

# **Ensuring Successful Ageing: Report of a National Study of Day Support Service Options for Older Adults with a Disability**

Short Report

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This report was commissioned by the National Disability Administrators and undertaken by researchers from the La Trobe University. The views represented within this report are those of the authors and do not necessarily reflect the position or policy of National Disability Administrators or the individual Commonwealth and State/Territory Governments.

The 'issues for future consideration' within this report are intended to inform the processes and priorities of the National Disability Administrators group. They are not formal recommendations, and while they may assist the National Disability Administrators in the development of future priorities and policies, these 'issues for future consideration' must be considered in the broader context of existing initiatives, competing priorities and alternative perspectives.

The project report is available in three forms:

- The Executive Summary containing key findings and issues for future consideration. The Executive Summary is at the commencement of both the short and the full reports.
- This short report including some discussion of key findings and issues for future consideration.
- The full report including literature review and other appendices.

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The project was undertaken through the work of the project team, the project reference group and many people with disabilities and their family members, and staff of disability day support services and aged care and community services throughout Australia. (See Appendix B for full details of the reference group and project team.) The reference group provided critical insight into the range of complex issues and contributed significantly to the conclusions reached.

Many people with disabilities of all ages and staff gave freely of their time, experience, ideas and knowledge in relation to the issues of day support or lifestyle support for older people with disabilities. The willing contribution of all of these people from all States and Territories highlights the importance and timeliness of the project. The quality of the information from which the project team could reach the conclusions and issues for future consideration is acknowledged and appreciated by the project team.

# Introduction

## Project Aims

This study aimed to:

identify the issues for governments, community service providers, people with a disability and their carers associated with the development and provision of day support services for older adults with a disability and make recommendations to address these issues (Department of Human Services, 1999a, p. 2).

The study focuses on older people who have a disability that is unrelated to the ageing process.

The project brief developed by the National Disability Administrators required the study to report on:

- The demographic profile of the target population.
- Specialist disability day programs currently provided to older people.
- Alternative services and supports for people wanting to ‘retire’ from specialist disability day programs.
- Service models that address the transition from specialist disability day support programs to alternative activities.
- Recommendations to assist in the development of State-based implementation plans within the context of the National Healthy Ageing Strategy.

## Terminology

Throughout this report, the term ‘older people with disabilities’ is used to refer to all older people whose disability is unrelated to ageing, that is, people who will reach their older age with pre-existing disability.

## Research Design

The research design used a multi-method approach that enabled data on similar issues from multiple sources to be collected, compared and contrasted. The various components complemented each other and allowed findings to be verified, increasing the reliability and validity of the research. The research design provided opportunities for the views of all stakeholders to be heard, included all key groups with an interest in the area, and had representation from metropolitan, rural and remote interests across all States and Territories.

The design had seven main components:

- An international and national literature review.
- A demographic analysis of potential service users.
- A national survey of specialist disability day support and leisure services.
- A regional-based survey of the use of aged care day services and mainstream community-based day activity and leisure services by older people with disabilities.
- A telephone survey and series of focus groups with older people with disabilities.
- Targeted consultations with key stakeholders in all States and Territories and an open invitation for written submissions from any interested party.
- An evaluation of services representing the various programs’ models that are currently used to

meet the day support service needs of older adults with a disability.

The major research questions were:

- Which groups of older people with disabilities are likely to require day support services?
- What type of support will they require?
- Will they require assistance to plan and choose activities?
- How will this assistance be provided?
- What proportion of time is spent in active engagement and what in passive, what degree of support can be funded from public revenue?
- What external changes may reduce the amount of individual support required?

## **Describing Older People with a Disability**

People with a disability can be divided into three broad groups based on the age of onset of their disability:

- Those whose disability occurred at birth or during the developmental period (for example, intellectual disability, cerebral palsy, hearing and vision impairments).
- Those for whom it occurred during adulthood (for example, acquired brain injury, progressive neurological disorders, spinal cord injuries).
- Those whose disability is uniquely related to the ageing process (for example, hearing and vision impairments, arthritis).

The first two groups, although different from each other in many ways, comprise the group regarded in this study of older people with a disability. For this group, their pre-existing disability is a significant additional factor impacting on ageing processes. Living with a disability affects life course experiences and impacts on the support needs and experiences of the ageing process.

Definitions of 'older' and 'ageing' are subject to debate. In Australia, 60 years is generally regarded as the benchmark for inclusion as an older person. A notable exception is for the Aboriginal population: 45 years of age denotes entry to older age. For this study, in line with most published Australian research on ageing and disability, the age of 55 years was chosen to define an 'older person with a disability'.

# Findings

## Who Are the Older People with Disabilities?

Considerable diversity exists among people ageing with a disability in terms of the type and severity of their disability and the rate and nature of the ageing process. In common with the general population of older people, this group is far from homogeneous in terms of rate and impact of ageing and requirements for supports.

Older people with a disability are a diverse set of sub-groups whose numbers, though small relative to the aged population in general, are likely to increase significantly over the next 20 years. The largest sub-group is people with intellectual disabilities who, until recently, have been the primary focus of the disability day support services system of most States and Territories. Consequently, this group is a heavy user of day support services and many are ageing within services. For the other groups, who are newer and for whom services are less well developed, it is difficult to predict future demand from current service use. For example, it is estimated that the numbers of ageing people with acquired brain injury (ABI) may be similar to those with intellectual disability though most are currently outside day support service systems and under-identified (Wen & Fortune, 2000).

The CSDA minimum data set indicates that people with intellectual disability are the largest sub-group of older people with disability currently using CSDA-funded disability services (64%). Other smaller groups are those with physical disability (12%), ABI (3%), vision impairment (3%), hearing impairment (1%), neurological disorders (2%) and psychiatric disabilities (7%) (AIHW, 1999). This latter group is not within the remit of this study.

A dimension that differentiates people ageing with a disability from those with an age related disability is the extent to which ageing impacts on health and activities of everyday living. At various ages, some of this group will develop additional disabilities because of their ageing process. This differentiation between 'well aged' and 'frail aged' is not well articulated in the disability sector. Our research located very few frail aged older people with disabilities, reflecting the very reduced numbers in the 'old old' age group due to higher age specific mortality rates of people with disabilities. Tackling the needs of this group was not a major issue for service providers.

## People with Intellectual Disability

The prevalence rate of intellectual disability in Australia is 1.86% (328,000 people) and 0.99% (174,000 people) for those with a severe or profound activity restriction (Wen, 1997). Prevalence rates differ by age, with the highest rate found in the early teenage years and an estimated rate for those aged over 55 years of 0.13%. People with severe and profound intellectual disability require significant support across their life course, which is provided by families or the service system, and many are lifelong users of day disability support services.

Forty-four per cent of people with intellectual disability report associated physical impairments, more than a quarter report speech problems and 22% also have psychiatric disabilities. People with intellectual disability have a higher age-specific mortality rate across their life course than the general population (Eyman & Borthwick-Duffy, 1994). However, their life expectancy has increased dramatically in recent years and, with the exception of people with Down syndrome, it is now quite similar to that of the general population (Janicki et al., 1999). In the United States, the life expectancy from birth for a person with Down syndrome is 55.8 years, for all other groups

with intellectual disability it is 66.1 years and for the general population it is 70.1 years.

### **People with Severe Physical Disability**

Wen and Fortune (1999) estimate that 11.9% of Australians (2,099,600) have one or more physical impairments resulting in one or more activity limitations, whilst 3.8% (620,400) have a severe or profound activity restriction resulting from a physical impairment. In contrast to intellectual disability, the prevalence of physical disability increases with age.

This group, people with physical disability includes people with developmental disability such as cerebral palsy, which can also be associated with intellectual disability and also includes those with impairments acquired during adulthood as a result of trauma, such as spinal cord injury. Many do not have cognitive impairments but require high levels of support with self-care, mobility and activities of everyday living. People with severe physical disabilities experience changes associated with ageing at an earlier age than the general population (Balandin & Morgan, 1997; Crewe, 1990; Cooper, 1998). They also experience secondary disabilities or health complications associated with long term changes in their physical functioning (Gething, 1998). As early as their 30s and 40s this group may require increased levels of support to facilitate their continued community living.

### **Other Groups**

There is a small sub-group of people who are ageing with a pre-existing disability as a result of neurological diseases, usually acquired in mid-life and often degenerative. These include Multiple Sclerosis, Motor Neuron Disease, Parkinson's disease and Huntingdon's Chorea. Due to associated health issues and the disabling nature of the disease, people in this group may experience high levels of dependency at an early stage in the ageing process and the requirement for specialised medical support may dominate provision of services. However, this does not preclude the importance of disability support for lifestyle.

Older people with long term sensory disabilities have often led very independent lives and developed an identity and culture associated with their disability. In Victoria, people with sensory disability are high users of CSDA day support services (33%, Department of Human Services, 1999), but they constitute a relatively small group in the younger age groups, indicating a high rate of use by people with late onset sensory disabilities associated with the ageing process (who are not the focus of this study).

People with ABI are recognised as a separate group, although comprised of several quite distinct groups, including people with traumatic brain injury, alcohol related brain injury and those who have had a stroke. Fortune and Wen (1999) estimate a prevalence rate of 1.9% for ABI related disability across all age groups in Australia (338,700). A high proportion of people (41%) with ABI have a severe or profound activity restriction associated with their disability, with an estimated prevalence rate of 0.9% for this group. The prevalence of ABI related disability increases with age, reflecting the high incidence of brain damage caused by stroke in older age groups. The prevalence of people with ABI related disability in Queensland and the Northern Territory is significantly higher than average prevalence rates, 2.6% and 3.6% respectively. People with ABI are a significant group due to their growing numbers, the underdevelopment of targeted services and the focus on new initiatives being undertaken to redress this in most States and Territories.

Currently very few older people use CSDA funded community access services. The over 60 age group accounts for only 9% of all users (AIHW, 1999). The three largest groups aged over 60 using all services are those with intellectual disability (39%), vision impairment (25%), and physical disability (17%). Notable is the decrease with age in the number and proportion of people with intellectual disability due to a higher age-specific mortality rate than the general community. This contrasts with an increase in number and proportion of those with vision impairment and



physical disability in the older age groups (which includes both older people with a disability and people with age-related disabilities). More than half of all the service users aged over 60 are under 75, therefore probably representing the younger, rather than the frail, aged.

## **Projected Population**

While most data sources fail to clearly differentiate older people with disabilities, the currently available age and disability specific prevalence data suggest that the number of people ageing with a disability is small. 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. They will, nonetheless, remain a small proportion of the general aged population.

The findings from the national survey and consultations suggest that different patterns of day support service use and age of entry to day services are found within and between the different groups of older people with disabilities. The pattern of access to day support varies as a function of an individual's service history, disability type, residential arrangements and life circumstances. These typical patterns (summarised in Table 1) are important in considering patterns of service use by older people and as an indicator of where, and from whom, demand for day support services is likely to occur.

As Table 1 indicates, some groups, such as people with intellectual disability, have a long history of day service use and many are ageing within existing services. However, those who have later onset disabilities often do not seek to use day support services until mid-adulthood, at which time the options are more diverse, with the availability of specialist disability, HACC or carers' initiative funded services. A third group, and one highlighted during the consultations, were people who sought to access disability day support services for the first time in later life, who may have lived with parents and not used services or who have been in employment. The issue of a previously hidden group at home with parents who may seek to access services in later life was a particular issue raised by Queensland and Tasmanian respondents.

Those who seek to access disability day support services for the first time in later life found their options were often different compared to those offered to people entering in their younger years. They tended to be offered fewer hours of support and only by HACC day services and in home support, which have a primary orientation towards respite care. One reason for this is that most of the development of day support services for older people with disabilities has occurred within specialist disability age integrated services and in response to existing ageing clients rather than groups outside this specialist service system. Another reason is the notional age limit of 65 years, often imposed by disability services for new entrants but with leeway provided for existing clients to be served past this age.

An exceptional group, however, is those people who have lived in institutions for most of their lives but are relocated to the community during mid to late adulthood. This group has been a major driver for the development of age-related specialist disability day support services in Victoria and Tasmania in particular.

**Table 1: Patterns of Entry and Use of Day Support by Different Disability Groups at Different Life Stages**

<b>Historical Entry Point to Day Support</b>	<b>Typical Accommodation Support</b>	<b>Most Likely Disabilities</b>	<b>Typical Model of Day Support for Current Older Cohort</b>
<ul style="list-style-type: none"> <li>After leaving school/continued from school</li> <li>(This is the largest group of older people identified now)</li> </ul>	<ul style="list-style-type: none"> <li>Parents, family members</li> <li>Supported accommodation</li> </ul>	<ul style="list-style-type: none"> <li>Intellectual disability</li> <li>Autism</li> <li>Physical disability (eg . cerebral palsy, spina bifida</li> <li>Hearing impairment</li> <li>Vision impairment</li> </ul>	<ul style="list-style-type: none"> <li>Five days a week - 'full time' - at a centre (may have community access) may be part time</li> <li>No day program</li> <li>Could include supported employment and movement between supported employment</li> </ul>
<ul style="list-style-type: none"> <li>During adult hood (This older group will be increasingly identified )</li> </ul>	<ul style="list-style-type: none"> <li>Own home/with partner</li> <li>Parents</li> <li>Supported accommodation including private</li> </ul>	<ul style="list-style-type: none"> <li>Later onset and acquired disabilities (eg ABI and neurological conditions)</li> <li>Intellectual disability moving from institutions</li> </ul>	<ul style="list-style-type: none"> <li>In home support and attendant care</li> <li>Flexible day support options</li> <li>HACC day support (ADASS)</li> <li>No day program</li> <li>Five days a week - 'full time' - at a centre (may have community access) may be part time</li> </ul>
<ul style="list-style-type: none"> <li>At older age</li> <li>(This group of older people cannot be quantified)</li> </ul>	<ul style="list-style-type: none"> <li>Family/individual cannot continue care/need more support</li> <li>Supported accommodation including private</li> </ul>	<ul style="list-style-type: none"> <li>All/any</li> <li>Intellectual disability moving from institutions</li> <li>People retiring from supported employment</li> </ul>	<ul style="list-style-type: none"> <li>HACC including day care, respite</li> <li>Nursing home</li> <li>Community programs e.g. neighbourhood houses</li> <li>No day program</li> </ul>

It is important to note that, as current use of services reflects historic funding patterns, service models and the different pattern of service development in each State and Territory, it may be a poor indicator of future demand. This is particularly the case for the disability groups more recently located within the mandate of State/Territory disability programs such as people with ABI, spinal cord injuries or neurological impairment for whom few services of this kind have been developed. For example, Victoria has the most well developed community access services, the highest expenditure, and accounts for over half of all community access service users.

In addition, considerable unmet demand exists across Australia for day support services, with an estimated 12,000 people without an appropriate day support program (AIHW, 1997). Perhaps not counted in these statistics are the older people with disabilities who live in the private supported residential sector for whom 24-hour supervision and support is available but who frequently do not access more formal day support services. Another separate group is the high number of people still living in institutions. There are approximately 3000 in NSW with institutions also existing in Victoria, South Australia and Queensland.

Sub-groups of older people with disabilities who are currently not using community access services but may require services in the future are likely to be the non-traditional disability groups. That is those:

- With an acquired disability, such as ABI.
- With later onset physical disabilities and neurological impairment for whom services have yet to be developed.
- Leaving or reducing their involvement with open or supported employment.
- Who have chosen to remain outside the service system until older age (such as those with milder disabilities) or who are currently on service waiting lists.

Three factors stood out as characterising the current cohort of older people with disabilities, which are predominantly those with an intellectual disability. They have:

- Had few opportunities for skill development.
- Had low expectations held about their potential.
- Been institutionalised for substantial periods of their life (a sub-group).

Comprehensive planning for older people with disabilities is impeded by a lack of data at national, State and Territory levels. The existing national data sources do not clearly distinguish between older people with disabilities and those whose disability is associated with the ageing process. This makes the estimate of future service demand from the former group very difficult and produces a tendency to inflate expectations of service demand by including the latter group. Asking people the age of onset of their disability in the relevant data collection processes would be a major advance in this regard.

## Untangling What Is Meant by Day Support Service Options

Day support has different purposes for different individuals or sub-groups of people with disabilities whose need and intensity for support is mediated by their micro social circumstances and macro social context. This includes the activities the person chooses to engage in, personal characteristics such as the nature and level of disability and health status, and the nature of the social environment including residential, economic and social issues, community location and resources, and physical accessibility. The interrelationships of factors that mediate individual decisions about the day support services and costs are in found in Diagram A.

Two simple examples highlight some of the typical differences in the purpose and type of day support services required by people with differing characteristics and social circumstances.

The first example profiles a person without cognitive impairment but with high physical support needs and limited financial resources living alone at home with the minimum necessary attendant care hours.

**Example 1:** This person does not require assistance to locate and choose activities or to participate in social discourse, nor does he require supervision while at home to ensure he is safe. However, to exercise his choice of lifestyle, through such activities as going to a pub with friends, this person requires day support services, in the form of finances for a taxi and for dinner eaten out, and additional hours of attendant care to assist with accessing the physical environment, transfers and help with eating, drinking and personal care while away from home.

If this person had substantial personal financial resources or an extensive network of non-disabled friends and family, he may have no need for day support services as he could meet his desires for a

social outing to the pub from his own financial or informal resources.

**Example 2:** This person is without physical support needs but has severe intellectual impairment and requires support to exercise choice with activities of everyday living and lives in shared supported accommodation without staff support from 9.00am–3.30pm. This person will require someone to monitor her safety while at home engaged in domestic chores, personal care, and leisure activities of choice during the time when no residential staff are on duty. In addition, she will require someone to assist her to choose, locate and participate in more active leisure pursuits for some periods during the week. She may be happy to stay at home most of the week with several other residents but have a particular interest different from those of other residents that she chooses to pursue several afternoons on her own. Residential staff are available to provide the required support during the late afternoon, evenings and weekends but not at other times.

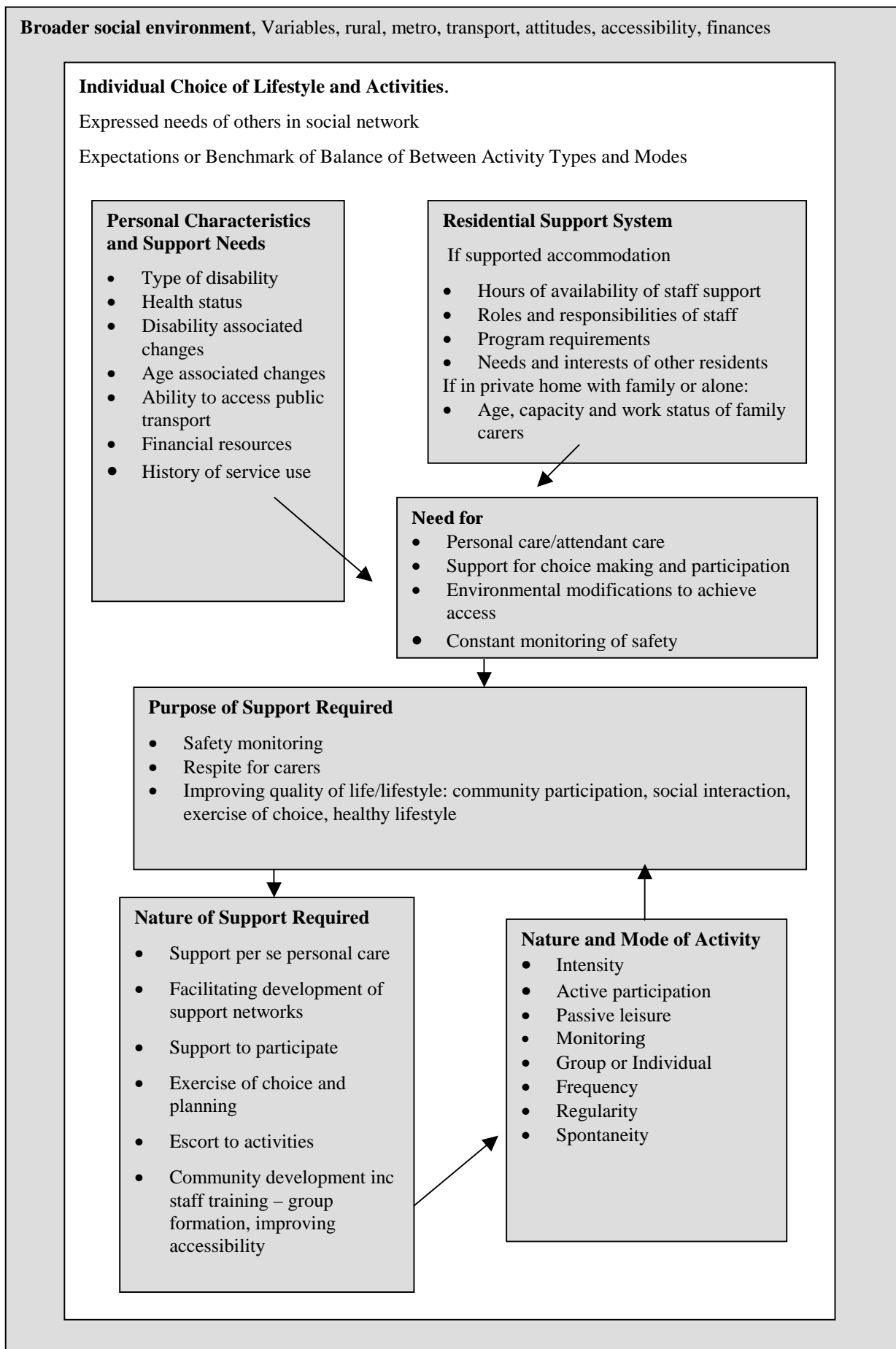
For the person with intellectual disability, day support services must fulfil the function of monitoring and ensuring safety as well as assisting in the exercise of choice, participation in meaningful activity and opportunities for personal development. However, it can be argued from these examples that some types of ‘day support’ are all-encompassing while others are more targeted and require quite different skills. Contrast a support person being directed to assist an individual to transfer from a taxi into a wheel chair, to assisting a person to choose the type of activity in which they would like to participate. What is also clear from these examples is that across the week, similar functions/purposes are performed for the person with intellectual disability under the guise of day support and residential support, which clearly raises the questions of what is the difference between the two and where should the line be drawn for someone who does not go out to work in paid employment every day? Indeed, is the distinction between the two services for someone who requires both necessary and, in this case, are notions of full- or part-time day support services redundant?

Much more clarity exists in regard to day support services for people who do not require monitoring for their own safety or do not reside in any form of shared supported accommodation where daytime support may or may not be available at specific times, as illustrated by Example 1. In these cases, the primary purpose of day support services is to enhance capacity for independent choice of lifestyle and to facilitate full community access, such as assisting with personal care when in the community or negotiating entry to buildings.

These examples and the questions they raise demonstrate that day support services cannot be considered in isolation from an individual’s personal characteristics, social or service context. When considering the nature of the required support and its delivery, the purpose of the day support is a fundamental issue.

A range of factors that shape the type of support required, its purpose, intensity, frequency and timing, mediates the nature of day support services. What is clear is that these various mediating factors have been accommodated implicitly, in an ad hoc manner in the development of day services for people with various disabilities. As such, no models of core or minimum service provision based on these factors have been proposed.

**Diagram A: Factors That Mediate Individual Needs and Costs for Day Support**



A broad understanding of day support services reflecting the new emergent paradigm of lifestyle support is used throughout this study. We have elected to understand day support services as the provision of support of varying intensities provided to individuals, during their waking hours, or to external organisations, which facilitates access for people with disabilities to activities and pastimes of their choice that are meaningful to them, which increases their quality of life and which may also ensure their personal safety.

This understanding omits respite as a purpose of day support as our view is that respite services have a dual focus of outcomes for both carers and the person for whom they care. Thus, any respite service provided for a carer of a person with disability should meet either or both of the two purposes outlined for day support services for people with a disability.

Clearly, the major questions that arise are:

- Which groups of older people with disabilities are likely to require day support services?
- What type of support will they require?
- Will they require assistance to plan and choose activities?
- How will this assistance be provided?
- What proportion of time is spent in active engagement and what in passive?
- What degree of support can be funded from public revenue?
- What external changes may reduce the amount of individual support required?

Many of the issues apply not just to day support services for older people with a disability but across all age groups. However, the focus of this study is older people. The service challenge is greatest for the current group of older people with disabilities and their carers, as many of the reforms in day service provision have occurred in services targeting younger people who, with their families, do not have a set expectation that day services will be centre-based and of full day duration. Consequently, the needs of older people with different expectations have been overlooked.

## **Defining Older People with Disabilities**

Service providers were extremely concerned and motivated to improve the circumstances for older people with a disability. There were several divergent trends about the perceptions held by many disability service providers of older people with disabilities.

There was an incorrect assumption that premature decline associated with ageing was a phenomenon applicable to all people with disabilities at a given age. These perceptions suggest there is little knowledge about ageing in general and that stereotypical views are held about people ageing with a disability.

There was a reluctance to use chronological age as a means of identifying 'older' people and their eligibility for the services targeted at this group. Instead, the importance of flexibility was highlighted to ensure that individual need, based on functional capacity and differential rates of ageing, was taken into account. While this perspective ensures flexibility for those who do age prematurely, it has the inherent danger of including younger people whose support needs are increasing due to health or disability factors in programs for older people. A trend to include younger people with higher support needs in an older group was found. In some instances, clients, particularly those in their 30s and 40s with high support needs related to their health or disability, but which were not associated with ageing, were nevertheless included in programs for older people.

Many service providers had a tendency to use ageing, 'getting older' or being an 'older person' as an opportunity to change programs and provide more flexibility related to individual need and preferences—generally to improve a person's lifestyle. This accounts for the attachment of the inappropriate label of 'ageing' to much younger people and suggests that ageing is sometimes confounded with other aspects of their lives. It appears that services are seeking to be more flexible for particular client groups such as those in the older age group and those with high support medical and care needs. Thus one way to achieve flexibility, in the absence of program changes, is to identify clients as older.

Apart from people with disabilities themselves, ageing was almost universally described in terms of losses and decline in health, mobility, skills and physical activity. There was a perception of an overall slowing down in pace of life and a requirement for reduced pace in any activities that are offered. The typical images portrayed of older people with disabilities are reflective of the very frail aged rather than the younger old who are the biggest group currently in touch with disability day support services. Compared to younger people, older people are seen to require less strenuous activities, with a change of focus from skill acquisition to leisure and skill maintenance at best but with often a 'do nothing' flavour. Notions of ageing as an 'all or none' event rather than a highly individual process were also prevalent.

These negative images were often contradicted by many service providers who described images of some older people continuing to be vibrant and active. Similarly, negative images were not reflected in the objective characteristics of many older clients noted by providers in the national survey.

There was a belief that when people are older they should be able to exercise more choice and greater flexibility in regard to the programs and support they are offered. However, there was little reference made to the more active images or participatory and productive roles of the aged associated with the Federal Government's Healthy Ageing Strategy. Almost no acknowledgment was made of factors that mediate the ageing process, such as exercise, nutrition and lifestyle, or the ongoing potential of older people for skill development, which was typically explicitly rejected.

### **Perspectives of People with Disabilities**

The older people with disabilities who participated in the study had an active view of later life. They were keen to have the choice and flexibility to keep doing things that interest them. People with disabilities did not talk about retiring from their current day activity although some described changes in what they would like to do. They identified choice as a critical characteristic of effective day support for older people.

### **Perspectives of Informal Carers**

Concerns of the informal carers, who were predominantly older mothers, extended beyond day support to the more fundamental issues of long term safety, security, stability and accommodation for older people with disabilities when they lose the support of parents. Many older parents perceive day support services in terms of respite and in the longer term want to be reassured that the person with a disability has stable and secure support.

### **Appropriateness of Aged Care Services**

Most older people in the general community do not use formal day support services but rather access, under their own steam, a whole range of informal and formal programs of choice, which are not necessarily targeted at their age group.

The national survey and consultations indicated a strong trend towards wanting improved access to the community and the use of services and facilities available to other older people.

The policy shift towards a Healthy Ageing Strategy has increased the range of community-based leisure services geared towards encouraging an active lifestyle and targeting the well aged. A smorgasbord of activities exists in some communities from which older people can select.

Older people with disabilities are just one of the many minority groups to which mainstream and aged care services are attempting to respond. Inevitably, access for this group must be championed and supported by people with disabilities and disability service providers if their needs are to be taken into account by larger, more diverse service systems. This is consistent with moves to promote access to community services for people with disabilities at other stages of the life cycle.

The frail aged or people living with informal carers are the primary target of most of the formal day support services available to older people in the community funded by the aged care system. Consequently, a primary stated purpose of such services is often carer respite, and they are not designed for younger healthier older people or accessible to those living in disability funded accommodation, where there is no informal carer. Therefore, such services may only be appropriate or accessible to a relatively small group of older people with disability. Our consultations also suggest that in some States/Territories standards in home type HACC services are becoming more targeted towards people with low support needs.

## **Retirement or Change of Direction**

Retirement did not emerge as a major issue for those who attended disability day support programs, however, providing people with choices to ‘do things differently’ as they got older was considered important. Ongoing support for day activities remained important.

Lifestyle planning over a lifetime was seen as preferable to more sudden or discrete notions of ‘retirement’ or ‘transition planning’. This is also consistent with day support being conceptualised in terms of lifestyle support.

## **Issues in Delivering Effective Day Support Services**

Key criteria for effective delivery of services to older people with disabilities were identified. These criteria combined aims and objectives sought for older people and identified characteristics of service delivery to achieve these. They were:

- Provision of choice and individualised planning.
- Maintenance and strengthening of social networks.
- Support for participation in the community.
- Maintenance of skills.
- Opportunities for self-expression and sense of self.
- Promotion of health and a healthy lifestyle.

Contrary to initial expectations, the service type into which a program was categorised did not differentiate performance against the key criteria, rather it was the manner in which key concepts were put into operation that was important in determining performance.

The literature and our current study identify the main barriers to effective provision of day support services for older adults with disabilities as:



- Restrictive program boundaries at every level and few incentives for program collaboration around an individual.
- Lack of leadership and limited staff knowledge and expertise in disability, aged care and community sectors.
- Limited resources to support access and community participation.

## **Specialist Programs for Older People with Disabilities**

Most specialist programs were developed in response to the changing needs of existing older clients, which included a reduced ability to work in the employment arm of the organisation, slowing down, loss of stamina, preferences for a quieter environment and expressed desires for change. Other reasons for the establishment of programs were the deinstitutionalisation of older clients and the provision of funds for the establishment of day programs tailored to their needs as part of the community relocation process.

Overwhelmingly, specialist programs for older people are targeted at people with intellectual disabilities. Although significant numbers of older people with ABI and vision impairment participated in day support services, they do so in general age integrated programs rather than age specific programs.

Programs designed specifically for older people varied in size from 1–32 participants, with an average of 12 people. The age range of participants is 24 to 90 years with the bulk falling in the 40–60 years age group. These programs often include people with high support or medical needs who are not older but have been assessed as needing a less active or strenuous environment. Key themes in regard to the eligibility for specialist aged services are flexibility and negotiated entry to take account of functional capacity, health and choice as well as chronological age. As mentioned earlier, it is clear that in some programs age is being confounded by other factors, and programs are, in reality, being organised around populations with high and low support needs rather than age-related factors.

Some specialist programs for older people are offered as several sessions or days per week and some clients participate in these programs in addition to continuing in the mainstream age integrated program offered by the parent service.

The majority of specialist programs are offshoots of age integrated day services for people with intellectual disabilities with funding derived from the parent service's main source of funding, primarily State or Territory government day or leisure program disability funds.

Integration and participation in the local community for older people was the most common aim, followed by opportunities for social interaction and peer support. They also stated the more global aims of meeting the changing needs as people aged, and of providing programs tailored to age and capacity. Strategies for doing this were often cited as providing a program with a more relaxed and less programmed focus than that provided for younger clients. Relatively few programs included amongst their aims aspects of continued personal growth and development for people.

Seven broad types of programs utilised by older people with disabilities were identified. These were:

- Specialist aged programs located within age integrated day, leisure or vocational services for people with disabilities.
- Stand-alone age specialist services specifically funded and designed for older people with disability.

- Initiatives combining a specialist disability service with aged care services.
- Community development projects.
- Brokerage services.
- Centre-based or non-centre-based age integrated leisure or day program with individualised planning.
- Residential-based programs with no day support funding.

No one service type demonstrated a unique or exclusive capacity to excel on all key criteria for effective services. Programs demonstrated variable capacities on criteria of individualised planning and choice, maintenance of social networks and participation in the community. Overall, not all types performed as well with respect to skill maintenance, opportunities for self-expression and sense of self and promotion of health and a healthy lifestyle.

The service evaluations highlighted that structural arrangements or service types alone do not guarantee that the criteria for effective services are satisfied. Few services paid any attention to unfunded or informal options for support. Those that did pay attention to these forms of support had had a mandated role to undertake individualised lifestyle planning for people. In some programs, individual planning was equated with matching people to a pre-determined menu of activities. Various structural arrangements transcended the traditional program boundaries between accommodation and day service. Specialised services for older people with disabilities do not guarantee superior performance on any of the criteria compared with services that did not differentiate on the basis of age. The analysis showed that grouping people in the first instance according to age may actually introduce some impediments to effective service quality by reducing the range of options available and increasing the risk of referring people to service types on the basis of age (such as aged care) rather than on the basis of individual preference, which would enhance lifestyles.

## **Overcoming Barriers to Effective Service Delivery**

### **Program Boundaries**

Program boundaries have been identified as significant barriers to effective services for older people with disabilities. In particular, rigid boundaries can exist between accommodation and day support and between disability support and other program types such as HACC. The design of several of the programs evaluated overcame such structural boundaries. When the individual can plan and coordinate the support they received, choose what services might come to their home and what pursuits and supports they wished in the community, decisions about individual choice and preference become less ambiguous. Services that planned prior to any decisions about activities could consider a person's total lifestyle and were less constrained by pre-existing service boundaries. The ongoing participation of the individual was a fundamental aspect of successful planning. It must be noted, however, that for many people with physical and sensory disabilities this individual planning role does not need to be located with other people or services.

### **Relationships between Accommodation and Support**

The relationships between accommodation and day support services had been developed in various ways to enhance the individual's day support opportunities. These included cooperation around each individual between the day and accommodation services, the accommodation support staff being responsible for delivery of what has been traditionally called day support, or day support staff providing in home and community-based support using a person's home as the base. All of these approaches abandon notions of full- and part-time delivery of day support and recognise day support in the broadest sense.

## **Packages of Support**

Examples were found where aged care and disability programs worked cooperatively to build a package of supports around an individual. These hinged on disability providers taking on the lead role in coordination and planning and providing support staff to aged care settings. For example, in one instance a disability program applied for HACC funds to provide day support in supported accommodation to older people with and without disabilities.

## **Late Entrants**

Several programs accepted people who were 'late entrants' to the disability system. This seemed to be related to both an organisational willingness and the availability of additional funds to support people.



# Conclusions

## Lifestyle Support Not Day Programs

It is important to re-conceptualise the traditional model of day programs for older people with disabilities to reflect the current service paradigm of individualised support for community membership and participation. This entails:

- Broadening the scope of day support services from the traditional 9.00am–3.30pm five days a week to all the waking hours of every day.
- Removing the distinctions or, at a minimum, ensuring greater permeability between day, residential and leisure programs.
- Thinking more broadly than day centres as to the context of delivery.
- Mandating day support services to intervene at multiple levels, providing not only individualised support but also operating at more systemic levels to ensure increased access or improved lifestyle for groups of people with disabilities.

Day support services are fundamental in supporting the chosen lifestyle of an individual with disabilities and ‘giving people a reason to get up in the morning’. They are not, however, just about providing intensive periods of activity or engagement in order to be away from home. Day support services fulfil a variety of functions which at different times or concurrently may include monitoring a person’s safety, providing respite for carers or improving the individual’s quality of life by assisting access to meaningful and individually chosen social interaction or activities.

A range of factors mediate the type of day support services required by an individual, its purpose, intensity, frequency and timing. These relate to both the micro context of the individual, their characteristics and immediate social context as well as macro factors such as community attitudes, location, development of the service system, and levels of funding. The overriding factor that should drive the nature of day support services for every individual is their individual choice of lifestyle. This is the key element that lies behind activities and gives similar activities different meanings and satisfaction for each individual. Very simply, within a context of individual choice and broader social factors, the personal characteristics and support needs of an individual in conjunction with the nature of their residential support system will influence the need for various kinds of day support. The balance between these various kinds of day support will also be influenced by the mix, nature and mode of activity, be it active or passive, group or individual.

As a result of this study a suggested working definition of day support services is:

provision of support of varying intensities provided to individuals or external organisations, during the waking hours, which facilitates people with disabilities to access activities and pastimes of their choice that are meaningful to them, which increase their quality of life and may also ensure their personal safety.

## Comparing ‘Ageing in Place’ with ‘Transition and Retirement’

The concept of transition has limited applicability to older people with disabilities who have used day support services for significant periods during their younger years. As they aged, people with disabilities wanted to remain active and engaged and not retire from day support services. They still required support to undertake lifestyle choices.

The primary issue for those people using disability day support services as they age is the provision of continuing support adapted to their changing needs rather than transition to a fundamentally different sort of day support service. In this way, day support services are fundamentally different from employment services.

The nature of a person's disability significantly affects the nature of day support services they require, as will their prior connection to day support services. Thus, the balance between the various types of day support will vary between and within the different disability sub-groups, with perhaps the greatest differences occurring between those with and without cognitive disabilities. For the latter group, physical access, transport, costs of entry and attendant care are major issues, while for those with cognitive disability, support to choose, plan and participate in activities and monitoring physical safety are the more pressing issues.

The aims of day support services at earlier stages in the life course are very similar to those proposed for older people, involving elements such as choice, community access, community participation and skill development and maintenance. The most commonly identified issues in relation to older people were the necessity to reduce the intensity of programs and hours of active programming, and to alter the environment in which programs occurred.

The characteristics of effective day support services were not dependent on the design of the service. A coherent organisational philosophy, management who attend to the quality of service delivery outcomes for individuals, individual staff who are skilled and sensitive in respect to people with disabilities, and positive ageing were the most critical variables in performance against key criteria for effective services. In addition, a strong focus on lifestyle planning, unencumbered by any preset menus of activities or services, achieved the most effective delivery of services.

Reframing the concepts of transition and retirement to flexible, continuing support still involves assisting individuals with disabilities in planning for and understanding older age. However, this should be a part of lifestyle planning across the life course, as many issues associated with successful ageing stem from earlier lifestyles.

## **Responses to Those Outside the Disability System**

The approach of adaptation rather than transition potentially disadvantages those people ageing with a disability who are outside the disability day support system. The practice of an upper age limit for entry into CSDA-funded community access services makes late life entry to such services difficult, if not impossible. These are people in supported employment, and those without formal day support who may be on waiting lists, living with older carers or in congregate care situations. Included in this group are people with ABI for whom few day support services exist and people with milder disabilities who may need support at an older age.

Where older people with disabilities sought day support services in later life their options were often limited to HACC day centres or in home services, neither of which catered adequately for their needs if they required high levels of support related to their disability. Rigid program boundaries and notions of double dipping sometimes not only created obstacles to packaging such aged care services with disability day support services but also made people who lived in disability supported accommodation ineligible for such services.

## **Access to the Community and Aged Care System**

Although a range of formal and informal community leisure programs are found to varying degrees within different communities and many have inclusion of people with disabilities as a key

operating principle, significant barriers to access still exist. Typically, these barriers related to the absence of adequately trained support staff in services who are trying to respond to their diverse local communities.

Utilising the aged care system also presents significant barriers for older people with disabilities in terms of both appropriateness and accessibility. The primary targets of the aged care system are the frail aged and people living with informal carers in the community, neither of which are sizeable sub-groups amongst people ageing with a disability. Although, it must be recognised that as people with a disability grow older, they may acquire additional age-related health conditions or disabilities, which will mean that services for the frail aged might be more appropriate for them.

As older people with disabilities age, there is a potential for day support or activities to be available to them from generic community leisure or aged care services as well as the disability day support service system. However, in many instances, to gain access to such services requires additional supports (from the disability day support system) at either an organisational or individual level. This suggests a continuing role for the disability day support service system as people age, and the importance of entry into that system for people with disabilities who have spent their younger years in supported employment or without any day support.

## **The Interface of Accommodation and Day Support**

The nature of a person's accommodation plays a pivotal role in the type of day support they can access and can pose considerable cross-program challenges. For those people who do not require their safety to be monitored or who have 24-hour staff or carer support available, the issues are less pressing than for those who live in shared supported accommodation with restricted staff support.

For those people living in shared supported accommodation, the relationships and rigidity of program boundaries between accommodation and day support services create strong barriers to reconfiguring and adapting services to ensure a choice of lifestyle as people with disabilities age. The new paradigm of day support services is moving away from attendance at a day centre from 9.00–3.30 and towards the home as the base in which monitoring for safety and support for participation in activities of choice in the community occurs. This means day support and accommodation services must coordinate their support around individuals, particularly if the key program characteristics of flexibility and spontaneity are to be achieved. The absence of coordination around individuals' support needs between day and accommodation support was a significant barrier identified in this study. It is no longer tenable to require older people to vacate their homes for set periods of the day. If necessary, low level monitoring for safety support must be provided in the context of a person's home by day support or accommodation staff. However, constant staff presence may not be the only option to ensure people's safety is monitored. Disability services could learn from the aged care 'in home' support system where very vulnerable older people are enabled to remain in their own homes through the use of devices such as assistive technology, alarms, visiting or call services to monitor their safety.

It is apparent that some services that provide or fund both day and residential support to older people with disabilities have been able to introduce a degree of flexibility as to where day time support is offered and not to insist people are out of their homes at rigid times. In addition, the program evaluations clearly showed that relationships between accommodation and day support services could be developed in various ways to overcome program barriers. Examples included cooperative planning around each individual between the day and accommodation services, the accommodation support staff being responsible for delivery of what has been traditionally called day support, or day support staff providing in home and community-based support using a person's home as the base. The argument that the cost of accommodation services would increase if people

were allowed more ready access to their home during weekdays cannot be accepted in isolation from funding for day services and is a poor basis for service planning.

## **Different Starting Points for Service Development**

Just as the different starting points inside or outside service systems from which people with disabilities begin to age affect their trajectory of service use, each State and Territory has a different starting place and context for development of policy and services for people ageing with a disability. Within the common broad policy directions for disability shared by all States and Territories as a result of the CSDA and State Disability Services Acts, different avenues of service development and design will need to be pursued that build on existing local and regional service systems. Rather than describe the situation in each State and Territory, this section identifies the factors that differentiate States and will have an impact on the development of services for people ageing with a disability.

Most clearly, States and Territories differ in relation to the extent to which they have begun to develop policy and services for older people with a disability. WA and Victoria have led the way, with the Department/State instrumentality responsible for disability services taking the lead role.

Service development for older adults with a disability is a logical extrapolation of policies of choice, flexibility and individualised responses that are increasingly central to disability policy. An emphasis on individualised funding as the basis for more flexible service options is developing across all States and Territories, although the breadth of services to which this approach is applied varies. Initiatives that span residential and day support services are well developed in WA and Queensland and have already begun to break down the barriers that artificially segment people's lives into programs and demonstrate a supported lifestyle approach.

While all State/Territory disability services have traditionally emphasised services for people with intellectual disability, they are in various stages of transition to a broader disability focus for planning and delivery. Further, States and Territories differ in terms of the impact of deinstitutionalisation of large numbers of people on their disability cohort, many of whom have an intellectual disability. All States and Territories have closed some congregate care facilities for people with disabilities. ACT, WA and Tasmania have closed all such facilities. In Victoria and Tasmania, this process has been a catalyst for the development of specific day support programs targeted at older people with disabilities. NSW faces the unique situation of developing services for a large institutional population of older people.

States and Territories have different histories of service development for people with disabilities, for example, WA and ACT did not develop large institutions. They have very different per capita levels of State expenditure on older people with disabilities (South Australia has the highest and Queensland lowest). Similarly, expenditure and the nature of day support services have differed, with Victoria having the highest number of places in such services. The level of unmet need and the expectations of day support services differ too between States and disability groups within States. The extent of unmet need, especially for younger people with disabilities, will determine the pressure exerted within services systems for older adults to 'be moved on'.

States and Territories vary in terms of the resources allocated to community development, which is seen in this study as a key strategy for day support for older people with disabilities. Further, there is a differing specialist disability service profile in each State and Territory. Flexible funding packages assume a basis of service options to be selected. Some States and Territories are reporting the impact of limited community development strategies between the disability sector and the community sector generally. A policy of community participation is inevitably difficult to



implement unless work has been undertaken to develop community acceptance and inclusion of people with disabilities.

Access to HACC services and implementation of eligibility guidelines varies in different localities and States, as does the extent of cooperation between disability and aged care services. A trend to greater flexibility was found in rural compared to metropolitan areas.

In rural and remote areas, there is a lack of options due to the small number of services. This heightens the requirement for flexible funding and service models. In such areas it is difficult to recruit people with para-professional qualifications, and creative ways of getting services to rural and remote areas in Queensland, such as the 'fly in, fly out' teams, are being developed.

The profile of service types must match the population structure and dispersal of each State, Territory and locality. The dangers of proscribing service systems out of their historical and geographic context is recognised in all States and Territories. States and Territories differ according to the geographic dispersal of their populations (for example, Tasmania has many small population centres), distances between town centres (for example, Victoria and Tasmania have negligible remote areas) and numbers of people in the metropolitan compared with rural/remote areas (for example, Queensland has the largest numbers of people living outside metropolitan areas).

Non-English-speaking populations vary between States and Territories, being high in Melbourne and Sydney with specific and dispersed groups in Queensland. Particular responses are also needed for Aboriginal people who are recognised as ageing earlier than the general population. The Northern Territory has developed initiatives in this regard.

## **Making Healthy Ageing a Reality**

Despite genuine interest in their client group, many providers of disability day support services hold quite negative, stereotypical views of ageing and display little knowledge of ageing processes. Their visions for older people do not reflect many of the elements for healthy ageing, such as the importance of continuing development of skills and interests, continuing engagement, an active lifestyle and physical fitness. Their views are not only out of synchronisation with the thrust of the Federal Government's Healthy Ageing policies but also with those of people with disabilities themselves, who perceive later life in a much more positive and active light.

Older people with disabilities are not included in promotional material on healthy ageing and disability service providers have little training and education about the impact of ageing on health or the importance of an active lifestyle. These findings suggest the importance of broad-based community education on ageing to include people with disabilities and the need for pre- or in-service training on ageing processes for personnel within the disability system.

Conversely, some staff responding to the questionnaires within mainstream community leisure services and aged care services demonstrated little understanding of older people with disabilities, often perceiving disability in the simplistic terms of physical accessibility. People ageing with a disability are just one of the many minority groups that mainstream and aged care services must adapt to. This suggests the necessity for the disability sector to take a lead in regard to ensuring other service systems are responsive to the diverse needs of people ageing with a disability.

## **Choices Around Supporting Quality of Life**

The results of this study support the conceptualisation of day support in the broadest terms of lifestyle support, as distinct from a narrower service type. Therefore, all services provided to an individual should be planned cooperatively around that individual. The study cannot answer to what extent such individualised supports will be funded. Most States and Territories are implementing individualised funding packages using various maximum funding levels and options for recognising varying support needs. Issues relating to the optimum funding level for older people with disabilities are part of this broader trialing of individualised funding and identification of funds which were previously 'locked up' in agencies for individuals. The starting point is to specify the current funding to an individual across all existing services (for example, day centre, supported accommodation) and to plan lifestyle support based on that amount. However, it is important to note a trend in current developments of individualised packages that higher personal support needs tend to mean less available support for community participation. A clear challenge, therefore, is to reach decisions as to the balance between supervision and active engagement.

## **Service Dilemmas in Responding to People's Changing Needs**

Any change in a person's motivation, capacity or health status is at risk of being attributed to older age. Hence, for people with a disability, older age was described in terms of age brackets much younger than that used for the general population. Changing needs for a range of reasons or high support needs tended to be subsumed under the issues of ageing. This has the danger of skewing the sector's view of ageing. It raises an issue to be addressed by the sector in regard to day support services for younger people with high or changing support needs. Services have difficulty changing the nature of their service response over someone's lifetime. There is some indication that individualised funding models for younger people may progressively address these issues, but only if funding levels can change across the life course.

## Issues for Future Consideration

The following issues have implications for the next CSDA, each State and Territory disability and aged care policy framework, and the practice of individual disability services. While many of the issues depend on national policy directions, others will be able to be implemented by service providers or for particular individuals in their local communities.

Many of the issues are applicable to day support services for all age groups, not just older people.

The service challenge is greatest for the current group of older people with disabilities and their carers. Many of the reforms in day service provision have occurred in services targeting younger people who, with their families, do not have a set expectation that day services will be centre-based and of full day duration.

### Issue 1: State/Territory-Based Policy for Older Adults with a Disability

Policy and service development responsibility for older people with disabilities should rest with State/Territory disability programs in order to ensure ongoing and relevant support to people with disabilities across the life cycle. It is recommended that:

#### 1.1 Access

Each State and Territory develop policies for older people with disabilities that promote access for all people with disabilities seeking day support at older age. This includes people outside as well as inside the disability day support service system already. This means:

- Endorsing the Healthy Ageing Policy and adopting 'ageing in place' policies for older people with disabilities to replace notions of retirement and transition from current day support.
- Discontinuing the practice of a maximum age for entry to disability services.
- Allocating additional funding for several groups, such as those moving from open and supported employment and those presenting for the first time at older age.

#### 1.2 Principles To Guide Service Delivery

Policies describe the principles that are to guide service delivery to older adults with disabilities and the required service outcomes, including:

- Describing day support in terms of lifestyle support and the meaningful use of time with the aim of offering:
  - choice
  - strengthening social networks
  - participation in the community
  - skill maintenance
  - development of self-expression
  - a healthy lifestyle for older people.
- Providing planning and support around the individual's total lifestyle and across program boundaries.
- Encouraging cooperation between all services including community, aged care and disability as appropriate for an individual in a given locality.

### **1.3 There Is No One Service Type**

No one type of service model is recommended. However, it is strongly suggested that either a comprehensive individualised lifestyle planning approach form a component of the day support service or that such planning be undertaken by a separate agency and precede the development of specific day support options offered by a specialised day support service.

The key service characteristics for delivery of day support are an individualised, planned, flexible approach.

### **1.4 Broader Community and Service Development Tasks**

The following types of community and service development tasks should be explored, trialed and implemented:

- Promote and support inclusion for older people with disabilities in community leisure programs.
- Recognise resource demands to support access to community facilities.
- Develop strategies and incentives for coordination around individuals between day and accommodation providers (and other providers).
- Cease the practice that people cannot return to their supported accommodation at certain hours.
- Develop protocols regarding access to aged care services.
- Recognise that community development must occur, in addition to individualised funding, to develop initiatives that extend physical and social access and program options to underpin individual approaches.
- Recognise the need for day services, for all age groups, to be more flexible in order to obviate the need for younger people with high support needs to be included in programs for older clients as a way of achieving flexibility.
- Develop the capacity of day support services to respond to changing needs and interests over a time.
- Remove barriers to service entry that are based on notions of double dipping and adopt coherent criteria for entry to services based on a coordinated and integrated service system around individuals.

### **1.5 Increased Understanding of Healthy Ageing**

The competencies (skills, knowledge and attitudes) of staff working with older adults with disabilities are identified and a comprehensive training strategy developed on successful ageing concepts for staff at all organisational levels.

Notions of healthy lifestyle are injected in all programs for people with disabilities across the life course to ensure people with disabilities, staff and carers have a strong knowledge and commitment to this notion.

### **1.6 Demonstration Projects**

Demonstration projects in different States may respond to different local service systems and specific sub-groups of people with disability to further develop suggested key elements of service delivery and stimulate debate and discussion on models of service delivery. These projects would model cooperation between sectors and foster the adoption of a positive healthy ageing approach. Such projects would also consider:

- Packages of funding between different levels of government and policy sectors (for example, between State and Commonwealth).
- Incentives for partnerships for agencies and the development of responses to changing needs over a lifetime.
- Recognition of the lead role of disability in regard to linkages with aged care, community

leisure and health programs.

- Aged care/HACC 'top up' to disability to avoid parallel services and reduce referral to nursing homes.
- Differentiation of the needs of older carers from those of older people with disabilities for whom they care, while maintaining links between an individual and older parents in aged care.
- Role of brokers to manage the coordination between agencies.

## **Issue 2: Improved Databases to Enable Better Prediction**

National, State and Territory databases are limited in their capacity to identify older people with disabilities. It is recommended that:

### **2.1 Age of Onset of Disabilities**

The CSDA minimum data set collections and Australian Bureau of Statistics (ABS) disability surveys include questions regarding age of onset of the major disabling condition.

### **2.2 Predicting Unmet Need**

States/Territories and Commonwealth develop strategies to predict the number of people who will present for the first time at older age (this will include people from Commonwealth funded employment services, those in carer respite programs and on waiting lists). Such strategies would reduce crisis responses currently occurring when, for example, older carers suddenly discontinue care due to ill health or death.

Further investigations occur in examining and planning the different pattern of access and need for day support services for different disability groups.

## **Issue 3: Role of Aged Care**

It is recommended that:

### **3.1 A Lead Role for Aged Care**

The aged care system should take a lead role in ensuring that services for the frail aged are accessible and responsive for older people with disabilities who have additional age-related disabilities and frailty.

### **3.2 Appropriate Training**

Professionals within the aged care system should have basic training in current values, attitudes and strategies for providing support to, and communicating with, older people with disabilities.

### **3.3 Positive Ageing Publicity**

Public education and positive ageing publicity should include older people with disabilities in order to promote strong positive role models of ageing for this group and the wider community.



## Appendix A: Project Terms of Reference

- To provide a demographic profile of the potential target group.
- To investigate service models that address or seem to address transition from specialist disability day support programs to alternative activities in Australia and overseas.
- To identify any factors acting as impediments to appropriate transition from specialist disability day support programs from a personal, family, carers', service provider and funder perspective.
- To identify and describe the types of specialist disability day programs currently being provided to older adults.
- To identify and report on the nature and scope of issues surrounding the transition from specialist disability day programs to non-specialist day programs or to less than full-time placement as a result of ageing, including a description of the links between level of day support and the ability to continue living within the current accommodation environment.
- To report on alternative services and supports (Commonwealth and State/Territory) that may be used by older adults with a disability seeking to retire for specialist disability day programs and the barriers and obstacles that may impede access.
- To highlight and report on significant State by State variations to all of the above.
- To make recommendations to enable the development of State-based implementation plans to address these issues.
- To make recommendations within the context of the National Healthy Ageing Strategy.

## **Appendix B: Reference Group Members**

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## References

Australian Institute of Health and Welfare. (1999). *Australia's Welfare*. Canberra: Australian Institute of Health and Welfare.

Australian Institute of Health and Welfare, (1997). *Australia's Welfare, 1997: Services and Assistance*. Canberra.

Balandin, S., & Morgan, J. (1997). Adults with cerebral palsy: what's happening? *Journal of Intellectual and Developmental Disability*, 22(2), 109–124.

Cooper, M. (1998). Sharpening the focus on ageing and longterm physical disability. *Australasian Journal of Primary Health Care - Interchange*. 4(1), 87–92.

Crewe, N. (1990). Ageing and severe physical disability: Patterns of change and implications for services. *International Disability Studies*, 13, 158–161.

Department of Human Services. (1999a). *Day Support Service Options for Older Adults with a Disability. Tender Document*. Melbourne.

Department of Human Services (1999b). *Day Services for People Ageing with a Disability*. Melbourne

Eyman, R., & Borthwick-Duffy, S. (1994). Trends in mortality rates and predictors of mortality. In M. Seltzer, M. Krauss, & M. Janicki (Eds.), *Life Course Perspectives on Adulthood and Old Age* (pp. 93–108). Washington: American Association on Mental Retardation.

Gething, L. (1998). *We're Growing Older, Too: Quality of Life and Service Provision Issues for People with Long Standing Disabilities Who Are Ageing*. Sydney: The Community Disability and Ageing Program, The University of Sydney.

Janicki, M., Dalton, A., Henderson, C., & Davidson, P. (1999). Mortality and morbidity among older adults with intellectual disability: Health services considerations. *Disability and Rehabilitation*.

Wen, X. (1997). *The Definition and Prevalence of Intellectual Disability in Australia*. Canberra: Australian Institute of Health and Welfare.

Wen, X., & Fortune, N. (2000). *The Definition, Incidence and Prevalence of Acquired Brain Injury in Australia*. Canberra: Australian Institute of Health and Welfare.

Wen, X., & Fortune, N. (1999). *The Definition and Prevalence of Physical Disability in Australia*. Canberra: Australian Institute of Health and Welfare.