Review of services for older people
Brotherhood of St Laurence

Discussion Paper 5
The impact of dementia and disability
on services for older people

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BROTHERHOOD
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Introduction

As a consequence of the increasing use of assessment of functional need to determine access to services there is less distinction being made between services for older people and for people with disabilities. The level of frailty and dementia of older people seeking assistance from services has also markedly increased.

Increasingly community care and residential care services established to provide support and care for older people are considering the implications for their services of steady referrals to admit into their programs a range of people with a variety of needs, including:

- People with dementia
- Older people with an intellectual or psychiatric disability
- Younger people with varying degrees of brain damage (i.e. alcohol abuse, head injury and early onset dementia)
- Younger people who are in receipt of a disability pension who for varying reasons seek the services provided by aged care programs.

The purpose of this paper is to examine the trends and issues around dementia and disability, their impact on services and the people who use them and their implications for the Brotherhood.

The paper describes issues confronting Brotherhood services and asks key questions which include:

- To what extent are separate services necessary and what is required for existing services to integrate people with dementia/disabilities?
- Does the infrastructure of services for older people — (staff, buildings, type of care), offer a suitable service for younger people with disabilities?
- Should Brotherhood services respond to the needs of younger people with disability/dementia?

Dementia

Background

Nursing Homes were established in the main to provide care for older people who were mentally alert, but physically frail. Hostels often catered for the active older person who turned to residential care for social support, companionship and security. When the Brotherhood's residential care facilities were established, only a minority of residents would have suffered from dementia. With the increase in the incidence of dementia all organisations providing aged care have had to adapt and respond to the changing pattern of need.

The incidence of dementia has increased by approximately 15 per cent between 1986 and 1990, and it has been estimated that there will be a further increase of 20 per cent between 1991 and 1996 (Jorm and Henderson 1990).

The growth is due to the combined effects of rapid increase in the very old population, those aged 80 years and over, and the much higher rates of prevalence of dementia at those ages. While the rate of increase drops toward the turn of the century and for some years thereafter, the absolute numbers of people with dementia will continue to grow, so there will be an ongoing high level of need for dementia care. (Commonwealth Department of Health, Housing and Community Services (CDHHCS), 1992:5)

Figure 1 Projected numbers of elderly people with moderate to severe dementia in the Australian population, 1986-2006

Age group No.	Prev. Rate %	1986 '000	1991 '000	1996 '000	2001 '000	2006 '000
(a) Prevalence rates from Campbell et al. (1983)						
65-69/70-74	3.8	39.4	44.2	47.8	47.0	49.1
75-79	6.4	20.7	24.7	26.7	30.9	31.7
80-84	11.0	20.1	25.7	30.9	33.6	38.7
85+	28.2	34.8	42.2	53.8	66.1	74.7
Total 65+		*115.0*	*136.8*	*159.2*	*177.6*	*194.2*
% Increase			19.0	16.4	11.5	9.3
(b) Prevalence rates from Kay et al. (1985) and Preston (1985)						
65-69	1.6	9.1	10.5	10.7	10.2	11.5
70-74	2.4	11.3	12.1	14.0	14.4	13.6
75-79	6.7	21.7	25.8	27.9	32.2	33.2
80-84	11.1	20.2	25.9	31.2	33.9	39.0
85+	28.7	35.5	42.9	54.8	67.3	76.0
Total 65+		*97.8*	*117.2*	*138.6*	*158.1*	*173.3*
% Increase			19.8	18.3	14.1	9.6

Source: CDHHCS, 1992:9

Residential care facilities provide care and support to approximately half of those people with moderate to severe dementia, with Nursing Home accommodating just over one third.

Figure 2 Distribution of people with moderate to severe dementia between care settings

		No.
Nursing homes	60% x 73,000	43,800
Hostels	13% x 44,000	5,700
Other mental health facilities		3,000
Residential care total		52,500
In community total		64,700
Total		*117,200*

Source: CDHHCS, 1992:10

There are over 50,000 people with moderate to severe dementia living in residential care facilities, including an estimated 43,800 in nursing homes and at least 5,700 in hostels. The Commonwealth Government estimates that 64,700 people with moderate to severe dementia are living in the community. Yet only 19,000 people with dementia or their carers are estimated to receive services funded through the Home and Community Care Program (HACC) (CDHHCS 1992).

The Brotherhood's response

As has been identified in other Review papers, the Brotherhood Services for older people were initiated and developed largely in response to funding opportunities in the last decade. The changed external assessment criteria for services and targeted subsidies has seen programs react to the resulting increased frailty and dementia of service users as best they can, with minimal attention given to a considered approach to the management of aged care services individually or organisationally.

The dementia specific day programs and Barwon linkages have been established by the Brotherhood in response to the growing need to care in the community for people with dementia and their carers. Hostels were able to receive funding through dementia grants, but this funding has been phased out and absorbed into direct subsidies, depending on assessment and the levels of support required by individuals. Nursing Homes provide the most residential care for people with dementia and receive recurrent subsidies based on assessment of resident care needs using the Resident Classification Instrument (RCI). There is no guarantee that this funding is meeting specifically the needs of people with dementia. Up until this point, the Brotherhood has not developed a strategic plan for dementia care, but has supported each service area to develop their own response in integrated programs depending on resources and skills.

Action for dementia care

Whether or not services are provided for people in the community or in residential care, they need to be appropriate to the needs of the person with dementia. Services and support should meet each person's individual need and be provided in a way that promotes their human rights and personal dignity. Although there may be a difference in the residential care needs of people with dementia and of people who are frail, in many instances these needs can be met in the same facilities, particularly when programs and the environment is designed to assist residents with dementia and improve their quality of life.

Many providers of aged care have developed dementia specific programs and services that are segregated arguing that the care needs of older people who are frail are different to those of older people with dementia. The either/or approach to integration/segregation is less of an issue with the trend towards an integrated approach with separate care and accommodation provided only for those whose behaviour is most disruptive. A dementia specific service is considered to be the most appropriate response only for a person whose behaviour interferes with the quality of life for themselves and the people around them.

At present, residents with dementia whose behaviour is causing problems, are maintained in facilities with less than adequate resources, sometimes at risk because the environment is not safe or supervision by staff is not possible at the level required. This situation for staff causes high levels of anxiety and may result in unfavourable decisions being reached. An example may be the transfer to a less satisfactory residential care facility, or just the constant worry of the whereabouts of a particular resident. It is a dilemma for staff knowing that alternative care may restrict and restrain the individual reducing their quality of life.

The *Discussion Paper on Residential Care (No.2)* identified some issues that affect the capacity of the facility to provide an optimum service:

- physical design of buildings

- models of care
- service standards
- staff education and development
- resources

These factors will equally impact on the extent that the needs of the client or resident with dementia will be met. The priority improvements for residential care identified by the review — improved physical design of buildings and staff's training and model of care — are also the priorities in a strategy of action for low-income older people with dementia.

Figure 2 indicates that just over half the people with moderate to severe dementia are cared for in the community, but only 29 per cent receive assistance through the HACC program. These figures suggest that although community care may be preferred to residential care, 71 per cent of people with dementia are largely dependent on the informal support network of family and friends and not formal care. The evidence is that there are gaps in the provision of community care to people who have limited family support and networks. The higher than average incidence of dementia at Sumner House would support the argument that these people are more at risk of admission to residential care because of the lack of alternative support. The Brotherhood needs to have the capacity to respond to the needs of older people who are socially and financially disadvantaged as there will be continued external and internal pressure to meet these needs both in residential care and community care.

In comparison to its involvement in residential care, the Brotherhood has limited involvement in the HACC program, yet the traditional client group is one that lacks, or has limited family support. The Coolibah Day Centre provides social and life skills support to this group who otherwise might be at risk in the community. It has limited capacity to support people with moderate to severe dementia because of the program focus and building structure. Yet it is this group of people who have dementia, and live alone with limited family or social networks who may be more at risk remaining in the community and more likely to be admitted to residential care.

Both St Laurence House and the Banksia Centre have been developed to support people with dementia and their carers who are still living in the community. Both have demonstrated that by effective programs, providing a flexible approach of informal support and structured program in day care and respite services, people can be maintained well in the community. Planned and emergency short-term respite are available at both programs fulfilling a desperate need of carers. During the consultation with staff and carers, the particular value of the flexible respite at these programs was consistently highly rated. However, respite care in the residential care facilities is often found to be problematic for many of the reasons that have been discussed in relation to permanent care. In addition to these difficulties, the unfamiliar surroundings may increase the person's confusion causing more problems when they return home. Because of the extra resources required to provide the levels of support to people with dementia, most residential care facilities, including the Brotherhood are reluctant to provide respite care to people with moderate to severe dementia.

However, because there will be an ongoing high level of need for dementia care, it is imperative that the Brotherhood develop a capacity to provide services appropriate to these needs where the dementia is combined with low income.

Disability and Ageing

The Australian Bureau of Statistics (ABS) defines disability as:

> ... a person who has one or more disabilities or impairments which has lasted or was likely to last, six months or more (ABS 1990).

This is a broad definition of disability and includes a number of impairments such as loss of sight or hearing, or diseases of the musculo-skeletal system that are often part of the ageing process resulting in the slow decline of functional abilities and cognitive functioning. The incidence of disability increases with age; 46 per cent of people over 60 years of age and 83 per cent of those over 80 years of age having some form of disability.

ABS figures quoted in *Double Disadvantage Housing for People with a Disability in Victoria* (1992) indicate that in Victoria, the principal disabling condition for 78,200 people was head injury, intellectual or psychiatric disability whilst the principal disabling condition for 608,600 people was a physical or sensory disability. With the acceptance of normalisation polices and the philosophy of deinstitutionalisation, generic aged services are increasingly being asked to respond to the needs of older people with an intellectual or psychiatric disability.

This section of the paper will discuss the needs of older people with this particular disability: an intellectual or psychiatric disability.

As a person with an intellectual or psychiatric disability ages and their support needs change, they are turning to generic services to provide levels of care and support that previously would have been provided separately. The policy of mainstreaming seeks to ensure that services are co-located with generic services including support, health and accommodation. Longer life expectancies and, increasingly, the inability of elderly parents to continue to provide levels of care to their ageing family member means that support, and reassurance of ongoing support, and accommodation is being sought. Community care, adult day support services and residential care facilities will respond and provide care and support services if appropriate. However, because a person who has an intellectual or psychiatric disability will often lack informal networks, the level of support required to stay at home or move into residential care is often much higher than for older people in general. This lack of informal networks is often true of traditional Brotherhood clients too and what is important in developing a strategy in response to traditional clients, or people with a disability, is the level of resources the Brotherhood is prepared to commit to services. The growth of Brotherhood services for older people has developed in an ad-hoc manner with services reacting to the perceived needs of the region they operate in, and the wider community. Services have responded by accepting older people with an intellectual or psychiatric disability into their particular program or facility without the development of an overall strategy that incorporates the critical element of a good service response. These elements are discussed below.

Program designed around individual needs

It can be argued that high quality services for older people will meet the need of any individual if the environment is well designed and clear policies are in place. Too often in practice the individual adapts to the program instead of the needs of an individual being met by a personally tailored program that is agreed on after comprehensive assessment and consultation. The well resourced programs using a case management approach have been able to do this better than programs where funding is targeted at the type of facility providing the service. Restriction on staffing and award structures lessen the ability to be flexible. The reality is that organisations providing services for older people would strive towards meeting the needs of individuals. If nothing else, the outcome standards imposed and monitored by the Commonwealth Government demand this focus of service in residential care. Maintaining a high quality service for older people with the current resources available is difficult though. Clearly, if people have disabilities in addition to the frailty of ageing extra funding will need to be directed at programs that are responsive to these groups to ensure individual needs are given the highest priority. This is an important advocacy issue for the Brotherhood to document and take up with governments.

Effects of institutionalisation

For older people who have had multiple admissions or lengthy periods in institutions, social skills are often lacking and life experiences are limited. Taking into account the debilitating effect of institutionalisation it is necessary to acknowledge the profound needs of an older person with an intellectual or psychiatric disability. It is not enough to provide people with shelter and food and keep them occupied, ignoring the emotional, social and spiritual needs that may have been neglected in the past. Factors such as government funding, staffing and models of care have already been identified as barriers to a high quality service. Without additional resources only the basic needs of individuals will be met. Yet it is these people who are the most likely to be multi-disadvantaged because of disability, low income and lack of family and social networks, who have the greatest difficulty accessing generic aged services, particularly residential care.

Housing

Affordable and appropriate housing is an important issue for the disabled person, young or old. The ageing person with a disability is more likely to fall into the lower income group because of the additional costs associated with disability. This has not generally been recognised in income support policy. The low-cost, secure housing plus support, of the level that is provided in independent accommodation facilities operated by the Brotherhood, could be appropriate for an older person who has been financially disadvantaged because of their disability. Access to appropriate housing is often limited by the nature of chronic psychiatric disability. A poor record as a tenant for instance will limit a person’s access to low-cost appropriate housing and force them into a sub standard rooming or boarding house or Supported Residential Service.

An ongoing concern in the provision of independent accommodation is the level of support provided to residents. In stand alone facilities and those sited in the Retirement Villages there is an expectation by residents for support and care that would not normally be expected from an agency whose focus was primarily accommodation. One of the implications for housing people with disabilities in independent accommodation would be the need to develop a service policy in this area that clearly defined the range of support that could be made available in excess, or addition to housing support.

Staff Training

The Review has highlighted the need to re-focus on the provision of high-quality services that can demonstrate their flexibility, and respond to the needs of the individual. To enable best practice to be achieved, access and commitment to staff training in these areas must be given a high priority. For services to respond to older people with a psychiatric or intellectual disability it will be important to develop staff knowledge and skills in areas other than clinical care. To ignore or give less attention to the emotional and social needs may lead to inappropriate behaviour and depression in the client group, and a more stressed staff team.

If the Brotherhood is to actively demonstrate its support for the policy of mainstreaming and respond to emerging needs in its service areas, there needs to be a service policy framework that addresses the points outlined.

Young disabled

There is little written data on the effect of providing care for the younger disabled person in a facility that predominantly cares for older persons. The assumptions commonly heard from organisations working in either the field of aged care or disability is that appropriate facilities and services for young people with severe disabilities should be separate from those for older people. The exception may be in a well designed nursing home or hostel that is able to respond in a highly individualised way where the size and design of the facility, or section of it, would ensure that every person has the privacy and dignity of personal space.

The continuing care needs of younger disabled adults is one of great concern. For younger people with significant care requirements, the only option is often a nursing home even though nursing care may not be required to maintain long-term support. The emotional and social needs of a young disabled adult are the same as a young adult who is not disabled. These needs in the main are quite different to an aged person, and difficult to meet in an aged persons facility.

One example of this issue is the housing and support for younger people with acquired brain injury (ABI). Many are placed in inappropriate accommodation because there is no other option. This includes Supported Residential Services, Hostels and Nursing Homes predominantly caring for older people. The figure below shows that there are over 800 people under the age of 65 living in nursing homes in Victoria. At least 12 of these are under 20 years of age.

Figure 3 Data by age for all persons in a nursing home during the period Jan '92 — June '93

Age	**1-24**	**25-34**	**35-44**	**45-54**	**55-64**	**65-74**	**75+**
Frequency	13	26	45	151	533	2300	14974
Cumulative Totals	**13**	**39**	**84**	**235**	**768**	**3068**	**18042**

Source: Aged Care Division, Dept Human Services and Health, Melbourne

Nursing homes are frequently the only option for these young people because the service can respond to the high support needs of a young person with ABI. Although twenty-four hour support is provided, the physical needs, and not the life style needs of the individual is often the determining factor.

Most anecdotal evidence suggests that despite the best intentions and the provision of high-quality services the placement of young adults with ABI in aged care facilities is not usually successful. Examples of concern about aged care placements include:

- social needs and companionship is largely met by staff and volunteers;
- friends and family distressed by the environment cease to visit;
- parents and other carers distressed by having to place their daughter, son or spouse in an aged care facility because there is no alternative; and
- it is depressing for a young adult with a near normal life expectancy living with a group of people whose life expectancy in a nursing home is on average 20 months (CDHS&H 1994).

Consumer organisations like Headway Victoria provide advocacy and support for people with ABI and their families. They are involved in a project to create a housing and support model in a setting that is age appropriate.

Options for Brotherhood

Practice in aged care facilities is largely affected by levels of resources and the tendency is for the physical needs of the resident to be given the highest priority, with the emotional, social and rehabilitation needs being met when time, resources and staff are available. This is not a criticism of the staff, but a criticism of the model of care where the individual has to fit into a program, instead of a program being developed round the individual. No Brotherhood residential care facility could offer the optimum service to young people without massive changes to current practice and design.

Alternatively, a future option for the Brotherhood would be not to admit young disabled people into service programs but to support initiatives such as MICHI and advocate for better and appropriate services.

Summary and conclusion

One of the themes that is constant in the discussion of services provided to all people whether young or old is the need for highly individualised services that are responsive to each person's needs. Equally important in residential care is the need to have personal space that will be private, safe and secure if necessary. Building design and layout must ensure that people can 'close their door' and be separate from individuals whose behaviour may be annoying, depressing, challenging or even threatening. Existing Brotherhood services have demonstrated their ability to provide high quality dementia-specific services. Integration in existing services is more difficult because of the building design, staff resources and level of funding, and needs to be given high priority in the planning and development of services for older people.

The implication of the increasing incidence of dementia and mainstreaming of intellectual and disability services, is that organisations like the Brotherhood providing aged services will need to be flexible in both policy and practice. Support for staff, and access to education and training to develop skills necessary to respond to the special needs that are additional to those of ageing, is essential.

This discussion paper has described many of the issues and particular difficulties confronting services for older people when combined with services for younger disabled persons. Some would be enough reason to limit access of young disabled to the support and accommodation offered by the Brotherhood's aged care services.

It also reveals the need for the organisation to develop a clear view as to whether and in what circumstances it has a service interest in or responsibility for young people with disabilities.

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