

# 9 Existing services models: some issues

This chapter reviews the literature relating to current service models in Australia and highlights some of the issues relating to ageing people with a disability.

## 9.1 General issues concerning the need for appropriate services

A large number of reports and special studies have indicated that the existing Australian service models and boundaries between different programs cannot accommodate the emerging needs of people with a disability who are ageing. In Australia, disability and age-related service organisations currently appear to be providing services to two distinct populations, with little crossover or linkage (Buys & Rushworth 1997). Older adults with an early onset disability are falling between disability services and generic aged care services. They may be perceived as 'old' and unsuitable by disability services but quite 'young' and/or unsuitable by the aged care services that focus on the needs of the frail aged (Bigby 1998).

Functional abilities, not age, should be the factor in determining the suitability of services and supports, according to Williams (1999). Thus, it is important to develop effective collaboration and cooperation between services within the disability service system and between the disability system and aged care and other generic service systems to meet the needs of older people with an early onset disability. However, the complexities surrounding service provision, particularly in relation to the interface between the aged care system and the disability services system, have resulted in difficulties in service planning and provision (e.g. Gatter 1996; Williams & Chad 1998; Bigby 1999).

It appears to be widely agreed that one of the principal goals of a service program for ageing people with a disability is to maintain people in the community accommodation option of their choice for as long as possible and to minimise premature admission to nursing homes (e.g. Gatter 1996; Williams & Chad 1998).

It has been suggested that, where appropriate, generic services should be seen as the first option for older people with an early onset disability, especially for people with moderate or mild intellectual disability (Bigby 1992). This option is to meet the needs common to ageing people generally, corresponding to their biological, psychological and social ageing. Nevertheless, specialist services may be necessary to assist people in accessing generic services, or to ensure that generic services are provided in a sensitive and appropriate manner.

Since older people with an early onset disability are not a homogeneous group, service provision must be flexible to meet individual needs and circumstances and to accommodate individual differences in life experience, the ageing process, independent skill levels, health status, and particular interests and choices (Bigby 1992).

The existing problems of meeting the emerging needs of ageing clients with a disability are, to a large extent, related to the structures of service programs and the models of service delivery in use. For example, some ageing clients may not necessarily need new or additional services, but rather changes in the method of service delivery. People ageing with an early onset disability may need the same services but at an earlier age than the general ageing population. Day services may need to be restructured from full-day to part-day activities, or day activity arrangements should be more flexible to provide opportunities for socialisation (e.g. Janicki et al. 1985; Gatter 1996; Ruggi 1998).

Even though some service agencies have been providing services to older adults with intellectual disabilities living in the community, further information is needed to assess whether these services are appropriate and adequate to meet the needs of those people (Buys & Rushworth 1997).

In developing services that meet the needs of older people with an early onset disability it is necessary to consider:

- The decreased functional abilities and increased frailty of the target population.
- The decline in the development and retention of skills.
- The reduced appropriateness of some components of existing services suitable for younger people with disabilities (e.g. Janicki et al. 1985; Bigby 1992;).

A number of reports have raised the issue of defining a target group for the purpose of developing and planning services in response to the emerging needs of people with a disability who are ageing (e.g. Gatter 1996; Re 1991; Ruggi 1998). It is necessary to develop an integrated-service planning approach focusing on the needs of specific population target groups rather than the requirements of the existing funding programs. Broadening the planning process beyond a focus on program funding would enable greater collaboration across different programs and encourage joint planning efforts (NSW Health Services Research Group 1997).

The New South Wales Ageing and Disability Department and Health Department have jointly developed the Community Care Assessment Framework (response from New South Wales Ageing and Disability Department 1999). This framework assists in establishing a collaborative inter-agency process for comprehensive assessment of people who need complex, multiple or high levels of support. The framework applies a client-based approach, taking into account a person's overall needs. This new initiative has the potential to assist in resolving the issues arising for older people with an early onset disability whose needs cannot be met due to current program boundaries (see Section 10.1).

There is evidence that the number of workers with disabilities approaching retirement is growing. The issues surrounding the transition from work to retirement for people with disability are being examined in a study commissioned by the Commonwealth government. The study investigates the nature and extent of retirement issues for people with disability in Commonwealth-funded employment services and identifies strategies that may facilitate the transition from work to retirement for this group of people (Department of Family and Community Services 1999).

The study examines both mainstream and specialist options for retirement support services, and identifies client needs and best practice models. The study particularly considers:

- Who makes the retirement decision?
- If there is a tool to evaluate retirement suitability, how is it to be used and by whom?

- What are the best mainstream and specialist service options?
- Commonwealth and State government boundary difficulties (Williams 1999).

There are particular issues related to the interface between services for older people with psychiatric disability and aged care services. A scoping study on older people and mental health explored possibilities for further improvement of health care services to meet the needs of older Australians with mental disorders and their carers (AIHW 1998b; AIHW 1999b). A report on the second stage of the study concluded that it is very difficult to obtain data on the target group from current national data collections. Therefore, it is difficult to draw conclusions about the adequacy and appropriateness of services for older people with mental health problems. However, the report identified the national hospital morbidity database and the Aged Care Assessment Team data set as the most promising potential sources of data to gain information about service target groups (AIHW 1999b).

Caring is a matter of mutuality and partnership between governments, community and informal carers (McDonald 1997). Currently there is an absence of clear policy regarding the intersection of formal and informal support systems, so that decisions and rules become ad hoc, local and inconsistent, and often result from informal negotiations between older people and formal and informal providers of support (McDonald 1997).

## 9.2 Service gaps and needs for new services

A survey was conducted among 162 community-based organisations that assist older adults or people with intellectual disability in Brisbane, Queensland, regarding the types of programs offered to older adults with intellectual disability.<sup>8</sup> The results showed that only 36% of the organisations had provided assistance to at least one older adult with intellectual disability in the past 12 months. Agencies assisting people with disabilities were more likely to have provided services to this group than organisations assisting the general older population. None of the agencies surveyed reported that they provided specialised programs or services to older adults with intellectual disabilities (Buys & Rushworth 1997).

A study on services for older people with an intellectual disability in Victoria found that older people with intellectual disability living in the community were less likely to be registered with Intellectual Disability Services than their younger counterparts. Those who were registered had a low level of contact with regional services and attended few registered residential or non-residential services (Bigby 1992). Further investigations would be needed to examine whether this is a general pattern across the jurisdictions. This pattern may not indicate a lower need or demand for services among older people with intellectual disability. Rather, it could reflect that their special needs cannot be accommodated within the existing service framework.

A recent survey of adults with cerebral palsy in Australia reported that, although many respondents noted increased depression, fatigue, frustration, anxiety and anger as they aged, only 16% had seen a psychologist in the past year and 11% had seen a rehabilitation specialist. Some respondents also commented that generic services are difficult to access. Hence, ageing people with cerebral palsy may benefit from more accessible specialist counselling services (Balandin & Morgan 1997).

---

<sup>8</sup> For the purpose of the study, older adults with an intellectual disability were defined as persons with an intellectual disability over the age of 60 years (Buys & Rushworth 1997).

Because of the relatively low numbers and wide dispersal of older people with an early onset disability living in the community, it may not generally be feasible to establish separate programs just for this client group. However, separate programs may be viable and necessary where and when concentrations of older people occur (Bigby 1992). It may be necessary to 'cluster' groups of older clients with early onset disability (ideally based on similarities of need) in order to achieve economies of scale (Ruggi 1998).

Studies that report on service structures and patterns of service use and provision in the United States may provide lessons and insights for Australia. One such study reported that there were three service sectors in Massachusetts that were used by older people with intellectual disability: an age-integrated mental retardation service sector, which caters mainly for younger adults and some older clients; an age-specialised sector for older people with mental retardation; and a generic ageing service sector. (Seltzer 1988: 181).

The study found that nearly 62% of the services used by older people (aged 55 and older) with mental retardation were age-integrated mental retardation services, 33.9% were generic ageing services, and only 4.8% were age-specialised mental retardation services (Seltzer 1988).

Analysis of different usage patterns across the three sectors indicated that if the services used by older clients with mental retardation were grouped into broad program types, the age-integrated services sector contained the highest proportion of support services. The generic ageing service sector contained the highest proportion of residential programs, and the age-specialised sector contained the highest proportion of day programs (Seltzer 1988).

This usage pattern can be explained by a number of factors. Firstly, the age-integrated sector is the most fully elaborated sector of the three and is better equipped to provide support services, such as respite care and therapeutic services, to older people with mental retardation. Secondly, residential services were dominant in the generic ageing sector with its focus on nursing home care. Finally, the emphasis on day programs in the age-specialised service sector reflected the service responses of this sector to the retirement needs of older people with mental retardation (Seltzer 1988).

On the basis of responses from a client survey, the study also identified 66 strengths of age-integrated services as against 65 weaknesses; 84 strengths of generic ageing programs as against 45 weaknesses. The greatest number (94) of strengths were identified for programs in the age-specialised mental retardation sector, while 66 weaknesses were also pointed out (Seltzer 1988).

Some Australian studies have compiled these strengths and weaknesses in table form (see Table 9.1) and proposed that the Massachusetts service structure may be adapted as an integrated framework for service delivery to people with a disability who are ageing (Queensland Department of Family Services and Aboriginal and Islander Affairs 1994; Parsons 1993; Gatter 1996).

It is important to note that although 62% of the people with mental retardation used generic ageing services, many of them also used services provided within the disability system (either age-integrated or age-specialised). The 5% of people who used age-specialised mental retardation services was considered low, especially in light of the respondents' reviews of the strengths of these services. However, as suggested by the author, it is possible that the age-specialised mental retardation services will evolve rapidly, given the expected increase in the size of the potential population and the favourable attitudes of clients toward these services (Seltzer 1988).

**Table 9.1: A proposed integrated framework for service delivery to people ageing with a disability**

	<b>Strengths</b>	<b>Weaknesses</b>
<p><b>Age-integrated disability services</b> e.g.:</p> <ul style="list-style-type: none"> <li>• Group homes with residents whose ages vary widely;</li> <li>• Supported employment programs;</li> <li>• Alternatives to work programs with Participants whose ages vary widely;</li> <li>• Leisure/recreation programs with participants whose ages vary widely.</li> </ul>	<ul style="list-style-type: none"> <li>• Situations and programs that stimulate and challenge, and encourage clients to continue developing;</li> <li>• Higher quality of social experiences Than in other settings and larger variety of peer groups;</li> <li>• Appropriate for people who do not see themselves as 'old';</li> <li>• Age is not a central issue in normalisation.</li> </ul>	<ul style="list-style-type: none"> <li>• Programs are not always appropriate And age-related peer groups not always available;</li> <li>• Activities often too intense and difficult, and not sensitive to clients' health needs;</li> <li>• Generally designed to meet group, not individual needs;</li> <li>• Absence of retirement option and people have little opportunity to disengage from social activities.</li> </ul>
<p><b>Age-specialised disability services</b> e.g.:</p> <ul style="list-style-type: none"> <li>• Post-retirement leisure programs for People with a disability who are ageing;</li> <li>• Group homes specially designed to accommodate the needs of people with a disability who are ageing;</li> <li>• Respite programs designed to meet the needs of an aged carer caring for an ageing person with a disability who has retired.</li> </ul>	<ul style="list-style-type: none"> <li>• Potential to facilitate retirement option and less pressure on skill development;</li> <li>• Potential to be more flexible and Individualised;</li> <li>• Designed to meet participants' ages and levels of ability concurrently;</li> <li>• Able to foster relationships between clients of similar ages, encourage development of friendships;</li> <li>• Staff trained and experienced in both age and disability fields.</li> </ul>	<ul style="list-style-type: none"> <li>• Potential to isolate, stigmatise and segregate clients because of age and disability;</li> <li>• Clients may be separated from past friends and service settings;</li> <li>• Expectation of clients may be lower than realistic;</li> <li>• Programs may be less stimulating with fewer options.</li> </ul>
<p><b>Generic aged services</b> e.g.:</p> <ul style="list-style-type: none"> <li>• HACC Day Care Centres;</li> <li>• Meals on Wheels;</li> <li>• Senior Citizens Centres;</li> <li>• Home Help Services.</li> </ul>	<ul style="list-style-type: none"> <li>• Age-appropriate situations and services;</li> <li>• Generally flexible and community integrated;</li> <li>• Normalising and beneficial to relationships with age peers.</li> </ul>	<ul style="list-style-type: none"> <li>• Some staff and non-disabled clients not receptive;</li> <li>• Staff lack specialist expertise;</li> <li>• Services not always appropriate.</li> </ul>
<p><b>Generic aged services 'topped up' with specialist disability services resources, services (e.g. training and consultancy advice) and funds</b></p> <ul style="list-style-type: none"> <li>• A new concept.</li> </ul>	<ul style="list-style-type: none"> <li>• As for above, plus;</li> <li>• Allows for development of specialist expertise in staff;</li> <li>• Allows for generic service to be modified;</li> <li>• People with a disability who are ageing do not have to compete with mainstream demands for places.</li> </ul>	<ul style="list-style-type: none"> <li>• Some staff and non disabled clients may still not be receptive</li> <li>• People with a disability may feel isolated from the rest of the service.</li> </ul>

Source: Seltzer 1988; Gatter 1996; Queensland Department of Family Services and Aboriginal and Islander Affairs 1994.

## 9.3 Need for service responses in some key service areas

Modification in some key service areas may be required in response to the emerging needs of people ageing with disability. Service areas include accommodation and housing supports, day activities, advocacy, family support and case management relating to accessing multiple services.

### Accommodation support services

Many people ageing with a disability want to remain living at home, but the question is: will the support be there to enable them to do so? A study of the needs of members in the Paraplegic and Quadriplegic Association of New South Wales aged 50 and over showed that 60% of them reported that their support needs had changed over the last five years (Williams 1999). The report also found that respondents had great difficulty in identifying appropriate accommodation options with which they have no experience. Hence, 24% of respondents preferred nursing home accommodation simply because that was the one they were familiar with and which they thought would provide adequate support. The respondents also indicated that share housing accommodation was not a preferred option, though supported housing, where privacy was maintained, was seen as desirable (Williams 1999).

At present, group home residents with an early onset disability are expected to be away from their home during week days, either at work or at day or recreational programs. Current funding for group homes usually does not allow for a staff member to be on duty during the day. This will create an increasingly untenable situation in those homes which have an ageing resident (Gatter 1996).

The demand for accommodation support services by ageing parents for their adult sons and daughters with disabilities is expected to increase. Demand for respite services can also be expected to increase, especially from those families who have chosen to continue to care for their ageing relatives with a disability in the family home. The capacity of services to respond to more frequent crisis needs should be enhanced (Gatter 1996).

The use of flexible program times, part-time placements and 'phasing down' of attendance hours for day programs has a direct impact on the clients' accommodation situation. Older parents or family carers require respite from caring for their dependant adult with a disability (Ruggi 1998).

It was suggested that accommodation services may be supplemented by the provision of day activity and leisure programs either through assisting residential staff to develop a program or facilitating direct provision by specialist services (Bigby 1992).

Age-specific group homes (or cluster homes) for older people with a disability have been suggested for consideration in future service planning. If 'ageing in place' is a policy priority, then the choice of people for new group homes and assessment of new residents for existing group homes should consider not only social compatibility but also age compatibility (Gatter 1996).

The design of group homes aims to meet the accommodation needs of people participating in outside activities during the working week. However, the ageing trends in people with a disability may have implications for future housing design and existing accommodation may need to be modified. As ageing people with a disability become frailer, they need to spend more time at home and engage in more home-based activities. This means more space

may be required for low-level indoor recreation and craft activities, and more consideration may need to be given to the design of gardens and outdoor living areas (Gatter 1996).

## **Age-appropriate day activity and leisure service programs**

Although it is generally agreed that there is a high need for participation in generic activity or leisure programs by people ageing with an early onset disability, they are more likely to require assistance to choose, locate, negotiate access and travel to community-based day programs. Programs for older people should have a reduced emphasis on formal vocational training and skill acquisition and more emphasis on retention of skills and the constructive use of leisure. Activities arranged should be age appropriate though this should not necessarily preclude age-integrated activities (Bigby 1992).

The main areas that should be developed or emphasised to improve day activity programs for this target group are summarised as:

- flexible arrangement;
- individualised planning for participants;
- recognition of the need for: skill maintenance and development, social interaction, maintaining friendships, fostering or maintaining informal support and advocacy networks, enjoyable and stimulating activities and participation in valued social roles;
- skill development of staff in service networks; and
- the development of a policy framework for disability services that recognises and incorporates the above principles (e.g. Bigby 1992; Ruggi 1998).

## **9.4 Differences and similarities of the current disability and aged care service systems**

In order to be able to proceed with an analysis of needs, it is useful to summarise briefly some of the common features of the aged care and disability service systems, and some of the differences.

A recent review of the development of aged care and disability services reported that both service systems have adopted similar service philosophies, policy directions and service delivery mechanisms (Bigby 1999):

- Both aged care and disability services have undergone substantial changes in strategic direction and have followed similar broad policy directions, moving away from institutionalisation and emphasising home- or community-based care and services.
- Similar services have been developing in the two service systems, moving towards the concept of managed care for people with more complex needs and emphasising tailored care packages to meet individual needs.
- Both systems have recognised the importance of informal carers and family support and have developed services to support informal caring roles.
- Both systems are moving away from submission-based models of funding towards more pro-active need-based planning models. More active funding management techniques are being used in the two systems, such as unit cost funding.

Some similarities of the two systems also highlight limitations in existing service provision. One such similarity is limited resources. Resource limitation may motivate administrators of disability services to encourage their ageing clients to access or transfer to aged care services. Likewise, administrators in aged care services may resist such access or transfer without a transfer of resources (Bigby 1999).

Both systems place an emphasis on 'supported independence' and reliance on informal carers. Ageing people with an early onset disability are less likely to have co-resident informal carers, or may be reliant on the care of ageing parents. The needs for supported accommodation may occur at earlier ages for ageing people with an early onset disability, not because of their own ageing but because of the loss of their informal support network (e.g. the death of their parents).

The limitations of the aged care service system in meeting the needs of older people with an early onset disability are largely associated with the differences between the aged care and disability service sectors (Bigby 1999):

- The aged care system has some services that may be used by older people with a lifelong disability. For example, programs targeted at frail older people who have dementia may also be appropriate for younger people with an early onset of dementia. However, because of the focus of the aged care system on the health needs of frail older people, it is unlikely to address the wider range of needs of most people ageing with an early onset disability.
- The existing types of residential aged care facilities may not meet the needs of ageing people with an early onset disability who are younger and perhaps more physically able than most frail older people. Large congregate care arrangements are much less acceptable in the disability service sector than in the aged care sector.
- HACC services mainly target people living in the community. It is less clear whether these services may be accessed by people with disability living in supported accommodation.
- Although various day and leisure activities exist for older people in the general community, few programs offer the structure, supervision or continuity required by many people with an early onset of disability.
- There is a lack of effective mechanisms in the services to package the existing retirement activities in the aged care system into coherent programs suited to ageing people with a lifelong disability.