Research
Another minority group: use of aged care day programs and community leisure services by older people with lifelong disability

Christine Bigby
School of Social Work and Social Policy, La Trobe University, Bundoora, Victoria, Australia

Susan Balandin
School of Communication Science, The University of Sydney, Sydney, New South Wales, Australia

Objective: *This study examined the extent to which programs available to the general aged community are accessible to older people with lifelong disability.*
Method: *Forty Victorian generic aged day activity and community leisure programs used by older people responded to a survey that sought information on the extent to which such services are used by older people with a lifelong disability.*
Results: *More than half of these services are accessed by a small number of people with lifelong disability and overall there was a willingness to include this group in generic services. Barriers and solutions to successful generic service use were reported.*
Conclusions: *The findings indicate that the issues for people with lifelong disability differ little from those of other minority groups. It is proposed that disability services have a role in brokering services for their older clients, and continued planning and collaboration between disability and aged services will benefit all older people.*

Key words: *ageing and intellectual disability, disability, specialist and mainstream services.*

Introduction
Older people who have lived with a disability for most of their life, such as those with developmental or physical disability acquired during childhood or their early adult years, can be deemed to have a lifelong disability. Lifelong disability specifically excludes those with aged related disabilities (e.g. age related hearing loss, arthritis, dementia). Living with a lifelong disability affects life course experiences and is likely to impact on support needs and experiences during the ageing process [1–2]. For example, living with a cognitive impairment or severe physical disability may impact on the need for informal supports (e.g. ongoing care from family members or friends [1]), the degree of community inclusion achieved during the individual's life, and the level of financial security available in old age [3]. It is not known if generic services for older people are suitable for or indeed desired by their ageing peers with lifelong disability.

Correspondence to: Dr Christine Bigby, La Trobe University.
Email: c.bigby@latrobe.edu.au

Currently the number of people ageing with a lifelong disability is small, but due to their increased life expectancy and the demographic bulge associated with the baby boomers born between 1945 and 1964, their number will increase quite dramatically over the next 20 years [4]. They will nonetheless remain a small proportion of the general aged population. For example, the number of people with intellectual disability, who are the largest subgroup of older people with a lifelong disability, will increase by 68% over the next 20 years but from a very small base of 5323 people to 8921 or 0.13% of the total population aged over 55 years [4]. Nevertheless, both the community and aged services will need to accommodate an increasing number of older Australians with lifelong disability. Already service providers and policy makers are asking if their needs are the same as those of their non-disabled peers or peers who acquire a disability as part of their ageing process.

The applicability of retirement to people with lifelong disability, particularly intellectual disability, is contested. This group has low participation in the labour force. Many who are now ageing have spent much of their life in sheltered employment or day programs for people with disabilities which may no longer be suitable for them [5–6]. Those who are employed may be unwilling to take retirement and the resulting loss of status, income and social contact [7–8]. The overarching question is therefore, not whether older people with lifelong disability should retire from their employment or day programs but rather what type of day support programs will meet their needs for ongoing meaningful activities and participation in the community.

The concepts of inclusion and participation are at the core of both international and Australian policy for people with disabilities [9–10]. These concepts are also found in broader social policies on ageing and community building at the federal and state levels. The translation of such concepts into practice suggests day activity and leisure programs available to the general community of older people should also be accessible to those ageing with a lifelong disability. However, an Australian survey of older people with intellectual disability indicated that the majority used specialist disability funded day programs available to all age groups [8]. Since this survey, in the absence of strong policy leadership, there have been a number of small innovative local initiatives across Australia resulting in the delivery of new disability funded day support services to older people [3]. Many of these services have sought partnerships with, or access to, mainstream day programs for their clients. However, it is debatable whether people with lifelong disability should be reliant on disability programs to negotiate and

support access to mainstream day programs available to the general community. It is also not clear if these generic programs offer an appropriate model of service for this group of Australians.

In 2000, the Australian National Disability Administrators group began a process of policy development around ageing, and funded a project to examine and recommend directions for day support options for older adults with lifelong disability [11]. This paper reports the finding of a survey, conducted as part of the larger project, that examined the extent to which programs available to the general aged community are used by and accessible to older people with lifelong disability.

Method

The population studied was older people with lifelong disability aged 55 years and over. Definitions of old age selected by researchers reflect differences in culture and life expectancy within and between developing and developed nations. Fifty-five years was used to define an older person with lifelong disability. In Australia this is the age commonly used to denote an older person in this group [11–12].

A postal survey was sent to all the aged care day programs and community leisure services in two regions of Victoria, a total of 133 services. Forty-eight surveys were sent to a rural region that included a provincial town, and 85 were sent to an inner city region. Local and regional community information directories were used to compile the list of services. The survey was addressed to the service coordinator and only those services likely to have a paid staff member available to complete the survey were included. Smaller informal groups, such as Senior Citizens clubs organised by volunteers, were excluded on the basis that it was unreasonable and unethical to request volunteers to complete information on the personal details of others who participate in a leisure activity.

The postal survey was designed to collect data on the extent of participation by older people with lifelong disability in generic day and leisure programs available to older people in the community. Also, it targeted issues that may arise for service providers attempting to accommodate older people with lifelong disability in generic programs for older people.

The survey sought information about the nature of the service, its aims, programs offered, hours of operation and the demographics of its participants. In particular, it sought information about the number and characteristics of people with lifelong disability who participated and the types of activities in which they participated. Questions were included about the specific programs or policies for this group of older people and if their participation raised any particular problems for the service. The survey had 29 questions, both open (e.g. Has this program developed any particular initiatives to support access and participation of older people with a lifelong disability? Please describe) and closed (e.g. Do any of the people using your program aged 55 and over have a lifelong disability?).

An explanatory letter, requesting that the survey be completed and returned within 2 weeks, was sent with the survey to the coordinator of each program. A follow up phone call was made 4 weeks later to remind staff to complete the survey form.

The quantitative data was analysed using descriptive statistics that included frequencies and percentages. Qualitative data were entered into the N Vivo program [13] and examined and coded for common themes. A thematic analysis of the data from open-ended questions was conducted using a constant comparative method [14]. Specifically, the responses were read to develop a set of objectively defined and mutually exclusive response categories (e.g. lack of resources). As additional data were analysed it was often necessary to expand and create new categories to accommodate responses that did not fit into an existing category. The aim was to develop and catalogue the least number of categories that would adequately summarise the data.

Results

Responses

One hundred and thirty-three survey forms were sent out and 46 were returned, although six of these were incomplete and were not used in the analysis. The overall response rate of 30% was similar to a national survey of specialist day disability programs conducted at the same time as part of the overall project [15]. Seventeen surveys (35%) were returned from rural programs and 23 (27%) from the inner city region. It was not clear why there was a better response from the rural region, nor was it possible to surmise if services that did not respond differed in any way from those services that did participate. However, the responses included the three main types of day activity and leisure programs that Bigby [16] noted older people used (i.e. neighbourhood houses, day care programs and community leisure services). Most of the day care programs were Adult Day Activity and Support Services (ADASS), which are day centres funded by the Home and Community Care (HACC) program. These are targeted primarily at the frail aged, but also include some services designed for younger disability specific groups such as people with acquired brain injury. The programs that responded had, on average, 93 participants, with a mean of 49 participants over 55 years. Most participants attended a variety of time-limited sessions during each week.

Participation by older people with a lifelong disability

Twenty-six (65%) of the 40 programs reported participation by at least one older person with a lifelong disability. As shown in Table 1, over half of all three types of program available to the general community of older people are accessed by older people with lifelong disability. They participated in a broad range of social, recreational and health related activities, including outings, exercise, podiatry, luncheons, arts and crafts, bingo, walking, painting, and educational classes such as literacy, computer skills, numeracy and cooking.

Table 1: Number of participating aged care and generic leisure services used by older people with lifelong disability

Type of service	No. city (%)*	No. rural (%)*	Total (%)
Neighbourhood houses	5 (63)	7 (78)	11 (65)
Aged care day programs	5 (71)	2 (67)	7 (70)
Community based leisure	4 (50)	3 (60)	7 (54)
Total	14 (61)	12 (71)	26 (65)

*Percentage of total number of services that responded.

The number of older participants with a lifelong disability in programs ranged from 1 to 55, but in all instances they comprised only a small proportion of all participants. It was notable that, despite stating a willingness to include older people with lifelong disability, none of the ethno-specific programs included anyone from this group. One ethnic agency noted the difficulty of reaching those in their particular community with disabilities as 'they do not like to expose their difficulties to others' and proposed a greater need for individual family support services.

Many respondents noted it was hard both to be exact about the number of older participants with lifelong disability and to specify the nature of their disabilities. Responses from services that did provide this data pointed to the diversity of this group, which included people with psychiatric, intellectual, physical and sensory disabilities, with the first three predominating, as well as those with acquired brain injury or chronic illnesses. There was, however, a strong sense that the particular nature of the disability was not important:

> *There is no differentiation between types of disability, lifelong or otherwise.*

Participation issues for older people with lifelong disability

Forty-eight percent of responding programs reported difficulties in accommodating people who are ageing with lifelong disability. The need for additional support to facilitate participation was the most frequently identified issue. The three most commonly identified types of additional support required were: accessible transport (e.g. buses with lifts and hoists); basic facilities such as disabled toilets and accessible buildings; and human resources (e.g. paid or volunteer staff to provide individualised support). Another common issue identified was the need to resource and train professional staff and volunteers in the tasks associated with supporting people with lifelong disability to participate in programs. Other factors mentioned included the need for specialised equipment (e.g. computer touch screens), cross agency support, additional space to accommodate wheelchairs and equipment, and the extra support staff required. The personal characteristics of some people with lifelong disability (e.g. poor concentration, limited social skills, challenging behaviour, mobility problems) were seen to create barriers to participation. Such characteristics can also make finding appropriate activities and fostering a sense of belonging difficult but not insurmountable.

> *Appropriateness of a group or activity can be problematic, but we work very hard to overcome each individual's particular circumstance to make situations inclusive and valuing.*

Eight services (20%) reported instances where an older person with lifelong disability had been prevented from participating. Reasons cited included inability to physically access the program, inability to find a class at a suitable level with an appropriate mix of participants, social behavioural problems, the need for and unavailability of one to one support for a program.

Adaptation to needs

Twenty respondents (50%) reported provision of additional support to older people with a lifelong disability. This included creating an accessible environment by the use of ramps, small classes or operation of an access and equity policy. It also included the provision of support workers or volunteers for individual assistance. The responses to open-ended questions demonstrated both a willingness of respondents to include older people with lifelong disability and a desire to work together with disability services to achieve this. Some comments were:

> *People with a lifelong disability are regarded as being no different to the rest of our service users except that they often require extra resourcing.*

> *How can we do it or could we do it . . . we have never had to turn someone away . . . hope we never have to.*

> *What ever peoples' interests are we try to accommodate them.*

Only six (15%) respondents reported the development of programs specifically designed for older people with lifelong disability. These programs fell into three broad strategies: (a) acting as a host or base for another organisation that provided a specialist program; (b) design and delivery of specially designed programs in partnership with an external disability specific organisation; and (c) internal design and delivery of classes, programs or activities exclusively for people with disabilities.

One-third of programs reported the existence of policies that supported and promoted inclusion of all minority groups. These policies included access, equal opportunity, volunteer and grievance procedures. Comments included:

> *Council has an access and equity policy.*

> *All people with a disability have access, not necessary to have a specific policy [for this group].*

Similarly, one-third reported initiatives to implement such policies. These included training volunteers to work with people with lifelong disability, adaptations to make the building or transport physically accessible, liaison with groups in the community with knowledge about people with disabilities, providing specialist computer equipment or additional staff resources, and holding forums to discuss the needs of specific groups.

Forty-two percent of programs reported contact with other organisations or the use of resources to assist in access issues, but as with policies and other initiatives these were relevant to a range of minority groups, not just people with a lifelong disability. Respondents reported a variety of useful resources. They included the Inclusive Communities manual produced by the Association of Neighbourhood Learning Centers (ANLC), training provided by HACC programs, disability organisations such as Adult Training and Support Services, local shire community services, community health services, psychiatric hospitals, and local aged and disability service networks. Another identified the support received from a large non-government organisation in modifying the environment for those with vision impairments.

We have regular contact with mental health and community health agencies and these have proved most beneficial.

Only one organisation referred to people with disabilities being 'dumped' and difficulties encountered when trying to access specialist support from the disability service sector:

They leave individuals without support information or discussion with coordinator.

Discussion
The results of this study give an indication of the willingness of day support and leisure services available to older people in the community to accommodate those with lifelong disability, and the issues that arise in ensuring accessibility. The finding that over half of the aged care and community leisure services in this survey had at least one older person with a disability unrelated to ageing, supports earlier findings by Bigby [16] that older people with intellectual disability in Victoria use community based aged care and day support services. The current findings suggest that community based services have a strong commitment to inclusion.

Access was reported as poor, but was generally viewed in terms of physical access such as accessible buildings and transport, rather than the more complex social access barriers that often confront integration of minority groups, particularly those with intellectual disability. These findings reflect those of earlier studies that individual characteristics such as poor motivation, lack of choice, or lack of skills may hinder participation in activities [17–18]. However, the results support Hawkins' conclusion that structural and contextual elements such as availability of staff support and other factors such as attitudes of other participants are important when considering the use of generic aged services for older people with lifelong disability [19]. In a multicultural society such as Australia, it is a concern that as yet none of the ethno-specific programs are providing support to older people with a lifelong disability. Although there are differences in how a disability may be viewed within diverse cultures [20], there is no information on how such differences impact on ethno service provision for older people with lifelong disability, including Aboriginals and Torres Strait Islanders.

The policy shift towards 'healthy ageing' [21] has increased the range of community based leisure services geared to encouraging an active lifestyle and targeting the well aged. Older people can select from a smorgasbord of activities in some communities, however, it is clear from this study and the literature that although many services are willing to accommodate people with disabilities and have access and equity policies in place, they require additional resources such as staff training, extra staff or volunteers, physical adaptations to the environment or transport to make access for all groups a reality. Support at both an organisational and individual level is often necessary to achieve successful integration of a person with a lifelong disability [22]. Older people with lifelong disability are perceived as just one of the many different minority groups encompassed by equal opportunity and access policies that services try to accommodate. The current findings suggest that access issues relevant to older people with lifelong disability do not have to be singled out from those of other minority groups. Thus, this group together with other minority groups is likely to benefit from generic policies and resources that support inclusion. Services demonstrated a willingness to collaborate with specialist organisations, although there was evidence of mixed perceptions of the responsiveness of such organisations, no doubt reflecting agency differences within the broader communities in different localities.

Limitations
Although the response rate to the survey was similar to that of the national study [15], the sample was small. Consequently, these results must be reviewed with some degree of caution. Nevertheless, the study provides a clear indication that older people with a lifelong disability are accessing services and barriers and solutions to service access that require further investigation.

Conclusion
This study demonstrates that there is potential both to build on and support the inclusive attitudes demonstrated by the generic aged service sector and to foster the use of these types of service by older people with lifelong disability. There is also potential for successful collaboration between specialist disability day programs seeking access to community-based programs for their older clients with lifelong disability.

It is important to remember that the views of older people with disabilities, particularly intellectual disabilities, have not been widely canvassed in respect to their preferences for support in later life. However, another part of the larger study [11], did seek their views on day support options and found that choice, flexibility, spontaneity and activity were perceived as key elements, and the particular types of activities nominated were highly varied. A need for enablers to facilitate day support options was described by all people [11]. These views emphasise the importance of ensuring people with disabilities have the opportunity to access the widest possible range of activities which suggests the importance of their access to the large pool of day activity and leisure options available to all older people

in the community. This perspective, together with our findings from the survey, supports the broad policy direction of inclusion of people with disabilities in mainstream services [1,9]. Such a direction suggests that the role of specialist disability services should be that of a broker, supporting choice for clients with limited cognitive skills, negotiating and facilitating access to mainstream services rather than the direct provision of day programs that duplicate those available to the general community of older people.

Key Points

- Older people with lifelong disabilities are a group increasingly likely to seek access to day care and community leisure services.

- Services support the concept of access for all minority groups but require environmental adaptation and additional human resources to accommodate people with lifelong disabilities.

- The role of specialist disability services should be to facilitate choice and support access for people with lifelong disabilities to mainstream day care and community leisure services.

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