that the care this client received was inadequate (SP11 – for verbatim comments, see first quote in Table 4 below).

Another service provider, SP8, expressed worries about the future of all of the males who were currently working and living in a group home on a farm. This situation gave all of the residents the opportunity to maintain practical and life skills ranging from domestic duties, personal care, caring for animals and doing work on the property such as fencing. This gave all group home members a high degree of autonomy and multiple interests, which SP8 stated would be greatly missed by all of the men if they were moved to a nursing home as they aged. The loss of contact with animals would be particularly distressing for SU8. SP8 also noted that this was the happiest stage of these men’s lives, since they had suffered abuse in their earlier years when they were institutionalised.

[INSERT TABLE 4 HERE]

**Theme 5: WHO outcome of increased and well-established social network**

The quotes in Table 5 below illustrate the importance and sometimes the challenges of maintaining social networks. With their ageing parents now being either deceased or frail and in poor health, very few still had actively engaged family members who regularly visited or took them on outings – the following comment was typical, “I think he’s got some distant relatives, but none of them have really played much part in his life” (SP9). Instead, paid staff and volunteers, particularly those from church organisations, often formed a very large part of the social networks of older adults with IDs. According to service providers’ descriptions, approximately a fifth had non-existent or very limited informal social and support networks, either because friends and family had died or moved away or, in a few isolated instances, because they did not have the social skills to form or maintain relationships. For
example, SP5 described SU5 as not being part of a social group despite the opportunities that she had had in this regard, due to her not wanting “to do anything that requires learning” and her tendency to “fry everybody” and “exhaust” her carers. Her service provider concluded that SU5’s life was “full of conflict and very boring and laborious” (SP5).

[Intertable 5 about here]

Theme 6: WHO outcome of regular participation in community life, with friends/chosen acquaintances

Service providers felt the majority of their respective clients were participating actively in community life, although this was primarily through planned activities in external settings via their service providers, senior citizens clubs and the church. External organisations facilitated this participation, with those engaged in these activities typically being accompanied by staff and co-residents. One service provider explained how much the female who nominated her for interview really enjoys the various planned activities where she works (at ATSS) (“She likes it here. She never wants to stay home. Her mother said she’s always up and ready to go”), as well as being a current member of a craft club where members come together “to share ideas and run classes” (SP1). Many also described how the older adults under their care knew local shop-keepers and would have regular conversations with them whilst doing daily errands, as well as how leisure activities – especially bowling, swimming and going to the library – were greatly enjoyed. There were some gender differences, with service providers explaining that men particularly valuing going to the races and the sports-betting process, whereas women typically identified going to concerts, movies and specific art and craft activities as a highlight.

Discussion
This study focused on service providers’ perceptions of active ageing among older adults with lifelong IDs, analysing their responses against the six target WHO outcomes. Service providers, who are often uniquely placed to notice changes, felt that disability was not defining their clients, who were - for the most part - ‘actively ageing’. Critically, service providers themselves were found to play a primary role in promoting active ageing among their clients and also identified several key overarching barriers and facilitators that affected the extent to which these older adults with IDs could actively age. In terms of facilitators, service providers highlighted that the vast majority of their clients had a strong personal desire to keep active and keep learning new things. Key barriers to active ageing however, included the presence of small social networks able to provide unpaid support (thus reducing older adults’ potential opportunities for activity), leading to a heavy reliance on paid staff to facilitate activities; limited self-understanding of the ageing process among older adults with IDs and the management of subsequent health impacts; and issues surrounding transitions to aged care. There was a strong underlying sense that the environment, often created by service providers, was the key to whether an older person with an ID would actively age or not.

In relation to the WHO objectives specifically, the findings highlight their inter-relatedness. The capacity for individuals to experience ongoing development of their skills, engagement in a range of activities, as well as involvement within the broader community was found to be contingent upon factors such as health status and the size of their support networks. Nevertheless, considering each of the WHO objectives one by one from a service provider perspective serves to highlight efforts already being made to facilitate active ageing among older adults with IDs, as well as numerous factors that require attention in the delivery of services across various domains. Service providers in this study believed that older adults with IDs were, with their assistance, generally achieving the three social participation-related outcomes of: developing practical, leisure, or life enhancing, skills; enjoying a varied rhythm of life; and regularly participating in the general life of the community. Although a few led
quite isolated lives with limited activities, service providers felt that the majority were quite busy and active - although it is important to emphasise that these social activities were typically formal, organised activities with co-residents and staff. Achieving the WHO outcome of having an increased and well-established social network was more complicated, with service providers describing how they felt that, for the majority, most regular social interactions were not with family or friends, but instead limited to formal staff and/or volunteers. There was a sense that deceased or frail elderly parents no longer had the capacity to provide outings, and wider family members were often too busy for regular commitments. With the small existing body of international research on levels of social participation and activity among older adults with IDs (e.g., McCausland et al. 2010; Zijlstra & Vlaskamp 2005) reporting challenges in terms of the amount and quality of activities, it is encouraging to note that these service providers generally felt that their clients were active, empowered to drive their own activities and to choose what they wanted to do, as opposed to always fitting into existing programming. Whether service providers’ perceptions match the views of family members and older people themselves, however, is an issue for future research analyses.

Progress towards the WHO outcome of improved or maintained dietary and general health status was mixed. On the one hand, whereas some service providers proudly described the capacity of their clients to self-manage ongoing health challenges, such as diabetes, they more often described seeing a general health decline and ‘slowing’. Both service providers and their clients seemed to struggle to differentiate between ‘aches and pains’ that are part of the ageing process and more serious health issues; for example, one individual with an ID attributed significant pain to ‘just normal ageing’ when in fact, he needed a hip replacement. Several others had withdrawn from activities or started eating poorly after adverse events impacted their health (e.g., incontinence, operation). As managing the health impacts of ageing is challenging and can clearly create significant setbacks for older people with IDs, our research suggests that service providers need to be better educated about the ageing process and
encouraged to act on, not dismiss, any reports of pain or health concerns. As early treatment can significantly enhance quality of life, a proactive approach is needed for pain assessment and intervention among older people with IDs. Unfortunately, as older adults with IDs do not always understand pain signals or verbally express their pain well (Haveman et al. 2010) and since these are the first cohort of people with IDs to reach older age, even healthcare professionals are:

...ill prepared to recognize symptoms or appropriately examine patients who have the physical limitations, communication difficulties, or behavioral issues that often coexist in persons with ID. This often results in unsatisfactory clinical consultation, poor rapport, and inappropriate or suboptimal treatment choices (Perkins & Moran 2010, p.92).

Achieving the WHO outcome of maintaining challenge and productivity throughout old age was also challenging. The finding that many of the older adults with IDs in this study had given little thought to retirement appears to have both positive and negative implications. On the one hand, this may mean that their expectations are that they will continue to engage in activities as they have done in the past and will therefore seek to maintain their activity levels into the future. On the negative side however, the realities of ageing in terms of them tiring more easily, as well as experiencing the onset of physical health problems and/or a declining capacity to perform their usual tasks might be particularly difficult for older people with IDs because these eventualities are contrary to their expectations. Several service providers identified the need for a lengthy preparation period prior to ‘retirement’ for older adults with IDs, in order to minimise any adverse impacts experienced by them as a consequence of transitions that involve a distinct shift from one set of activities to reduced activities or placement in nursing homes. The need for this kind of preparation has been identified previously (Ashman et al. 1995, Llewellyn et al. 2004), with this research showing that these older adults – who represent a diverse range of personal histories, agency affiliations and places of residence – are also not prepared for the process of ageing.
Given that previous research has identified the positive impacts of a group counseling intervention program to help prepare adults with ID for the physical and psychological changes associated with ageing (e.g., Merrick et al. 2002), our results suggest that service providers and policymakers need to formally integrate the delivery of such programs into their planning.

Placement of older adults with lifelong IDs in nursing home facilities emerged as a key concern for several service providers, because of their fears that these establishments were ill-prepared to provide care appropriate to the particular needs of people with IDs. This finding points to the need for greater attention to be given to older adults with IDs and their needs during and post transition within aged care services, both in terms of policy, program development and professional training of direct-care staff. One of the key domains outlined in the current Australian National Standards for Disability Services is the meeting of “individual needs and personal goals” (Disability Studies and Research Centre 2010). Achieving this objective in regard to active ageing among older adults with IDs will rely in particular, on service providers’ expertise with individual clients, which as Schuengel et al. (2010) identifies, rests on their interpersonal relationships and knowledge of these clients. Interviews with service providers in this study revealed varying levels of tacit knowledge about their clients. While the majority demonstrated a keen interest in their client’s lives and wellbeing and histories with their level of care reflecting this, a few appeared to have little more than superficial knowledge of their clients and were thus unable to provide much information in relation to their respective clients’ current or past life experiences or possible futures in any comprehensive way. This provides support for the view that constant interaction between individuals with IDs and their service providers does not guarantee that the latter’s knowledge about the former will necessarily increase (Schuengel et al. 2010). Given that older adults with IDs have diverse backgrounds, living arrangements, work histories, experiences of abuse and skill ranges, it would seem essential that employers (governmental or agency) ensure that staff are chosen on the basis of their understanding that professional expertise with this group rests on
both their preparedness to build both strong interpersonal relationships with their clients and a comprehensive knowledge of their lives, both past and present. The experience of one service provider in this study, who managed to reverse her client’s social withdrawal after she experienced abusive treatment by a former service provider supports the argument made by Hall and Hall (2002) that direct-care staff have the potential to bring out the best and worst in their clients. Staff action or inaction in response to happenings in their clients’ day-to-day lives may have profound implications for their capacity to age in ways outlined by the WHO (2002).

Of course, our findings need to be interpreted with its limitations in mind. First, this analysis focused specifically on the views of service providers – whilst they play a key role in the lives of older people with ID, future research must explore the extent to which their perceptions are consistent, or not, with older people themselves and key family members. The sampling method used in this study means data is limited to the experiences of those adults with IDs who are currently working in sheltered workshops or attending skills training programs, and the experiences of those who work in other contexts or are not involved in programs are not represented here. Moreover, the older adults with IDs in this study nominated service providers, who were thus selected on the basis of their helpfulness. Their views cannot be taken in any way therefore, as being representative of all service providers. Second, our relatively small qualitative study focused on the experiences of individuals with relatively good communication skills, but a diverse range of histories, agency affiliations and places of residence; future research should use larger samples, more fully explore the impact of such contextual differences and also include people with moderate, severe and profound IDs. As the WHO active ageing outcomes do not appear to have been explicitly utilised in research or as practice guidelines, there is a clear need for more qualitative and quantitative research on the process, barriers and facilitators of active ageing for older people with IDs.
Overall, our results highlight a range of diverse factors that require consideration within the disability services sector when devising ways to promote and facilitate active ageing among older adults with IDs. Despite the uncertainties inherent in the individual variability of ageing and in the likelihood of emerging demand for services from people not currently in care, it will be critical for agencies to do their best to maintain an ongoing analysis of the probable impact of demographic change on their operations, both for the practical purposes of year-to-year program planning, and to help frame the longer term strategic issues. Critically, the unprecedented increase in this ageing population means it is essential that service providers are supported in their efforts to facilitate the active ageing experience for older adults with ID.

Conflicts of interest

The authors have declared no conflicts of interest.

Acknowledgements

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References


Table 1: Characteristics of participants

<table>
<thead>
<tr>
<th>Case</th>
<th>Service Providers (SP)</th>
<th>Service Users (SU)</th>
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</thead>
<tbody>
<tr>
<td></td>
<td>Nature of service provision</td>
<td>Gender</td>
</tr>
<tr>
<td>1</td>
<td>ATSS</td>
<td>Female</td>
</tr>
<tr>
<td>2</td>
<td>Sheltered workshop</td>
<td>Male</td>
</tr>
<tr>
<td>3</td>
<td>Sheltered workshop</td>
<td>Female</td>
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<tr>
<td>4</td>
<td>Sheltered workshop</td>
<td>Male</td>
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<tr>
<td>5</td>
<td>Disability case manager</td>
<td>Female</td>
</tr>
<tr>
<td>6</td>
<td>ATSS</td>
<td>Female</td>
</tr>
<tr>
<td>7</td>
<td>ATSS</td>
<td>Female</td>
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<tr>
<td>8</td>
<td>Sheltered workshop</td>
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<tr>
<td>9</td>
<td>ATSS</td>
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<tr>
<td>16</td>
<td>ATSS</td>
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</table>
Table 2: Service provider interview questions

Service provider participants were asked the following questions about their service user (SU)

1. What does getting older mean for SU?

2. Tell me about the things SU does with his/her day? Have these changed since getting older? How? [Prompts include: work, activities/leisure, learning how to do things, social (relationships), decision making, finances, housing (type, location), health]

3. How do you think getting older might affect SU? [Prompts include: work, activities/leisure, learning how to do things, social relationships, decision making, finances, housing (type, location), health]

4. Are there things stopping SU from having the life he/she wants in the future? Explain.

5. How would SU like his/her life to be in the future? [Prompts include: work, activities/leisure, learning how to do things, social relationships, decision making, finances, housing (type, location), health]

6. Are there things SU doesn’t want to do in the future? Explain.

7. What’s needed to help SU have the life he/she wants in the future?

8. What do you think active ageing means for SU and for older people with lifelong intellectual disability in general?

9. Is there anything else you would like to talk about?

Note: These questions are provided as samples only and are not all-inclusive, as full prompts are deleted for brevity
Table 3: Service providers’ perspectives on maintaining health and a varied rhythm of life

<table>
<thead>
<tr>
<th>Theme 2: Improved or maintained dietary and general health</th>
<th>Theme 3: A varied rhythm of life</th>
</tr>
</thead>
<tbody>
<tr>
<td>He’s got slower, yeah. Where he used to work five days a week, he now is down to three and for the last maybe two years, he keeps telling us he going to retire, going to retire (laughing). Well I suppose what he does now, he’ll keep doing it… until he drops dead. If he’s still with us he’ll just keep plodding along (SP2).</td>
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<td>Choice can keep someone stimulated and motivated, you can have a balance. My goal for SU6 is that she could sleep in every single day and have breakfast when she likes and when she wants to come in or join us or meet us at different places or come here on certain days, plan her day (SP6).</td>
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<td>She has bad eyesight, is an asthmatic and has cerebral palsy. Her mobility has perhaps slipped - she does wear a brace on her leg - and certainly perhaps her access a bit. (SP14).</td>
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<td>She loves to be a home body too. She loves her home, she loves to stay at home, if there are choices (SP14).</td>
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<tr>
<td>He just kept saying I’m old, I’m old, I’m old, you know I can’t do things but now that he knows it’s the hip and that he’s been in this incredible pain. It restricted his mobility to be able to attend a lot of things he used to do independently, so I think that is perhaps been a bit frustrating for him…he thinks once he’s had his hip operated on he’ll be able to do all those things that he used to do, which is, he used to love going dancing (SP13).</td>
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<td>She goes bowling I think twice, they go, they do different activities... bowling, I think they go to a movie, I think they go to barbecues. She doesn’t want to do anything that requires learning or I think, previous case manager, the one previous to her, tried to get her to do some cooking and that was a disaster, she threw a pot at someone (SP5).</td>
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<tr>
<td>She has diabetes and she has to have a needle with insulin in her stomach...she does it herself. The doctor thinks she’s competent enough to do it on her own and she knows everything about her sugar...if it’s high she knows, she has to get up and do more exercise. She is very aware about what is good for her and what’s not. She is aware of her health, her diet and exercise (SP10).</td>
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<tr>
<td>She goes bowling I think twice, they go, they do different activities... bowling, I think they go to a movie, I think they go to barbecues. She doesn’t want to do anything that requires learning or I think, previous case manager, the one previous to her, tried to get her to do some cooking and that was a disaster, she threw a pot at someone (SP5).</td>
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<tr>
<td>It is certainly not how he used to, he has certainly lost...he’s lost skills, certain skills. He’s got a three wheeler bike - he used to ride it quite a distance whereas now he’s rides it to work and home again. I suppose his mobility has had some impact on his social life and things that he chooses to do (SP16).</td>
<td></td>
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<tr>
<td>She would have to [stay active when retires] – even if she went to an ATSS or something during the day – just to give her something to do during the day otherwise she’d probably get pretty bored by herself. If she went there, she’d have people to talk to (SP3).</td>
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<td>She ended up with double pneumonia [after routine gall stones operation], so it was a real big thing. And she came out of hospital and she was just a mess you know, having a nervous breakdown. She put on a lot of weight, wasn’t cooking, she was eating a lot of junk…I’ve got no control over her eating habits (SP11).</td>
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<tr>
<td>She loves her independence, her independence is really important, she grasps it, any bits that she has - loves and just likes being out amongst it (SP11).</td>
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<tr>
<td>They get the opportunity to do a lot of things from the house. It’s a mobile house. Everyone in the house is mobile so they do a lot of social things. There is a dance every second Saturday night and they do day trips and he spends Thursday, he does a cooking program, in the afternoon. Wednesday’s he’s out bowling, he goes bowling I think...oh no, he goes bike riding in a bike program (SP16).</td>
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<td>She goes visiting Monday, does community singing at a Senior Citizens place. Tuesday and Thursday she works. Wednesday she goes to craft group (SP10).</td>
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Table 4: Service providers’ concerns about transitions to aged care

Sub-theme of Theme 4: Recognising challenge and productivity must continue throughout old age

She was sitting in this room by herself, had no socks on, she was blue….she was absolutely freezing and I said to the nurse, I said “listen she needs to have socks on her feet”. “That’s not my job”… so I rang my supervisor at the time… and I said to her, I said [name of other resident] is absolutely freezing in here, can something be done”? She said “if she’s in there, it’s [for] them to look after her, it’s got nothing to do with you”… so I tried. It was so hard. It is so hard to think of the future with these people. There’s nothing out there if SU11 had a complete breakdown. She’d end up in a nursing home or over in a mental thing [ward] in a hospital (SP11).

I think our people shouldn’t go off to the mainstream nursing homes…we want them out in communities, why can’t they go in [into] the community? (SP6).

I just wonder what’s going to happen to them all. When there’s no family or if they’re too old for [name of current accommodation], they’ll go into a nursing home and they’ll deteriorate really fast (SP8).

Moving SU10 anywhere else and putting her into a nursing home…I think that would be quite devastating (SP10).
Table 5: Service providers’ perspectives on maintaining social networks and active community life

<table>
<thead>
<tr>
<th>Theme 5: Increased and well-established social network</th>
<th>Theme 6: Regular participation in community life, with friends or chosen acquaintances</th>
</tr>
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<tbody>
<tr>
<td><strong>Wednesdays he goes out with a volunteer who’s a very good [friend]. They’ve built up a real rapport. They’ve been together for a number of years and Alan, his volunteer is about the same age as him so they go out into town and have a coffee, and talk about life...he used to also be very close to another volunteer, but she moved away (SP13).</strong></td>
<td><strong>Yeah she’s got a fair few friends here [at work]...pretty much all of them go to bowls. Three or four of them go to bowling. So they all associate on the weekends, for 4-5 hours at bowling (SP3).</strong></td>
</tr>
<tr>
<td><strong>Yes, absolutely, with her family and her brother and his wife. They’re very good, she’s got nieces and nephews, and it’s a very committed family. She travelled all around the world with her mother, she’d be able to tell you, the holidays to New Zealand and everywhere (SP7).</strong></td>
<td><strong>I know that he’s heavily involved in his church. They’ll come and pick him up and take him to the men’s meetings and things like that. They go to church every Sunday. He’s involved with the horses (SP2).</strong></td>
</tr>
<tr>
<td><strong>It’s mainly the church. I’m sure it’s just church people that she sees...they come and have tea with her as mainly she started to go to Lifeline. They’re lovely ladies so they include her in different things (SP11).</strong></td>
<td><strong>Most of her programs are centre based. Music four times a week. She goes to the YMCA to do gentle exercise, Friday fitness. And then [on] Friday she goes out for a mystery tour all day (SP14).</strong></td>
</tr>
<tr>
<td><strong>We run a lot of craft...and then they’ve got the library. Some of them go into the city library and go on the internet, go the movies [or] they might go to bowls (SP10).</strong></td>
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