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## **Issues of Active Ageing: Perceptions of older people with lifelong intellectual disability**

**Objective(s):** *The study aimed to (1) investigate the lived experiences of older people with lifelong intellectual disability and (2) explore the meaning of active ageing for this group.*

**Methods:** *Data were collected using semi-structured interviews with 16 service users (people with lifelong intellectual disability aged 50+ years); 16 service providers and 16 key informal network members from regional/rural and urban areas in Queensland and Victoria.*

**Results:** *Themes identified: being empowered, being actively involved, having a sense of security, maintaining skills and learning, having congenial living arrangements, having optimal health and fitness, being safe and feeling safe and having satisfying relationships and support.*

**Conclusions:** *Service users wanted to “keep on keeping-on” in areas of life that gave them pleasure rather than discontinuing them because of age. They wanted more control over issues affecting their lives and to be given meaningful roles. Mental stimulation, companionship, reliable support and safety were valued by this group.*

**Key words:** *Active ageing, service providers, lived experiences of older people with lifelong intellectual disability, support, safety.*

### **Introduction**

Active Ageing is a 21<sup>st</sup> century global approach to older people achieving healthy, productive, safe and fulfilling lifestyles. According to the World Health Organisation [1] active ageing is the “process of optimising opportunities for health, participation and security in order to enhance quality of life as people age” (p. 12). Essentially it is about people being physically active, and continuing their participation in social, economic, cultural, spiritual, and civic affairs in older age. Recent Australian studies in this area include the Australian Active Ageing survey of National Senior members [2] and research by Western Australia Department for Community Development [3] that has developed Active Ageing Benchmark Indicators. These studies conceptualise active ageing for older people in terms of being pro active in keeping healthy, eating well and being physically and mentally active, living in safe environments, working and actively participating in family and community life. However, these studies do not indicate how active ageing is conceptualised for older people with an intellectual disability. Indeed there is a general absence of literature on active ageing for this population of older people.

‘Ageing’, for older people with lifelong intellectual disability is a relatively new phenomenon and we are only now seeing the first substantial group of older adults

with lifelong intellectual disability reach old age [4, 5]. Many are now surviving to their mid 60s, and some are living well beyond this age. Until more recent times, people with intellectual disability were not expected to survive past their 20s and certainly they were not expected to outlive their parents [6]. Traditionally, this group were either cared for at home or lived 'separately' from society within institutions. In Australia, older people with lifelong intellectual disability represent a small but growing cohort of our ageing population and today, many are living independently in the community, or are cared for at home or in supported living accommodation. With these changes has come a host of new challenges in terms of lifestyle support issues as they move through this new 'unknown' phase of their lives.

The aim of this paper is to present the issues of active ageing of a subset of older people with intellectual disability, based on their experiences in older age and their goals/expectations for the future. Seeking the views of the people themselves is significant, as much of the research in the disability field has traditionally drawn upon the perspectives of others, rather than including those of the people themselves [7]. By adopting this approach, the research provides insight into how this group would like to experience this next phase of their lives, as opposed to others' expectations or plans.

## **Method**

Sixteen case studies across two Australian states were conducted. Each case study comprised a service user (a person with an intellectual disability aged over 50 years who could communicate verbally); a key informal network member (KINM) (a person who had frequent contact with the service user for at least 3 years, and whose relationship was not in a paid/work capacity); and a service provider (staff who had hands-on service delivery or front line management within either a disability or aged care service).

## **Sample**

Participants were identified by using purposive sampling strategies, which is particularly useful for locating 'difficult to reach' and 'particular types' of cases for in-depth interviewing [8]. Service users who were known to have sufficient verbal skills to be able to participate in the interviews were identified by assisting

community organisations. Each service user who agreed to participate, nominated a KINM and a service provider to also participate in the study. Inclusion of people with intellectual disabilities in research is critically important as they are the experts on their own experiences, however, potential benefits must be weighed against the risks. In particular, ensuring participation is voluntary given the unequal relationships experienced between people with intellectual disability and service providers who facilitate recruitment, avoiding a tendency to acquiesce when answering questions and being certain that the purpose of research is fully understood and consent is informed [9]. We sought to guard against some of these risks by use of Plain English information sheets, seeking consent from both the person with intellectual disability and someone who knew them well who had discussed it with them, and through use of open ended questions rather than closed questions.

The sample of sixteen service users (aged 52 – 80 years) comprised six males and ten females. Ten service users lived in shared support accommodation, three lived alone and three lived with family members. Five service users were in paid employment and three were involved in voluntary community work in locations such as charity retail outlets. Those not involved in work activities, regularly attended some type of day program such as Adult Training Support Services (ATSS) or aged/disability services.

This article focuses on the comments and perceptions of the service users. Views of the KINM and service providers will be addressed in the future.

### **Interviews**

Face-to-face semi-structured interviews were conducted each lasting 60-90 minutes. The WHO [1] framework of Active Ageing guided the development of the interview schedule. An interview guide set out the broad topics to be explored, including the service users' experiences in older age, and their hopes and expectations for the future. The topics for all three groups focused on daily activities, how getting older affected them, and how they would like life to be in the future. In each of these sections they were asked about work, other activities, learning, social relationships, decision-making, finances, housing and health. The questions were open ended and were followed by probes as necessary. This format enabled the phrasing of initial and follow up questions to be adapted by the interviewers, who were both experienced in

working with people with intellectual disability, and ensured participants had the opportunity to express their understandings of ageing and their future aspirations in their own terms.

### Data Management and Analysis

All interviews were audio-taped and transcribed verbatim. Data analysis followed an inductive process, using the constant comparative method as outlined by Glaser and Strauss [10]. This involved a process of coding, developing categories and constantly comparing and regrouping these categories to explore the meaning of active ageing for this group.

### Results

The findings suggested that the older people with lifelong intellectual disability in this study essentially wanted and needed the same things in later life as the general population of older people in the community. Eight key categories emerged from the data. Each category overlapped the other, and all were important in terms of the individual’s ability to age actively and positively. These categories were: being empowered; being actively involved; having a sense of security; maintaining skills and learning; having congenial living arrangements; having optimal health and fitness, being safe and feeling safe; and having satisfactory relationships and support. See Figure 1.

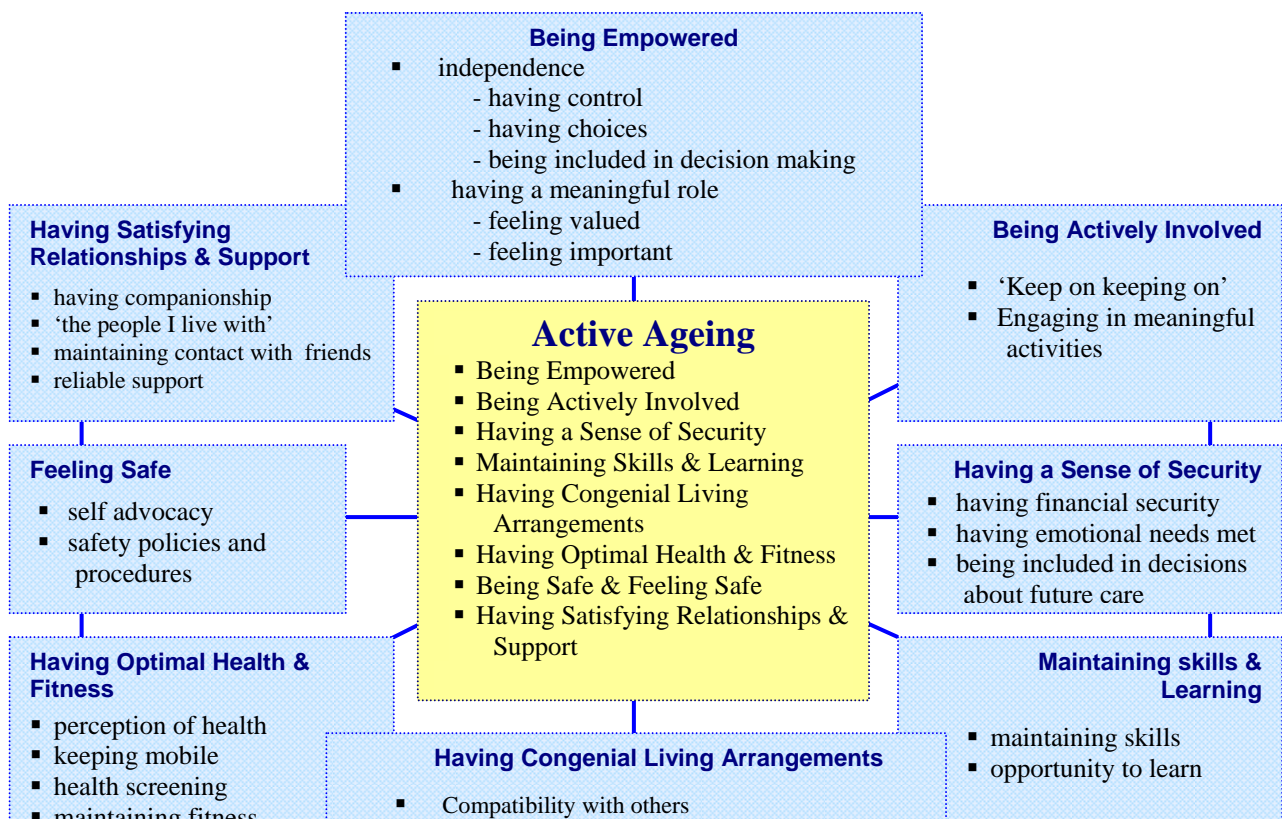


Figure 1: Preliminary framework for developing an integrated Active Ageing Model:  
Issues identified by 16 older adults with lifelong intellectual disability

### **Being Empowered**

The themes of empowerment and independence emerged as central in the lives of these participants as illustrated in the observations of one service user who previously had spent years within institutions. She explained:

*“I like to be as independent as much as I can.. I’ve been to every residential .. It was [an] institution, I used to get locked up in my room...” (female)*

Having the opportunity to be involved in making decisions about issues that affect their lives and to have real choice featured as a major driver of concern for many service users. Similarly having a meaningful role in life and feeling valued was also an important contributor to feeling empowered. As indicated by one of the participants who stated:

*...the Deacon down there said “would you like to be a Server for me?” I said “yes”...also I’m a side person ....hand out the books and collect the money...I also light the candle (male)*

### **Being Actively Involved**

Having a daily routine that includes meaningful activities that keeps them busy and actively engaged were clearly important aspects to their lives. Boredom featured as something to be avoided if at all possible, but was commonly reported by many participants as a regular feature of their day. One service user explained how they keep busy and get jobs done:

*If something wants doing...I’ll do it straight away (female)*

Those who were active members in leisure groups/organisations, wanted to keep doing these activities in the future. Similarly, those who were still working wanted to continue. It represented a very important part of their lives, gave meaning and purpose to their days and provided social interaction and friendships. Individualised planning as opposed to group-focused plans enabled service users to achieve satisfying and meaningful experiences.

### **Having a Sense of Security**

Having a sense of security impacted many aspects of their lives. Three areas of sense of security areas were identified: financial, emotional and future care. Those living in shared supported accommodation were not concerned to any great extent about their financial security. However, those living independently were more aware of these matters and a few were unhappy about how their finances were managed.

Their emotional sense of security meant having their emotional needs met and was closely linked to the maintenance of their day-to-day routine, including familiarity with their environment. As one service user explained:

*S/user: I know more people there and know where everything is there.*  
*Int: You got shops near there?*  
*S/user: Yeah – right on the corner. If it's closed at night, I just have to walk down to the garage there. Or just catch the train (male)*

The future did not feature as a major concern for some of the participants. Several had had some discussion with their families, but few had formal plans in place. Most assumed that their life and daily activities would continue as usual. However, one person was aware of future plans being made by her family, which did not make her happy.

*S/user: ...when I get really old I have to go to a nursing home*  
*Int: And how do you feel about living in a nursing home?*  
*S/user: Terrible (female)*

### **Maintaining Skills & Learning**

Life long learning and the maintenance of current skills were an important aspect to many of the participants. They felt that having the opportunity to learn new and exciting skills or activities kept them engaged with their community and in their daily lives. Several wanted to keep learning in areas that they were already familiar with,

such as improving reading and writing, or using the computer. A few wanted to take courses or keep on learning:

*“I’ve been doing first aid training...I know how to do it” (male)*

*Int: You want to learn things on the computer?*

*S/user: Yeah I’m just doing the Christmas cards on the computer (female)*

*Int: ...you’re learning to drive a forklift?*

*S/user: Yeah. I had my first day.... I went straight on me own (male)*

### **Having Congenial Living Arrangements**

Service users valued having their own space, their own quiet room, and they wanted to live in convenient location near places of interest, shops and transport:

*...it’s quiet at home, no fights. Nice and comfy. Get on well together...it’s handy. It’s just across the road from the station (female)*

Living arrangements impacted significantly on their sense of wellbeing and in shared supported accommodation, this was largely dependent upon the quality of relationships between house members (including staff). Those living in shared supported accommodation wanted to live with people they liked. However, their involvement in these decisions did not seem to occur and a few service users disliked living with certain others because of their behaviour.

### **Having Optimal Health & Fitness**

‘Health’ did not emerge as a major concern. Most participants perceived they were healthy even though many had one or more health conditions. Visual and hearing problems were experienced by several, which was contributing to change in their lives, such as limiting the nature of activities in which they could effectively be involved. Many felt they were slowing down or getting tired and problems with walking, falls and in particular, hip and knee conditions (some requiring surgery), were their main health concerns.

Generally, those who had no problems with mobility, enjoyed walking, exercising and were interested in maintaining their fitness and health:

*I go to line dancing....good exercise, good moving around, better than sitting down all the time (female)*

*I go out for a ride on my bike (male)*

Some however, did little exercise and seemed to lack motivation to engage in activities that required physical exertion. These service users were generally unhappy or were dissatisfied with their lives.

### **Being Safe & Feeling Safe**

A number of participants described experiences of abuse or threatening situations which led them to highly value safety, including being safe and feeling safe. Some felt that the situation they were in did not make them feel safe, with reports of harm from other service users featuring most often. These incidents reportedly occurred in group homes/day centres run by disability service organisations, or during transit. Sexual assault, mental abuse and physical assaults such as strikes across the face, bruising to torso from being kicked and pinched, and a stabbing incident were described. The following description was provided by a service provider:

*...this particular client, he'll pick up anything and use it – knives – anything he can get his hands on...we were all sitting outside....this other client came out ...he just picked up a steel rake...it was one of those narrow steel rakes and it just went straight into the arm (male)*

### **Having Satisfying Relationships & Support**

Companionship and friendship were described as having someone to do activities with and someone with whom they could have a trusting and satisfying relationship. Some participants said that belonging to an organisation such as a church or social group, or place of employment, enhanced their social interaction and supported friendships. Not all service users had friends or family which often resulted in socially isolated lives which greatly impacted on them.

Most service users needed both informal and formal support to enable them to achieve those activities and goals which were most meaningful to them. One participant describes the impact of an unreliable service provider:

*I had a phone call from [organisation] saying “I’m sorry, I won’t be able to do it”. Why would they say? Why did they say that they’re going to do something and then they turn around and rang me up and tell me they couldn’t do it? (female)*

## **Discussion**

The concept of active ageing is increasingly being used in policy arenas within the ageing sector to promote healthy lifestyles for our ageing population. Our research has focused on understanding what this concept means for older people with lifelong intellectual disability by eliciting their perceptions of what they want and need as they become older. We found that this group had similar wants and aspirations to those of the broader ageing population. However, we also found that achieving these was often impeded because of a lack of appropriate support or because of the controlling influence of others. Our findings strongly suggest that ‘empowerment’ or ‘disempowerment’ were key factors underpinning the attainment of active ageing for the service users in our study.

We also found that service users wanted to ‘keep on keeping on’. That is, despite reaching older age, most wanted to maintain their routines, they wanted to keep active, and to keep doing those things in life which interested them. Retirement was generally not something they thought about. Perhaps this was because the context they brought to the process of ageing was somewhat different from the broader population and this was likely to impact on how they engage with the process of getting older. For instance, many have experienced significant lifestyle changes in recent years such as moving from a protective sheltered family life or moving from the controlling environments of institutions into more ‘normalised’ community living, with some experiencing independent living for the first time or a more ‘liberated’ lifestyle in supported group homes. These changes meant new experiences and learning opportunities, such as travelling, learning new skills (such as operating televisions, videos, DVDs and personal computers), participating in leisure activities such as dancing and bowling or other social group activities, or in paid or voluntary work and most importantly, being given more say in their lives were available opportunities. These opportunities enriched their lives by building upon their skills and increasing their social interaction. Many now have meaningful roles which give them purpose in life. They are not keen to ‘retire’ or to relinquish these new found interests.

However, while many service users experienced these positive changes in their lives, we also found that many were still living very controlled lives. Yet, with every new experience, every new skill and every new opportunity, they are growing as

individuals and their hopes and 'dreams' are broadening. Thus, ageing for this group is a new phase of 'activity' or 'potential activity' that builds upon their lifetime experiences and understandably most were not thinking about 'retiring' from their current activities just because they were getting older (if indeed they were aware of their ageing). Most were clear about what they wanted or did not want to do in the future. They wanted to experience more, not less, in their lives, to have someone to do these activities with, and to have more influence in decisions that affect their lives. These parallel with expectations held by the broader population, who according to recent studies, want to remain active and engaged in many activities well into their older age [2, 3, 11].

Interestingly, service users who had been provided with opportunities to extend their worldview, such as through learning new skills, having responsibilities or participating in stimulating environments, did not think of themselves as 'old'. It is important to note however, that the majority of our sample was in their 50s and 60s, therefore the views presented in this paper may not necessarily reflect those of much older service users. Further research incorporating the views of service users aged 70 years and over is recommended and would make an interesting comparative study.

## **Conclusion**

This paper has identified the key issues of active ageing as perceived by a group of older people with intellectual disability, and it has highlighted what they perceive as important in their lives. The paper has pointed out that for many service users, their current circumstances do not reflect an active engagement in life and fail to meet their 'dreams' or 'expectations'. It has been highlighted that many service users have had different experiences in the latter part of their lives that have led to new expectations on their part. What they now want is clearly paralleling what the general population want in older age, but there is considerable difference between what this group of service users presently have and what they would like. The findings suggest that safe environments and personalised lifestyle planning that reflect individual needs and aspirations, will help empower them to achieve a more meaningful and active lifestyle in the future.

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## **Key Points**

- Older people with lifelong intellectual disability want to “keep on keeping-on”
- Being empowered key issue for this group achieving active ageing
- Eight areas of active ageing for this group: empowerment, relationships, activity, safety, health & fitness, living arrangements, learning, security

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