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Active Ageing Among Older Adults With Lifelong Intellectual Disabilities: The Role of Familial and Nonfamilial Social Networks

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Little research has examined the extent to which active ageing is facilitated by family and nonfamilial support persons of older adults with intellectual disabilities. This study explores the role played by key unpaid carers/support persons of older adults with lifelong intellectual disabilities in facilitating “active ageing.” All key social network members conceived active ageing to mean ongoing activity. Family and extended family members were found to play a crucial role in facilitating independent living and providing opportunities for recreational pursuits for those living in group homes. Members of religious organizations and group home staff provided the same types of opportunities where family support was absent. The findings suggest the need for improvements in resource provision, staff training, and group home policy and building design.

Implications for Practice

- Improvements in group home policies, increased allocation of resources, and better training of group home and disability service staff can contribute to heightened activity and increased community participation for adults with intellectual disabilities.

The prioritization of active ageing in national health agendas has raised concerns about the needs of older adults with intellectual disabilities and how these needs might be met in a way that facilitates equity for this group compared with the rest of the ageing population. Changing patterns of service delivery toward deinstitutionalization in countries like the United States, United Kingdom, Canada, and Australia have served to increase emphasis on home and community care for people with intellectual disabilities (Bittles et al., 2002; Lemay, 2009). As a consequence, responsibility for the promotion and facilitation of active ageing among older adults with intellectual disabilities will largely fall on the shoulders of family members who are themselves part of the ageing population, younger relatives, and other social network members, as well as organizations and community groups that provide programs and services to this particular group—a responsibility that is set to be

shared by an increasing number of people, given that more individuals with intellectual disabilities are surviving into old age than ever before (Bittles et al., 2002; Janicki, Dalton, Henderson, & Davidson, 1999).

Older age represents a stage of life when older adults with intellectual disabilities are especially vulnerable—a period when they increasingly rely on group home staff for primary support (Webber, Bowers, & Bigby, 2010). The likelihood of individuals with intellectual disabilities residing with family members is known to decline substantially as they age. Research from the United Kingdom suggests that after the age of 50 years, around 70% live in supported accommodation and 30% live with family—representing a reversal of the pattern observed for those under 50 years of age (30% supported accommodation; 70% living in the family home) (Emerson, Hatton, Felce, & Murphy, 2001). Similarly, data collected in the 1990s suggest that the vast majority of Australian adults with intellectual disabilities aged 55 years and over live in either a hostel, supported dwelling, nursing home, or large institution (Ashman, Suttie, & Bramley, 1995), and that apart from those living with a relative, most have infrequent contact with family and friends (Ashman & Suttie, 1996). Research undertaken in hospital settings highlights the key role played by family members in ensuring quality of care for older adults with intellectual disabilities: providing not only direct care during hospitalization but also crucial information about patients' likes, dislikes, fears, and idiosyncratic behaviors to hospital staff so as to improve patients' hospital experiences (Webber et al., 2010). The value of family members' expertise in ensuring quality of care is supported by evidence gathered from family members and hospital staff (Hemsley, Balandin, & Togher, 2008). Siblings and other relatives have been observed to play a less active role than parents as carers in hospital settings, however, because of circumstances such as living far away and work and family commitments (Webber et al., 2010). In the absence of family members, group home or disability services staff often fulfill this role—either as part of their paid employment or on a voluntary basis because of staffing shortages or budgetary constraints (Webber et al., 2010). It has been argued, however, that high-quality care to people with intellectual disabilities by professional caregivers depends on the caregivers being both attached and attuned to the particularities of each individual under their care (Schuengel, Kef, Damen, & Worm, 2010).

Research has shown repeatedly that the size of social networks of individuals with intellectual disabilities is small compared with their counterparts in the general population and with those with physical disabilities (Lippold & Burns, 2009). This presents significant obstacles to the achievement of key outcomes that the World Health Organization (WHO; 2000) has outlined for assessing the presence of active ageing

among older adults with intellectual disabilities, including the development of practical, leisure, or life-enhancing skills; ongoing challenge and productivity; and regular participation in the general life of the community with friends and acquaintances of one's own preference. The increased likelihood of older adults with intellectual disabilities living somewhere other than with family as they age means that they will necessarily have to rely heavily on people such as service providers, volunteers, and group home staff for opportunities that facilitate active ageing. Overall, the available evidence suggests, however, that many from this population have limited access to these kinds of opportunities. After undertaking a systematic review of empirical studies that have investigated community participation among individuals with intellectual disabilities (published between 1996 and 2006), Verdonschot, de Witte, Reichrath, Buntinx, and Curfs (2009) observed that the most consistent findings across studies were that levels of community participation among people with intellectual disabilities are much lower than they are for nondisabled persons or other disability groups, and that those living in community settings have higher levels of participation than those who live in segregated settings. In a study undertaken in the mid-1990s in Australia, levels of involvement in community-based leisure and recreational programs were found to be relatively low for both retirees and those working part time, with the most commonly reported involvement being club activities provided by church or day care (52.3% of retirees and 18.8% of those working part time; Ashman et al., 1995). Even though a sizable proportion of retirees were found to be attending at least one type of program provided by disability services (60.5% attended craft and hobbies programs), relatively few of those engaged in part-time work attended any type of recreation or leisure program offered by the disability service sector (activity centers—18.8%; special senior citizens—6.3%; craft and hobbies—15.6%; and social activities—12.5%; Ashman & Suttie, 1996).

In order for active ageing objectives to be met for the ageing population of Australians with intellectual disabilities, significant headway will need to be made in regard to increasing work, leisure, and recreational opportunities for members of this population, thereby requiring increasing levels of input from persons who can facilitate these opportunities. While quantitative studies indicate that direct care of older adults with intellectual disabilities from family members declines with age, little is currently known about the extent that they and others act as facilitators of active ageing for this population or the obstacles they face in fulfilling this role. This article reports on qualitative research that examines this topic, considering those who live in supported accommodation as well as those who live in private dwellings.

Methods

Sample

Disability service providers in Queensland and Victoria, Australia, were asked to identify service users who met the two eligibility criteria for participating in interviews (namely, being over 50 years old and having the capacity to communicate verbally). Sixteen service users were located, including 6 men and 10 women aged between 52 and 80 years who had all been either born with an intellectual disability or acquired it during childhood. Half of these service users were engaged in work, and the remaining individuals regularly attended some type of day program such as Adult Training Support Services. Each of the 16 service users were asked to nominate one key person who provided them with unpaid care or support to also be part of the study, and it is these 16 service users and their respective nominated individuals who formed the sample for the current study. These 32 informants were interviewed for the purpose of exploring the everyday lives of older adults with intellectual disabilities as they age, from their own perspective as well as that of their respective key unpaid carers/support persons. Only 5 of the carers (or support persons) nominated for interview by service users were members of their immediate family; 6 were members of extended family networks; and 5 were friends who had met service users at some stage during their adult lives, with the length of these relationships ranging from 1.5 to 25 years. Relevant characteristics of each of the 16 pairs of informants are provided in Table 1. (Note that the term “service users” is used throughout the Results and Discussion sections of this article to refer to the older adults with intellectual disabilities in this study, due to the sampling method employed.)

Table 1. *Characteristics of Service Users and Their Respective Unpaid Carers/Support Persons*

Participant pair *	Service user			Key carer** or support person		
	Name	Age	Work status	Accommodation	Relationship	Nonfamilial relationship context
1a & b	Amanda	62	Involuntarily retired	Family home	Mother	–
2a & b	Andrew	62	Sheltered workshop	Family home	Sister	–
3a & b	Beverly	54	Sheltered workshop	Rental suburban unit	Stepmother-in-law	–
4a & b	Brian	56	Sheltered workshop	Own house	Brother	–
5a & b	Carole	59	Never worked	Own unit	Cousin (Female)	–
6a & b	Deidre	80	Retired	Group home	Niece	–
7a & b	Elizabeth	64	Never worked	Group home	Brother	–
8a & b	Colin	61	Sheltered workshop	Group home	Stepfather	–
9a & b	David	56	Used to work at sheltered workshop	Group home	Niece	–
10a & b	Frances	62	Involuntarily retired; currently doing voluntary work	Group home	Sister-in-law	–
11a & b	Grace	52	Voluntary work	Rental private unit (supported housing)	Friend (Duration 25 yrs; Female)	Church organization
12a & b	Heather	60	Voluntary work in the past	Group home	Support person (Duration 8 yrs; Female)	Program instructor
13a & b	Edward	71	Retired; voluntary work in the past	Group home	Friend (Duration 14 yrs; Male)	Service organization volunteer

14a & b	Ivy	53	Part-time work	Group home	Mother	-
15a & b	Janet	68	Sheltered workshop	Group home	Support person (Duration 18 mo.)	After hours program instructor
16a & b	Frederick	69	Retired; used to work in sheltered workshop	Group home	Friend (Duration 9 yrs; Male)	Church organization

* For each pair of participants, the letter “a” refers to the service user, while “b” refers to his or her key carer/support person. ** Including primary and secondary carers.

Interviews

Ethical clearance for this study was obtained from a university Human Ethics Research Committee. Written informed consent was gained from all interviewees before their participation. The open-ended questions and probes used during the semistructured interviews with the 16 service users and their 16 key carers/support persons were initially devised in response to information gathered from three focus group sessions. These sessions were held prior to the interviews as a means to identify the key areas of importance to older adults with intellectual disabilities as they age from three different perspectives within the caregiving relationship (involving separate sessions comprising 4 service users, 4 carers/support persons, and 4 service providers). Although similar questions and probes were used in the interviews conducted subsequently (with 16 service users and then their nominated unpaid carers/support persons), the wording of the questions differed slightly, such that those asked of the 16 service users tapped information about various aspects of their own lives, while those asked of their carers tapped their perceptions of these same life domains of the service users for whom they provided care. Interviews ranged in length from 30 to 90 minutes.

Analysis

A phenomenological approach was taken in conducting this research in order to gain insight into people's lived experience as perceived by those living the experiences (Moustakas, 1994). All interviews were audiotaped and transcribed verbatim, with these transcripts being read and reread as an initial step before being uploaded to NVivo 8™, a software management tool used for managing, exploring, and analyzing qualitative data. The data were explored for (a) information supplied by those providing primary or supplementary care for older adults with intellectual disabilities, about the meaning of active ageing for this group, as well as the history and nature of the care and support they provide; and (b) information supplied by service users in relation to their social interactions and activities within and outside of their current home environments. Data were coded into categories and concepts, with the results being reported according to the themes that emerged from the data. The anonymity of participants was protected through the use of pseudonyms for the older adults with intellectual disabilities in this study (service users) and the use of participant numbers for their respective carers/support persons in the findings.

Results

In this section, carers' and support persons' conceptions of ageing are discussed first; the main findings are then reported under thematic headings.

Carers' and support persons' conceptions of "active ageing." In terms of the meanings ascribed to the term "active ageing," the majority of carers/support persons conceived these two words to mean the ongoing capacity of those under their care to continue engaging in the activities in which they were currently participating, until such time that a decline in physical health status might necessitate the cessation of one or more activities. For a few interviewees, however, this term implied the need for increased opportunities for activity, because they perceived that the individuals to whom they were providing care or support were predominantly inactive (particularly David and Edward—Participants 9b and 13b).

Loss of service users' original primary caregivers. While the majority (14) of service users had been raised by one or both parents during their childhood, only 2 (Amanda, 62 years old, and Ivy, 53 years old) had parents who were still living. David's grandparents (his primary carers until early adolescence) were also deceased, while Grace, who never knew her mother and was fostered as a baby and subsequently institutionalized during childhood, had an aunt who was still living.

Independence

Two particular kinds of independence emerged as being important to older adults with intellectual disabilities, including engaging in everyday activities as part of the general community and performing tasks autonomously. As might be expected, service users living in private accommodation were the ones who had the greatest opportunities to carry out their daily activities as part of the general community and to do various tasks by themselves. Among the 6 service users who lived in private accommodation, siblings and extended family members were those who made this arrangement possible. Three of these family members provided various kinds of support that enabled their relatives to enjoy a high level of independence on a daily basis, with this support being tailored to their particular needs.

Brian (56 years old), for example, lived in his original family home on his own, managing all routine activities himself (with the exception of banking and shopping—an outside carer visited twice a week to perform these particular tasks). It was his brother who dealt with all the nonroutine matters of daily living, thereby allowing Brian to live by himself. Brian's brother attributed Brian's ability to function independently to the fact that he had been able to maintain his routine at home without interruption throughout his life and stated that it would be the "crisis of his life" if Brian ever had to leave the family home—this would inevitably break Brian's routine and thus compromise his capacity to function effectively. Brian's brother noted that this current level of independence was only achieved during the past decade, following the death of his mother. He commented that Brian "went ahead in leaps and bounds" after his mother's death because he started doing much more for himself, including domestic chores (for the first time in his life) with encouragement from his mother's cousin to "do things for himself."

For Andrew (62 years old), it was his sister's live-in support that fostered his considerable autonomy both at home and within the wider community. They lived in their own home, and Andrew traveled by train to and from work 3 days a week. Andrew also kept a horse on their property and regularly went riding. He takes responsibility for doing a range of chores around their home including mowing, gardening, cooking, washing, and ironing.

The independent living arrangement of Beverly (54 years old) and her husband (a fellow worker at the sheltered workshop where she worked) was made possible through assistance provided by her husband's stepmother, who had provided care and support to the couple for a period of 20 years. She helped the couple with daily needs such as shopping for grocery items and household items and lived nearby to their rented unit so that she could ensure that they would have any other assistance when needed, and she did likewise for her own son who had an intellectual disability as well. Although both Beverly and her husband shared domestic chores, her husband did all the cooking because Ivy was unable to safely operate the stovetop and oven: "She's liable to put the potatoes on to boil and go away and forget about them until they burn," said Participant 3b.

Two other women living in private accommodation—Carole (59 years old) and Grace (52 years old)—both lived in a unit on their own. Carole owned her own unit while Grace rented a unit within a supported housing complex. Carole's move into her own unit followed an extended period of living in her family home with three different family carers who had all predeceased her. After initially moving to a retirement village and

experiencing conflict with fellow village residents, Carole made the decision to purchase her own unit.

Assistance from her first cousin, who visited and took her shopping each week, as well as a neighbor who cooked meals to last her 3 to 4 days (Carole would buy takeaways on the remaining days of the week), enabled her to maintain this independent living arrangement. By contrast, Grace did all of her own cooking and domestic chores and managed her own financial affairs. Her support person was part of Grace's social network (including three other female friends); she met Grace through a religious organization (at a Crossroads meeting) 25 years ago. She commented that despite Grace being fostered as a child for a few years (she never knew her mother), institutionalized during her childhood, and subsequently placed in a group home, she is now highly independent and active within the wider community. Grace's friend believed that Grace had improved considerably since she had shifted out of the group home into a unit of her own. When asked about the differences in her life in the present compared to the past, Grace stated, "I'm proud that I've achieved so much." While feeling confident about being able to do everything she needed to do for herself, Grace believed that the only exception would be finding her own accommodation within the wider community:

If I was living in a private place like, for example, real estate, and the real estate said to me, "You have to get out and go find another place to live," I wouldn't be able to do that on my own. That's the only thing; I do the shopping, the baking, do everything else myself.

Unlike the 5 service users mentioned earlier, Amanda (62 years old), who lived in the family home with her parents, depended on both her parents and service providers for most things apart from self-care. Her mother noted that Amanda's main activity at home was cross-stitching and that she had to be prompted to do this because she would otherwise simply "sit all day." Nevertheless, Amanda would help her mother with some of the domestic chores: "I help her with the tea, and I cut the vegetables up for her every night, and I set the table for her, and I wash up, and I wipe up for her, and I wash up every weekend," stated Amanda.

In stark contrast to service users living in private accommodation, most of those living in group homes were found to have limited opportunities to engage with the wider community or perform daily tasks by themselves apart from self-care, with the exception of Colin, whose group home was situated in a rural location on a large property. Colin was able to spend his time fishing, keeping a dog and horse, and riding his motorbike. He stated that he enjoyed doing things on his own. The location of a farming equipment store on a neighboring property also allowed him the freedom to go shopping by himself: "I go next door.... I buy stuff for myself."

Apart from Colin, only 2 others of the 10 living in group homes appeared to have the freedom to go out unaccompanied at any stage. One woman, Heather, aged 60 years, sometimes had to go by taxi to the slot machines, and at other times, she was driven by car by a group home staff member. One man, aged 69 years, had a three-wheeler bicycle that he was able to use to go shopping on his own: “I go down town with it and go in and do myself a little shopping myself...what I want” (Frederick). The majority of those living in group homes were found to have little independence, with their daily activities being organized by group home staff.

Engagement in recreational and leisure pursuits. The extent that family and nonfamily members facilitated opportunities for their relatives to participate in recreational and leisure pursuits (either alone or in the company of others) varied considerably between individuals. Table 2 provides a summary of service users’ activities, classified according to whether these were home-based (including both indoors and outdoors) or occurred outside of the home environment (with those who facilitated the latter being identified in the “Facilitator” column). Service users are also categorized into two separate groups according to their type of accommodation (in the leftmost column).

Table 2. *Recreational and Leisure Activities Among Service Users*

Accommodation	Name	Recreational and leisure activity		
		Inside home	Outside home	Facilitator
Private home or unit	Amanda	Cross-stitching, computer, making recipe books, watching horse racing on TV	Rare these days due to mother’s age and remaining mostly at home; get-togethers with sisters and their children	Mother; parents/sisters
	Andrew	Looks after own horse/horse riding on own property; time with nieces and nephews	Member of Men’s Society; weekly church services	Sister
	Beverly	Telephoning friends; reading magazines	Indoor bowls (weekly); visiting friends; outings with husband’s family	Self with husband; friends transport to and from home; husband’s family
	Brian	Reading newspapers; gardening	Indoor bowls (weekly); Returned Services League with friends (monthly); weekly church services; family get-togethers	Self; friends; siblings
	Carole	Watching TV and videos	Community program 4 days per week (involves range of activities including dancing,	Community organization; cousin

Group home	Grace	Sewing and craft	barbeques, bowling, computer, etc); family get-togethers Overnight stays at friends' houses (4); travels interstate; visits aged aunt	Friends; sister twice each year
	Deidre	Embroidery; cooking; knitting	Regular overnight stays with niece and sister (has own bedroom there); senior citizens	Niece; group home
	Elizabeth	Brother and sister-in-law visit every two weeks; colouring	Travelling (occasional); Senior Citizens	Brother and sister-in-law; group home
	Colin	Fishing; keeping animals; motorbike riding; watching TV; playing pool	Various outings; visits to stepfather's house (has own bedroom there)	Group home staff; stepfather
	David	Inactive – sometimes watches TV	Day outings with family each fortnight Visits brother with autism	Niece
	Frances	Watching TV, reading; (prefers company of staff only)	Day trips to brother's and sister-in-law's home, and does colouring, scrapbooking and painting with their two children; dancing	Sister-in-law (past 7 yrs only due to living interstate); group home
	Heather	(prefers company of staff only); gym exercises once a week; visits from former group home staff members; watching TV (especially football)	Regular outings eg. shopping and a meal; pokies; Senior Citizens concerts once a week; visits the aged in nursing home	Brother; self by taxi; group home staff; program instructor
	Edward	Computer, cooking	Day long barbeque each Friday; shopping and dancing	Service organization volunteer; group home staff
	Ivy	Gym exercises twice weekly; exercising on rowing machine	Stays with parents one night per week (has own bedroom there); a drive and walks on weekends	Mother, father; group home staff
	Janet	Sewing, knitting, craft	Visits brother in nursing home once or twice a month; visits brother and his wife at Christmas time each year; occasional socials; line dancing once a week	After-hours peer program instructor (for last 18 mo.); brother and sister-in-law; group home staff
Frederick	Watching TV; crossword puzzles; friend visits once or twice a week; listening to music	Attends church weekly and goes for a drive after church; visits friend's brother who has cerebral palsy; dancing (fortnightly); indoor bowling once a week; goes shopping	Friend of 9 years from local church; church members; group home staff member; self (three-wheeler bike)	

Of the 10 service users living in group home accommodation, 6 were found to have regular contact with family and/or extended family members at their homes, enjoying family get-togethers (often involving a mix of

younger relatives and their children) and a range of different types of outings. Three of these 6 had a bedroom of their own within their respective families' homes. Even though Janet had contact with three family members, she only visited her brother and his wife at Christmas each year and was taken by her after-hours peer instructor to visit her brother in a nursing home once or twice a month. Two men (Edward and Frederick) were found to have no contact with family members at all and relied on a service organization volunteer and a friend from a local church, respectively, for activities that took place within the wider community (independent of any involvement of their group homes). While overall, those living in private accommodation appeared to have far more opportunities to participate in activities within the general community than those living in group home settings, Amanda was an exception. Because her mother mostly stayed at home at the time of the study, Amanda's outings with her mother had decreased substantially. Her mother stated, "It's just that I don't go out....I take her up to the park, but that's about all."

Two key problems associated with group home accommodation identified at interview were a lack of activity (particularly on weekends) and a heavy reliance on fellow group home members for company and social interaction. One female service user stated that "the weekend's the worst because we've got nothing to do on the weekends much." When asked by the researcher interviewer, "What do you do on the weekends?", she replied "Just hang out clothes and things like that or fold up clothes.... Jane gets me to empty the dishwasher or load the dishwasher for my exercise" (Frances, aged 62 years). David's niece also drew attention to lack of activity as an issue for all of the people living in her uncle's group home. Her long-standing knowledge of David and his life allowed her the opportunity to compare his life in the days when institutionalization policies were in place (when he lived with about 50 people) to the time of the study when he was in group accommodation with far fewer people. From her perspective, people living in her uncle's group home had much less to do to keep them occupied than previously. She believed that this had led directly to behavioral problems in the house because of residents' "sheer boredom." Being segregated from the wider community by virtue of being accommodated in a group home was also identified as a factor that inhibited activity. Two service users (Frances and Heather) were described by their relatives as having little to do with their fellow housemates and much preferring the company of staff.

A caring role was found to be played by 4 service users (Grace, Heather, Janet, and Frederick) as part of their activities in the wider community, facilitated by nonfamilial network members (Participants 11b, 12b, 15b, and 16b).

Problem solving by carers. Family members were found to play an important problem-solving role by taking action in response to various problems that potentially inhibit or restrict the activities of older adults with intellectual disabilities as they negotiate their daily lives. Four examples are provided next.

Although Andrew (62 years old) enjoys a high degree of independence in being able to travel on his own to and from work, he began to experience taunts from schoolchildren at the local train station, which consequently made him anxious about train travel. His sister purchased a mobile phone so that Andrew could phone her immediately in the case of an emergency, and she also started routinely picking him up from the station after work. Her actions served to alleviate his anxiety, and he had since continued to travel by train without any reoccurrence of the problem.

Several other interviewees outlined the details of circumstances arising for those living in group homes that required their attention and action. Ivy's mother was told by a direct-care female staff member at Ivy's group home that she and another staff member had been disturbed by Ivy "eavesdropping" on their conversations. In response, Ivy's mother explained to her that because of Ivy's limited eyesight (she is legally blind), she relied on hearing as her primary means of sensing what is going on around her and that she would not have intentionally eavesdropped on their private conversation; she advised that they should simply move to an alternative location away from Ivy, if and when they wished to have a private conversation. This may have averted ongoing negative perceptions being held about her daughter by staff within the home. Another family member, Colin's stepfather, commented that he had found it necessary to monitor the expenses charged to his stepson at the farm-based group home where Colin resided after finding that he had been overcharged for items such as mileage.

The most serious problem described by interviewees involved nondisclosure of a traumatic event that took place during attendance at a day program. David (56 years old) was sexually assaulted by a fellow service user diagnosed with Fragile X Syndrome-2 years ago. His niece witnessed a sudden and major deterioration in her uncle over that time. She recalled that David had developed many different life skills after being

institutionalized at the age of 13 years, since his grandparents, who were his primary carers during his childhood, had previously done everything for him:

He couldn't do a thing for himself. My granddad used to shave him, he did everything for him, because they didn't know any better.... I don't know how long he'd been there [in the institution], but I remember going to see him. He would make his own bed, do his own hair, shave himself. I was utterly amazed!

Following the introduction of deinstitutionalization policies, David moved to a group home and began participating in numerous community-based activities. The transition in David's behavior from being highly active and enthusiastic about these activities (up until 2 years ago) to the point where he had become loathe to engage in any activities whatsoever prompted his niece to make several enquiries at his group home to determine the reasons for this major change in her uncle. No explanation was forthcoming. After finally discovering that her uncle had been sexually assaulted from information supplied to her by a staff member from another group home (who was privy to information about the assault), she insisted that staff from David's group home provide him with some sort of assistance. Although he subsequently received several sessions of counseling, his niece believed that he required further treatment than what had been provided to date in order for him to make any real improvement.

Barriers to active ageing. One key barrier to active ageing that emerged for older adults with intellectual disabilities in this study was the lack of close family members' facilitating their participation in daily family life at home as well as within the general community, either because of the death of parents and older siblings or because the parents or siblings had themselves become infirm and needed care themselves. In some cases, potential input from family members was observed to be lost through lack of interest from siblings who chose to have little or no contact with their sister or brother or because they resided in a geographic location that made face-to-face contact an infrequent event. Others stay in the family home with younger members of their extended family and participate in family life; however, the family members' work and own family commitments meant that this form of support was necessarily limited to what was workable at the time. In Frances's case, the time she could spend with family was constrained by her health status. Her sister-in-law's

hesitation about administering insulin injections to help manage Frances's diabetes served to preclude overnight stays, thereby restricting her time with them to day visits only.

Other barriers to active ageing that were explicitly identified by family members and were structural rather than individual in nature included issues associated with loss of job opportunities; the ways in which some group homes are built, organized, or run; and insufficient resources available to fund activities. In relation to job opportunities, Ivy's mother highlighted that she had observed a shift away from "productive work" for older adults with intellectual disabilities over the past 7 years. She commented that light industrial work seemed to have disappeared, with paid work being replaced with "keeping people occupied with activities." She attributed this change to the amalgamation of various organizations into what she termed a "big conglomerate" and believed this change represented a backward step through the loss of opportunity for people like her daughter (aged 53 years) to do productive work.

Group home design was identified by 3 interviewees as limiting the activities of individuals living in group homes because their rooms only allow for storage of basic, essential items. Two of these interviewees continued to provide their relatives (who lived in two different group homes) with their own bedroom in the family home, thus giving them the opportunity to maintain activities associated with their own personal interests when they visited. Colin's group home accommodation was described by his stepfather as follows:

Someone had a bright idea and it wasn't really a bad idea, but it fell short. They built four separate little huts [with] three bedrooms in it—one, two, three, it might have been four [each with] a little kitchen, bathroom, and toilet. They're a very good idea, but the only trouble was you can't swing a cat in the bedrooms. I told [name of organization] once, that a prison cell would give them more room and comfort.

A lack of resources was cited by David's niece as having limited opportunities for recreational and leisure pursuits among residents living at her uncle's group home. She stated that she had observed a decline in outings organized for residents over time, such that people just seemed to "stay there" rather than go to movies or bowling as they used to do, and she assumed that this was because of government funding cuts. Her main concern was for other residents in the home who did not have family to take them out:

Like at least for David, I come over every second weekend, and he comes out and spends the day with us or half a day with us. For some of them who have no family...they're not getting a chance to go

anywhere. I just wonder if that's going to escalate the ageing process just through sheer boredom—like, if your brain's not stimulated.

Importance of accrued knowledge over time. Considering all of the information supplied by family members and other support persons about the care and support they provided to the older adults with intellectual disabilities in this study, it is clear that the latter group benefited greatly from those within the former group who held accrued knowledge of their life experiences over time. These benefits ranged from having primary attention given to their likes and dislikes, to activities or outings being arranged for them in line with their personal preferences, to being met with acceptance and understanding when their behavior is what might appear to others as being idiosyncratic or troublesome, to having someone committed to finding solutions for problems that arise when living independently or in group home settings. Although family members tended to be the ones who held the greatest store of knowledge about their relatives (spanning most of their relatives' lives) and thus had insight into their present-day lives within the context of their pasts, both Grace's and Frederick's support persons (Participants 11b and 16b) also demonstrated a detailed knowledge of their family histories, history of care, past and present activities, joys, sorrows, and aspirations, as well as a commitment to ensure what is necessary to help keep them active and engaged. For instance, while Frederick's friend praised the current management of Frederick's group home, "the leadership there is one of the best I've ever seen in operation. I think she is a very, very switched on woman in her attitude towards it all, supportive to everyone that's there," he also stated that he would take steps to address any lack of activity that might arise if there should be some change in the way the group home was managed in the future.

Discussion

The proportion of the service users in this study who live in group accommodation (62.5%) is similar to that found in the United Kingdom (70%) among its large population of older adults with intellectual disabilities (Emerson et al., 2001). It is important to note that when interpreting the findings from this study, however, the service users in the sample were recruited on the basis of their involvement in work or day programs, and thus their levels of activity and family involvement may not be representative of those experienced by their counterparts who have little or no contact with disability service programs. Nevertheless, the findings provide

insight into the varied life circumstances of older adults with intellectual disabilities, considering both those living in supported accommodation and those living in private dwellings.

The findings from this study suggest that individuals who play a key social support role for older adults with intellectual disabilities share a similar view of active ageing as meaning ongoing activity throughout the ageing process. Family and extended family members were found to play a crucial role in facilitating independent living arrangements that promote autonomy, the maintenance of practical skills, community participation, and the pursuit of interests in line with individuals' preferences, as well as providing those living in group homes with ongoing opportunities to participate in various recreational and leisure activities as part of their families' lives. Thus, familial networks were found to play an important role in facilitating active ageing for older adults with intellectual disabilities, as outlined by WHO (2000). While this particular finding would seem inconsistent with Ashman and Suttie's (1996) observation that apart from those living with a relative, most older adults with intellectual disabilities have infrequent contact with family, this may be a consequence of the current study's reliance on a much smaller sample than this earlier study with the same target population. Alternatively, it may be that this study was able to capture a more comprehensive picture of their social contacts by relying on interviews rather than survey data. The fact that the majority of service users' parents were already deceased meant that siblings and other members of their extended families were the ones who provided opportunities for activity. Issues associated with geographic location and family- and work-related commitments were found to prevent some siblings and other extended family members from having greater contact (both in terms of frequency and duration) with their relatives living in group homes, consistent with findings from previous research (Webber et al., 2010). In those cases where family members played little or no role in service users' lives, others (including group home staff and friends from religious organizations) played a crucial role in enabling them to participate in the wider community and to engage in recreational and leisure activities on a regular basis. Ashman and Suttie's (1996) finding that religious organizations provide much needed opportunities for community participation among older adults with intellectual disabilities appears relevant to the present study, given that 2 service users in this study reported having strong friendships with members of religious organizations that provided them access to companionship, social support, and participation in numerous community-based activities—some of which were organized to involve whole groups of individuals with intellectual disabilities. Nevertheless, for some group home residents, participation in community activities

was limited, their social networks were small, and the majority of their social interactions took place in segregated settings—issues that have been identified repeatedly by previous research (Lippold & Burns, 2009; Verdonschot et al., 2009).

From a life course perspective, immediate family members were found to be both facilitators and inhibitors of active ageing in this study. Through consideration of the life histories of service users, it is clear that the efforts of parents to ensure that their children with intellectual disabilities gain as much independence and lead active and fulfilling lives as they mature and grow old were taken up by other family members when/if the parents were deceased. In such cases, active ageing principles were inculcated in early life and had continued into older age. However, a number of interviewees identified primary caregivers in childhood as having been overprotective, thereby setting trajectories of dependence. In these cases, it fell to either other family members or direct-care staff (in institutions or residential group homes) to teach basic life skills such as cooking, self-care, and domestic chores and to promote participation in learning and recreational pursuits. It was thus not until adulthood that independent action and heightened activity were encouraged and fostered.

Several of the findings have direct implications for social work practice in relation to advocacy and direct involvement with the disability service sector. The first is the case of a male service user experiencing a drastic decline in his usual activities after being sexually assaulted by a fellow attendee of a day program, without his niece being formally and directly notified of this traumatic event. This suggests that direct-care staff in group homes and service providers need to be encouraged to work in collaboration with family and nonfamily social support persons to ensure that they are properly informed about any event that has the potential to adversely affect the well-being of older adults with intellectual disabilities as they age. Given that aggressive behaviors have been found in epidemiological research to be common among people with intellectual disabilities (Cooper et al., 2009), individuals attending day programs or living in group homes are at risk of experiencing verbal and physical assaults from fellow service users and housemates. Although only one experience of serious assault was discussed in the results section (within the context of problem solving by carers), another male service user in this study had also been physically attacked by a fellow resident at his group home with a gardening tool, and several others mentioned individuals within their present or past group homes, institutions, or day programs who made them feel uncomfortable or unsafe—leading them to avoid certain activities. It is essential therefore that policies are in place in each of these contexts that encourage

prompt and effective staff responses to ensure that harm is minimized for those affected over both the short and long term.

Second, the loss of family input into the lives of older adults with intellectual disabilities (whether from death, age-related illness, geographic location, work and family commitments, or unwillingness to be involved) represents a loss of long-term knowledge of the context of their lives, including their past experiences; specific needs, desires, likes, and dislikes; and idiosyncrasies. This form of expertise (known as “tacit knowledge”) is now argued to be an essential attribute of direct-care staff to ensure delivery of high-quality care and support to individuals with intellectual disabilities (Schuengel et al., 2010). Given that group home staff (and subsequently nursing home staff as the ageing process progresses) will be the ones who have the responsibility for the day-to-day care of this population as they age in the majority of cases, it would seem imperative that this kind of expertise be prioritized in both the selection and training of staff in these sectors, and that strategies be devised and implemented in a way that ensures that key knowledge is not lost through staff turnover.

Third, the management, location, and design of group homes have the potential to either hinder or promote active ageing. Access to transport, residents’ room design, and resource allocation all require due consideration for maximizing residents’ participation in activities within and outside of the confines of group homes. Research that specifically investigates differences in activity levels among older adults with intellectual disabilities according to the design, location, and organizational practices of group homes could potentially help to uncover the extent that these aspects promote or hinder active ageing and thus inform best practice in relation to the setting up and operation of group accommodation for members of this population.

Finally, the capacity to participate in productive work and to engage with the general community was highlighted by several family members as being of central importance to successful ageing among their relatives. The view that facilitating active ageing among all Australians is “a shared responsibility of governments, business, industry, community organizations, individuals, and the community in general”—as is currently being promoted by the Australian government (Department of Health and Ageing, 2008)—raises questions about the extent that all of these stakeholders will direct their efforts toward ensuring that older adults with intellectual disabilities gain as much attention and access to resources as the rest of the ageing population. New and innovative programs that provide opportunities for both paid work and community engagement are needed if older adults are to achieve equity in the area of active ageing.

References

- Ashman, A. F., & Suttie, J. N. (1996). The social and community involvement of older Australians with intellectual disabilities. *Journal of Intellectual Disability Research, 40*(2), 120–129.
- Ashman, A. F., Suttie, J. N., & Bramley, J. (1995). Employment, retirement and elderly persons with an intellectual disability. *Journal of Intellectual Disability Research, 39*(2), 107–115.
- Bittles, A. H., Petterson, B. A., Sullivan, S. G., Hussain, R., Glasson, E. J., & Montgomery, P. D. (2002). The influence of intellectual disability on life expectancy. *Journal of Gerontology: Medical Sciences, 57A*(7), M470–M472.
- Cooper, S.-A., Smiley, E., Jackson, A., Finlayson, J., Allan, L., Mantry, D., et al. (2009). Adults with intellectual disabilities: Prevalence, incidence and remission of aggressive behaviour and related factors. *Journal of Disability Research, 53*(3), 217–232.
- Department of Health and Ageing. (2008). *Ageing and aged care in Australia*. Canberra: Commonwealth of Australia.
- Emerson, E., Hatton, C., Felce, D., & Murphy, G. (2001). *Learning disabilities: The fundamental facts*. London, UK: Foundation for People With Learning Disabilities.
- Hemsley, B., Balandin, S., & Togher, L. (2008). Professionals' views on the roles and needs of family carers of adults with cerebral palsy and complex communication needs in hospital. *Journal of Intellectual & Developmental Disability, 33*(2), 127–136.
- Janicki, M. P., Dalton, A., Henderson, C., & Davidson, P. (1999). Mortality and morbidity among older adults with intellectual disability: Health services considerations. *Disability and Rehabilitation, 21*, 284–294.
- Lemay, R. A. (2009). Deinstitutionalization of people with developmental disabilities: A review of the literature. *Canadian Journal of Community Mental Health, 28*(1), 181–194.
- Lippold, T., & Burns, J. (2009). Social support and intellectual disabilities: A comparison between social networks of adults with intellectual disability and those with physical disability. *Journal of Intellectual Disability Research, 53*(5), 463–473.
- Moustakas, C. (1994). *Phenomenological research methods*. Thousand Oaks, CA: SAGE.
- Schuengel, C., Kef, S., Damen, S., & Worm, M. (2010). “People who need people”: Attachment and professional caregiving. *Journal of Intellectual Disability Research, 54*, 38–47.

Verdonschot, M. M. L., de Witte, L. P., Reichrath, E., Buntinx, W. H. E., & Curfs, L. M. G. (2009). Community participation of people with an intellectual disability: A review of empirical findings. *Journal of Intellectual Disability Research*, 53(4), 303–318.

Webber, R., Bowers, B., & Bigby, C. (2010). Hospital experiences of older people with intellectual disability: Responses of group home staff and family members. *Journal of Intellectual & Developmental Disability*, 35(3), 155–164.

World Health Organization. (2000). *Ageing and intellectual disabilities—improving longevity and promoting health ageing: A summative report*. Geneva, Switzerland: Author.

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