REPORT ON THE IMPACT OF AGEING ON THE NEEDS OF PEOPLE WITH DISABILITY

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People with physical disability: ordinary people; ordinary lives

PDCN The peak body representing people with physical disability in New South Wales

The impact of ageing on the needs of people with disability
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BACKGROUND

Population growth and life expectancy

The Australian population is projected to grow in size. The Australian population is projected to increase from 18.5million in 1997 to 22.1 and 23.1million in 2021 and between 23.5million and 26.4million in the year 2051 (AIHW, 2000). Growth in population size is likely to contribute to an increase in the number of people with a disability, but as a low level of overall population growth is projected (1 percent or lower per year up to 2051) the main impact of demographic change on the number of people with a disability will be the ageing of the Australian population (AIHW, 2000).

Contributing to the ageing of the Australian population is the trend towards longer life expectancy. Between 1998 and 2003 total life expectancy was higher for females than for males, although males gained more life expectancy over that period. Overall, a larger proportion of the gain in female life expectancy comprised extra years with disability (90 percent) compared with the proportion for male (37 percent). For older males, 67 percent of gains in life expectancy at 65 years (1.5 years) were years with disability (1 year), including 27 percent of years with severe or profound limitation (0.4 years). For older females, more than 90 percent of their gains in life expectancy at age 65 (1.2 years) were years with disability (1.1 years) including 58percent of gain with severe or profound limitation

(0.7 years) (AIHW, 2006 in AIHW, 2008). Expected years of life with disability increased from 14.7 years to 18.6 years for males and from 16.0 to 20.7 years for females and life expectancy for people with severe or profound limitations increased from 3.2 years to 5.4 years for males and from 6.0 years to 8.3 years for females (AIHW, 2006 in AIHW, 2008).

The data also reflects a significant proportion of people with disabilities. In 2003, 3,958,300 people or 20 percent of the Australian population had a reported disability (ABS, 2003). A further 4,149,000 people (21 percent) had a longterm health condition that di d not restrict their everyday activities. In 2003, of those people with a reported disability, 86 percent (3, 387,900) had a specific limited or restriction in the core activities of self-care, mobility or communication, or restricted in schooling or employment. Most people with a disability (76 percent) were limited in one or more of these core activities.

The Australian data also indicates that females expect to live longer with more years of disability. In 2003, total life expectancy was 77.8 years for Australian males and 82.8 years for Australian females. At that time, females had higher expectancies of years free from disability (20.7) than males (18.6). Females could expect more years (8.3) with a severe or profound core activity limitation than males (5.4).

In addition, the data on carers is useful in describing the demographic characteristics of people with disabilities. In 2003, there were 2.6 million carers who provided care to a person because of disability or old age. Just over half (54 percent) of all carers were women. About one fifth (19 percent) were primary carers and 24 percent of primary carers were more likely to be older than 65 years (compared to 13 percent of the total population) and more likely to have a disability (40 percent compared to 35 percent for all carers and 20 percent for non-carers (ABS, 2003).

In regard to the ageing of people with disabilities, the number of people with a severe or profound core activity restriction was estimated to increase by 11.6 percent from 2000 to 2006 and that this growth was mainly attributable to the rapid increase in the age groups 45-64 (19.3 percent or 59,500 people) and 65 or over (15 percent or 76,300 people). The report predicted a 9 percent increase in the number of people aged 0-64 with a severe or profound core activity restriction and a 12 percent increase in the size of the working-age population (AIHW, 2000).

In relation to NSW, recent estimates of population growth indicated that the proportion of people aged 65 and older will increase from 14 percent of the population in 2005 to 22 percent in 2030 (NSW State and Regional Projections 2001-2031, 2005).

Differences identified between older people and people with early-onset disability

However, there are differences identified in the data between older people and people with disabilities.

Level and type of need

Although people generally have a greater level of need for assistance as they age, among people with a disability, there is not necessarily a higher level of need for assistance than those aged under 65 years of age. However, there are differences in the types of assistance required by older people and people with disabilities. Among people living with a severe or profound core activity restriction living in households in 1998, there were differences in the profile of need for assistance between those aged under 65 and those older than 65, in terms of higher need for assistance with self care, communication and personal guidance than for people aged 65 years and over. For all other activity restrictions higher proportions of people aged 65 and more reported need for assistance (AIHW, 2000).

In relation to need for assistance with daily activities, between 1998 and 2003, the overall number of people reporting need for help with at least 1 of the 10 core activities, increased by 96,700 and most people (80,600) were aged 65 years and over (AIHW, 2008).

The overall number of people reporting need for help increased for each of the 10 activities, with the largest increases in the areas of mobility (81,900), housework (62,700), cognition or emotion (53,600), health care (53,400) and transport (40,900) (AIHW, 2008).

The number of people who needed help with any core activity but received no assistance remained almost the same (71,600 in 1998 and 70,500 in 2003) but the number of people who needed help with self-care activities but received no help increased by 9,800 from 40,700 to 50,500 (AIHW, 2008).

Among people aged under 65 years, the number of people requiring help in the areas of self-care, property maintenance, transport and health care declined whereas the need for help in these areas for people aged 65 years and over increased (AIHW, 2008).

Source of assistance

Between 1998 and 2003 there was an increase of 93,900 people who required assistance with one or more core activities, most people relied mainly on family and friends, 69,200 people received assistance from both informal and formal sources, 17,300 people from informal assistance only and 8,300 people from formal services only (AIHW, 2008).

However, the source of assistance differed between older people and people with disabilities. Most people with a severe or profound core activity restriction living in households were assisted by co-resident informal carers, however people aged over 65 were more likely to rely on a co-resident informal carer as their main source of assistance with all daily activities except communication, whereas those aged under 65 were more likely to rely on an informal non co-resident carer to assist with mobility, housework, property maintenance, paperwork and transport. These differences in sources of assistance could have implications for the nature of 'service transition' for people ageing with an early onset disability, since they may have a more limited network of informal carers and could be less likely to have a spouse (AIHW, 2000).

Living arrangements

There are also differences in living arrangements. In relation to the living arrangements for people with disability, the largest increase between 1981 and 2003, was in the number of people with severe or profound limitations living with family (an additional 318,000 people aged 65 yrs in 2003 compared with 1981) (AIHW, 2008).

Recent data show that the move away from living in cared accommodation was strongest among people aged 15-29 years; however there was also a decrease from 8 percent to 3 percent among people aged 30-40 years from 1981-2003 (AIHW, 2008). The data also indicated a trend away from resi dential care to community-based living arrangements (AIHW, 2002, AIHW 2005a, 2007a in AIHW, 2008).

Employment

In relation to employment, there was a decline of 21,200 people aged 15-64 years with a severe or profound limitation who were in the labour force between 1998 and 2003 (AIHW, 2008). In 2003, the unemployment rate for people with disability (almost 9 percent) was significantly higher than for people without disability (5 percent) (AIHW, 2008).

Older workers with disability benefited less from improved labour market conditions than people of similar age without disability (AIHW, 2008).

In relation to the sector of employment, in 2003, four out of five people with disability who were employed worked in the private sector (80 percent) (AIHW, 2008).

Recent data also shows that there was an increase of 3 percent from 2005-06 to 2006-07 in people who gained employment from open employment services for people with disability. In relation to supported employment services, the number of people who accessed supported employment increased from 18,463 in 2003-4 to 20,872 in 2006-7 (AIHW, 2008).

Service implications

Even though the data suggest that patterns of need vary with age, age at onset, type of disability and availability of informal care and that people with early onset disability may age earlier and have higher levels of need at earlier ages, none of these factors could reliably be used as indicators of need.

In the context of this data on population growth, increased life expectancy, projected levels of need and differences in the types of need between older people with late disability and those with early onset disability, it is useful to consider the findings of some reports on the projected needs.

One report states the need for flexible services designed around individual needs and for flexible approaches to needs assessment and service provision across program boundaries, particularly those spanning disability and aged care programs (AIHW, 2000). Another policy document from the NSW Industry Group on People Ageing with Disability reflected these needs with recommendations for funding of pilot projects to develop innovative responses to the needs of people with longstanding disability who are ageing. In addition, the document includes recommendations for the need to promote the development of interagency links between aged care, disability service and community care service providers as well as for the need to identify innovative services and the costs associated with quality service provision (2003).

Increased life expectancy has also been factored into estimates of health expenditure from 2008 to 2033 which project an increase of 127 percent in health expenditure by 2033 for the Australian population (AIHW, 2008). The NSW Government Submission to the Productivity Commission Research Study, Economic Implications of an Ageing Australia (2004) identified that as a result of longer life expectancy for people with a disability, there is likely to be an increasing need for home and community care which is jointly funded by the Commonwealth and State governments. This submission also pointed to increasing need for health and transport funding and for increased private and public housing stock. The Senate Inquiry into the funding and operation of the Commonwealth State/ Territory Disability Agreement also recommended a need for significantly increased funding to deal with unmet need and growth in demand for services; a need for a strategy for sustainable long term care and support based on need not age and a national rehabilitation strategy which ensures equipment for rehabilitation , provision for nursing levels of care for young people with high and complex needs and case management strategies for young people with acquired disabilities (Senate Community Affairs References Committee, 2006).

In terms of assistance, transport and housing required to support a growing population, a report by the Local Government Shires Association of NSW indicated that in 2004, of the 4,246,081 residents in Greater Sydney, 12 percent were aged 65 years and over and that of 2,506,006 residents outside Greater Sydney, 15.8 percent were aged 65 years and over. The report projected a population of 4,947,332 (17.1 percent aged 65 years and over) in Greater Sydney and that of 2,736,661 (23.6 percent aged 65 years and over) outside Greater Sydney, by 2022 and increasing to 5,652,500 (24.3 percent over 65 years) in Greater Sydney and 2,703,100 (32.2 percent over 65 years) outside Greater Sydney by 2 051. The report indicated the implications for the provision of services by local government include: increased demand for more and different community care services; integrated planning and co-ordination to those services; increased demand for modifications to

transport facilities, services and pedestrian facilities; planning policies that provide for sufficient levels of general housing that is adaptable, accessible, safe and ecologically sustainable (Local Government Shires Association of NSW, 2004). In relation to housing, a policy document from the Victorian Council of Social Services has responded to estimates of the population ageing by advocating for a universal standard of housing that is accessible and safe (2008).

LITERATURE REVIEW

In the context of these data and reports, we conducted a review of international literature in order to identify key issues surrounding older people with disabilities.

A review of the international literature on ageing and disability has indicated that older people with disabilities are treated largely as a homogenous group. The literature review also indicated that much of the ageing research and literature has neglected gender in relation to disability (Janicki, 2004 in National Disability Authority, 2006). Gender is regarded as a significant consideration as both the international and Australian data indicate that women are more likely to have longer life with impairment than men (Walsh and LeRoy, 2004 in National Disability Authority, 2006) and are more likely to be socially excluded and less likely to have children who will care for them in old age (National Disability Authority, 2006). To date, Australian research has largely focused on longitudinal studies of ageing men (Concord Health of Older Men Project, Florey Adelaide Men's Study, HIMS) and ageing women (Million Women Study, UK and the Australian Longitudinal Study on Women's Health).

For this reason, this review examines understandings of the concepts of disability and ageing and seeks to identify both differences and similarities between older people and people with disabilities.

Disability has been conceptualised in the 'medical model' as an individual problem (caused by disease, trauma or other health condition) which is treated by medical care (WHO, 2002a; 8 in National Disability Authority, 2006). The 'social model' of disability which originated in the disability movement in the UK and the USA distinguishes impairment (a condition of the body) from disability (a situation of social exclusion caused by the organisation of society). In this model there is a dichotomy between the private and public spheres and the experience of disability is marginalised in the private sphere (Thomas, 2001: 55 in O'Connor, 1996: 337). For these reasons, this model focuses on the need to change social institutions and the environment rather than the individuals and stresses the role of empowerment, participation and leadership of people with disabilities in effecting change (National Disability Authority, 2006).

Ageing has also been conceptualised as a medical problem (Robertson, 1997: 427 in National Disability Authority, 2006) traditionally been associated with physical and mental decline and conceptualised in terms of loss of faculties.

The concept of dependency has been used in relation to disability and old age. This concept emphasises the loss of control and the association between biologically based dependency and impairment (Morris, 1999 in National Disability Authority, 2006). This understanding of dependency differs from that of 'social dependency' which is a product of the interaction between the individual's life situation and social structures. This understanding focuses on the role of society in constructing dependency.

Some writers have argued that the relations of older people and people with disabilities within society are characterised by interdependence rather than social dependence and have called for the recognition of this necessary interdependence (Robertson, 1997 in National Disability Authority, 2006).

Older people and people with disabilities have advocated for civic rights and have common concerns in relation to the need for mobility, transport, accessible housing and independent living (Priestley and Rabiee,

2002; NCAOP, 2005a in National Disability Authority, 2006).

Thus the 'common agenda' between people with disabilities and older people generates questions about whether people with disabilities and older people have similar health, housing, social and transport service needs; whether they want similarly structured services or whether they prefer separate or integrated services (National Disability Authority, 2006).

In relation to independent living, people with disabilities have advocated for independence from the exploitative relations of care since the 1970s. People with disabilities have also challenged the idea that reliance on others for physical help inevitably leads to loss of choice and control and have called for purchasing power over care through direct payment schemes to change relationships from those of dependence to independence (Morris, 1999 in National Disability Authority, 2006).

In the USA, older people increasingly accept the need for services focused on individuals needs chosen by consumers and paid through cash benefit (Simon-Rusinowitz, 1999 in National Disability Authority, 2006). The cash benefit has been used by older people with disabilities to pay for personal assistance services as well as other services such as transportation, home modification and assistive devices (The American Association of Retired Persons, 2003). A number of European countries – Germany, the Netherlands, France and Austria – also provide some form of cash benefit to individuals who require assistance to pay both external services and family members (AARP, 2003; 171-172; Wiener et al, 2003 in National Disability Authority, 2006).

Recent policy in the USA and the Netherlands focuses on the idea of 'livable communities' that emphasise the common needs of people with impairments of all ages (AARP, 2005, Bakker, 2005 in National Disability Authority, 2006). In the USA, the adoption of a life course perspective to communities is emphasised in the focus on 'livable communities' which support home adaptation and universal design in building, develop accessible community public transport and provide access to members of communities to health and social services (National Disability Authority, 2006). In the Netherlands, the government promotes arrangements for informal and community-based care to enable older people to re main in their own homes and focuses on building assisted-living complexes (Bakker, 2005 in National Disability, 2006). The concept of 'livable communities' assumes that of 'ageing in place' and thus enabling the social integration of people who develop impairments (National Disability Authority, 2006).

METHODOLOGY

The issues identified in the literature informed the development of a survey conducted by the NSW Physical Disability Council aimed to investigate the impact of ageing on people with disability. In order to understand the degree of independence that people feel they have or will have in the future the survey investigated whether their basic needs are being met. For this reason, areas of investigation included personal assistance, mobility, housing, social integration, health and financial security.

The literature review identified barriers to participation by people with disabilities in the public domain. In order to understand the degree of access to necessary services and goods available in the public domain such as work, medical and household goods, respondents were asked about their experiences in terms of physical access to public transport and infrastructure.

To ascertain whether people thought their needs would be addressed as the population ages and life expectancy is projected to increase, the survey also investigated the anticipated needs of people and their individual concerns in relation to meeting these needs.

Five hundred and fifty one people commenced the survey and 335 completed the survey. This includes 242 postal surveys and 93 electronic surveys. As the survey employed a variety of questions, the analysis has focused on a thematic understanding of the issues. However, there are some questions relating to personal care, mobility/transport, housing, social networks and health, that are common to all versions of the survey. However, a sizeable proportion of respondents answered the question on financial security and for this reason it is also included. For these reasons, some quantitative analysis has been undertaken in terms of frequencies of use in relation to each area. Qualitative analysis, through the use of 16 case studies to illustrate the main issues arising from the survey, is also undertaken. These case studies represent older people with late onset disability and older people with early onset disability. Appendix A provides a synopsis of the case studies used in this report. Pseudonyms are used to maintain anonymity of respondents.

The findings address each area of need separately (in both quantitative and qualitative terms) to identify themes and issues emerging from the data. Finally, these issues are discussed and conclusions are drawn in relation to the extent to which people feel they are and can remain independent and the extent of access to the public domain.

THEMES EMERGING FROM THE DATA

Overall, it became apparent there is overlap in need between older people with disability and older people with early onset disability. For this reason, the themes that emerge reflect the priorities and issues of both groups.

The case studies illustrate particular themes that have relevance for the survey sample. For this reason, the issues relating to older people with late onset disability are represented by the situations of David, Kevin, Arthur, Phillip, Derek, Rita and Eva. The concerns of older people with early onset disability are reflected in the case studies of Bill, Helen, Elaine, Margaret, Bruce, Paul, Mathew, Susan and Patrick.

PERSONAL CARE

Of those people who reported a need for personal assistance, a large number of people reported that their needs are met by family: 30% by partner/spouse (as in the case of Elaine, Susan, Derek Paul, Kevin, Arthur, who are helped by their spouses); 11% by other family members (David and Eva, who are helped by their children and Bruce who is helped by his parents).

Home Care provides about half the assistance for personal care and domestic care (50%). Two percent of people reported assistance through the Attendant Care Scheme. A small number of people (2%) reported assistance is received through a residential facility. The use of Meals on Wheels was also reported by 2% of people surveyed.

People reporting unmet need include older people whose personal assistance is provided by family. Concerns of some older people are exemplified in comments from Arthur:

> *Wife's health is failing -will both need help to stay at home.*

and from Phillip:

> *My needs are much higher now; health has greatly deteriorated. In 5 years time, I dread going into full time care, away from home. My wife won't be able to manage me. We may both need Home Care or go to a hostel.*

Unmet need was also reported by older people with disability who suffer from a progressive condition and who are experiencing and expecting reduced mobility and greater need for assistance. Helen needs:

> *assistance when (she) is not well but family members do not live in (her) area. (Is) desperately in need of some Home Care services to do vacuuming and changing sheets etc. Was able to do this easily 5 years go. It's getting much harder and seems to be getting worse quite quickly.*

Margaret expresses similar concerns:

> *During the last 5 years my abilities have decreased markedly and I expect them to continue to deteriorate to the extent that I cannot work during the next 5 years.*

There was also concern expressed in relation to the availability of personal care staff in terms of current and future need given that the population is ageing and there is an expectation of increasing need for funding of personal care assistance by government departments. Arthur mentions:

> *the shortage of services and long waiting periods*

as does Phillip:

> *Home Care needed – but long waiting list for assisted accommodation*

MOBILITY

Of those respondents who answered questions regarding personal mobility, it was evident that people used a combination of aids and forms of transport. Thirty percent of people reported that they require assistance with walking (stick, crutches or frame). 53% reported the use of wheelchairs and 16% also use scooters. A large proportion of people (43%) drive their own car, whereas 14% are passengers in cars of family members. A small proportion of respondents (4%) are driven by friends.

12% use wheelchair accessible taxis whereas a small percentage 1% use non-accessible taxis, 6% use accessible public buses, 1% use accessible private buses and 5% use community transport.

It became clear that driving their own vehicle was the main form of mobility for a large proportion of people. For this reason, older people expressed the fear of losing their license. Helen observes:

> *If I am no longer able to drive a car I'll be forced to use a scooter to get around and I won't be able to get to the next town for services/shopping.*

Elaine is also concerned about:

> *retaining my driver's license*

as is Kevin who fears the:

> *loss of driver's license*

David's comments encapsulate the implications of loss of license.

> *Five years ago my wife was still alive and I was able to do everything for myself. I cared for her and was still able to drive I have had to recently hand in my license. I have to rely on my daughter to take me anywhere, shopping appointments etc.*

Older people with early onset disability who worked, like Margaret, voiced concerns about the rising costs of fuel and running costs of vehicles which could lead to dependence on public or subsidised transport:

> *When I retire, mobility aids and car may be unaffordable.*

Susan comments:

> *Couldn't do without my automatic vehicle.*

The importance of mobility through driving a car for both older and younger people was clearly expressed one respondent:

> *My car is 'my leg', without it I would be totally confined in my own home.*

Mobility, necessary, not only to access essential goods and services, but also to participate in social activities, is reflected in Kevin's expectations:

> *Without a doubt (things) will change because without a car, license and money for petrol, insurance, etc. we would be isolated.*

This point is discussed in more detail later.

In this context the issues raised in relation to the availability of disabled parking spots highlight barriers to access in terms of limited number and lack of access to shopping centres, medical centres and dentists.

Kevin notes:

> *Disability sites for parking are inadequate in shopping centres.*

Arthur needs to:

> *travel to hospitals, clinics and doctors in different areas*

and suggests the need for:

Central clinics with combined services in one place, for convenient access.

For people who did not drive and depended on wheelchair accessible taxis, there were clear indications that the subsidy provided for such taxis is regarded as too little by people who depend on pensions and for that reason some people, like Bill, did not use accessible taxis:

Because of the increasing cost of Maxi van fares, I cannot afford to use them as a form of transport.

Yet, some people, like Rita who depended on accessible taxis found the cost too when needed, sometimes in cases of illness:

Taxis are unreliable in arrival and sometimes don't come at all.

In terms of accessible public transport, it became apparent that there are inadequate public bus services and accessible buses. Paul notes:

buses have high steps and often not wheelchair access.

This is particularly evident among people living in rural areas (such as Riverina/Murray and Illawarra) and even in regional areas (Nepean). It is also apparent that community transport arrangements are currently inadequate in some regions (Hunter, Central Coast)[4]. Phillip comments:

Public and community transport buses don't accommodate us.

For some people, like Bill, the train services are also inaccessible:

I live close to an accessible railway station BUT I need to take a support worker with me when I go anywhere as I need someone to be in the hands – e.g. To press a button on a lift. I do not know that I will be able to physically travel even on a train – will not any long distance e.g. over half an hour's train trip (in the future).

In terms of people who used scooters, respondents, like Elaine, reported regulations preclude access to public :

Buses inaccessible because of the ban on 3-wheel scooters and the poor design of "accessible" buses for any 4-wheeled scooter.

For people who used wheelchairs or scooters, there were concerns expressed about the need for local councils to maintain smooth and accessible footpaths. Kevin observes that there are:

Still areas without footpaths. Telecom covers broken & dangerous

and voices the concern about accessible seating in public spaces raised by a number of people:
Also need accessible buses and bus stops.

Footnotes

[1] One respondent in Cumberland/Prospect, three in Central Coast, one in Northern Sydney.

[2] One respondent each in Central Coast, Hunter, Nepean, two in Illawarra.

[3] One respondent Southern Highlands, two in Central Coast.

respondents mentioned community transport hard to access in Hunter region, three respondents found community transport inadequate in Central Coast region.

[5] One respondent each in South East Sydney and Northern Sydney.

HOUSING

In terms of housing, out of the whole survey 33% of people reported they are living in the family home. A small proportion of people reported living in shared housing (1%) and group homes (5%). Three percent stated they are living in Department of Housing accommodation, 3% in retirement villages and a very small number 1% in residential care and private rental. A large proportion of people (20%) live .

In terms of housing issues, older people reported a need for smaller, more accessible housing as personal mobility decreased.

Helen comments: *I am finding it harder to walk upstairs and might have to move to a unit downstairs.*

Margaret notes: *I now need to live in a wheelchair accessible house.*

Derek observes:

(My) house is two storey – requirements have now changed and single storey would be more suitable.

Ten percent of people who live in their own home reported assistance is received for gardening/lawn maintenance but did not report whether they receive subsidised support or employ independent contractors. Some people, like Arthur, reported a need for such assistance: *yard maintenance required (affordable)*

Phillip expresses similar needs:

Can't do house and yard maintenance – must pay someone. Will need help with yard maintenance.

The need for modifications to existing housing (11% of the overall survey) was expressed by both older and younger people with decreasing personal mobility as Bruce observes:

I have needed further modifications to my parents' home. I may require a new bathroom which will cater for my needs.

Paul notes that the steps in his house are:

> *getting harder to handle.*

Phillip needs:

> *ramp and modifications for wheelchair and a bed lift.*

Some people, like Susan, who have already made modifications to their houses, still have barriers to access:

> *I do not use the two flights of stairs to access our rear yard and downstairs garage very often (including laundry).* [6] Forty four percent of respondents did not answer this question.

> Similar concerns are expressed by Arthur who requires: *modifications to bathroom, toilet, ramp (needed) for access.*

> In addition, it became clear that there is a need for more affordable housing for people ageing with disability who prefer to remain in the community. Affordable aged care accommodation is also an area of concern for older people. Concern was also expressed in terms of adequate affordable, accessible housing for an ageing population.

SOCIAL

Analysis of the data on social networks indicated that social needs are largely met through a combination of activities. Sixteen percent of people participate in community organisations, 23% undertake recreational or leisure activities, 9% participate in volunteer work, 8% find paid work a source of social support. A large proportion of people (22%) find family and 17% found friends meet social needs. Seven percent find neighbours meet social needs and 10% find church and religious networks met social needs. A large proportion of people (23%) find specific support networks meet their needs, whereas 7% of people find service staff provide the main social contact.

Of particular mention for older people are educational facilities such as University of the Third Age and social clubs including Probus and senior citizen clubs.

Older people, like Patrick, tend to report more need for social interaction:

> *I would like more interactions with other groups. Group activities where I can be picked up by transportation. Meet people my own age.*

Many people mentioned the desire to obtain access to leisure activities that are currently not available such as attending the theatre, opera and social venues. Helen mentions the barriers to desirable social interaction:

> *I would like to be part of a group of painters who meet in our next town. I am not able to visit friends in this town more because of costs involved.*

Arthur suggests:

> *Newsletters – support – phone enquiries about welfare. Consideration of accessibility and mobility concerns*

by the relevant authorities would increase the quality of his social life as he is:

> *missing mixing nowadays. People don't keep in contact.*

Similarly, Phillip notes the barriers to access to events and in particular to Probus:

> *this is for active seniors, so limited. Must provide own transport. Access restrictions.*

He suggests the need for:

> *more support with advice and education to help transport assistance. Carer network locally. Accessibility advice and help.*

In terms of social issues, some people who live in residential care, like Patrick, spoke of their social isolation in their current situation and the need for age-appropriate housing: *Living in a hostel for the rest of my life. I am 54. Being lonely. Not have enough mental stimulation and activities.*

Some older people, who live alone, like David, express their loneliness:

My daughter takes me out on the weekends, and she is the one that keeps me in touch with old friends. I would like more company as I feel quite lonely.

Overall respondents expressed their concerns about social isolation in the future as their needs increased and the health of family members who provided assistance declined. This was also an issue for younger people like Bill who feared: *Social isolation due to limited finances.*

As mentioned earlier, mobility and in particular driving a vehicle provides access to social activities and for older people the loss of a license affects not only access to essential goods and services but also increases vulnerability to social isolation.

Rita's hopes for the future demonstrated a desire expressed by many people:

> *To be able to live with a good quality of life; to be able to interact with people; to be able to be useful and help others when I can.*

HEALTH

Most people report that their health needs are currently being met even though a large number of people expressed concerns about their health needs increasing as their condition progresses or their health deteriorates in the future. In terms of current availability of health professionals, a large number of people expressed the need for more GPs and specialists in rural areas.

In relation to health issues, people, like Arthur, spoke of the need for home visits from general practitioners particularly as transport to doctors' appointments is inflexible and difficult to organise particularly after hours

and on weekends:

home visits by nurse, occupational therapists, medicos, etc.

In terms of visiting local GPs people spoke of long waiting lists and high associated costs. Helen says:

I have no access to specialists. Appointments at GP need to be made 4-6 weeks in advance. Specialist appointments even longer.

Access was also an issue for other people like Margaret:

more accessible doctors' surgeries and especially mammograms which can be done in chair.

As mentioned earlier, access to doctors and dentists in terms of accessible parking, accessible toilets, is also an issue and some people, like Arthur, mentioned the need for accessible medical clinics:

Central clinics with combined services in one place, for convenient access.

In terms of medical expertise necessary, it became apparent that there is a lack of knowledge among medical professionals about some conditions e.g. Post polio syndrome, diabetes, and some people identified a need for specialised clinics and training for medical professionals.

Another concern raised involved the lack of training of medical staff in hospitals regarding the provision of personal assistance to people with disability. Bill speaks of his fears about requiring hospital care:

I have a morbid fear of going to hospital as there is no quality of care in the hospital/medical system. The latter would have to be my biggest concern. Having to spend any extended period of time in hospital.

There were also concerns expressed about the inadequacy of health care to meet the needs of an ageing population given the shortages of medical professionals particularly in regional and rural areas. The necessity for prosthetic equipment not currently available due to the shortage of funding in the PADP Program was also mentioned by a number of people, including Arthur: *Increased funding for PADP for equipment needed for mobility and health*

and Phillip: *PADP funding increase to help me buy aids to assist with my mobility and breathing.*

FINANCIAL SECURITY

It was apparent that most people are concerned about the future in terms of financial security.

It is noteworthy that this survey was conducted in the first half of 2008, prior to the global financial crisis and at that time most people were financially insecure.

Of people who were asked about financial security, only 16% surveyed report that they feel financially secure about the next 10 years with only 5% of people reporting that they feel secure about the next 5 years.

79% of people feel financially insecure about the future. 31% feel slightly insecure about the next 5-10 years, 13% about the next 5 years. 31% feel very insecure about the next 10 years and 4% feel very insecure about the next 5 years.

People who are currently working, like Margaret, expressed concerns about the ability to manage the cost of living in terms of retirement:

> *I am afraid that I will not be able to stay in my house when I retire because of financial restraints.*

Kevin is also anxious about:

> *not being able to maintain our home.*

Mathew fears not being able to:

> *maintain the upkeep on my home which I own.*

People also spoke about their concerns about meeting the running costs of vehicles they currently use to meet a variety of needs. Margaret says:

> *When I retire, mobility aids and care may be unaffordable.*

These concerns have implications in terms of public transport and community transport for people who currently drive and either lose their license or cannot afford to keep vehicles**.** Concerns were also expressed about the costs associated with visiting specialists by people like Kevin:

> *We find it difficult to manage basic private health fund for specialists with gaps and any private hospital procedures.*

The high costs associated with medical treatment are mentioned by Elaine:

> *More than 5 Medicare claims should be available for chiropractic, physiotherapy, etc. I require treatment fortnightly.*

Anxiety was also felt about insufficient funding for necessary health, personal care and housing services and facilities in the future by people anticipating a decline in health or progression of condition. Susan speaks of her difficult situation:

> *our income from the pension and the rising costs of everyday expenses.*

In particular, some people spoke of insufficient funding for Home Care and Attendant Care services. The fear of failing health and increased need was expressed by people like Arthur:

> *Lost mobility and independence – degeneration of condition, requiring wheelchair, special transport. Nursing care – at home or hostel (if available). Shortages of services – long waiting periods.*

Other people like Phillip spoke of the high cost and lack of availability of aged care:

> *Coping physically and financially. Losing independence and mobility. Having to depend on other's assistance more and more. Affording to pay for services needed or nursing home place, if available and also supportive equipment.*

Other people, like Eva, fear their increasing needs will precipitate nursing home placement:

> *Needing to go into a nursing home if I become too ill for my daughter to manage and having enough money to survive.*

It is apparent from the foregoing that both older people with early onset disability and those with late onset disability share common concerns about meeting their current and anticipated needs.

SOCIAL INCLUSION?

A socially inclusive society is defined as one where all people feel valued, their differences are respected, and their basic needs are met so they can live in dignity. Social exclusion is the process of being shut out from the

social, economic, political and cultural systems which contribute to the integration of a person into the community (Cappo, 2002).

The issues identified in this report have implications in terms of social inclusion for older people with disabilities in a number of ways. To better understand how limitations in access to personal care, mobility and transport services, housing and related services, health services and financial insecurity impact on people with disability who are ageing it may be useful to note three stories from the case studies. The studies comprise the stories of Helen, Margaret, Arthur, David and Eva.

Helen is an older person with early onset disability who lives in a rural area. She requires assistance with housework but family members are unable to help her regularly as they live outside her area. Helen has very limited mobility as she is unable to walk any distance and unable to access the limited bus or train services. She cannot afford taxis but is still able to drive. Helen anticipates the rising costs associated with her car will force her to use a scooter for transport and this would preclude her gaining access to essential services and shopping as these are provided in the next town. She lives in her own home and is finding her house increasing inaccessible as it has stairs. Helen would like to move to a unit downstairs but can only afford handrails and modifications to her house. Helen's social life includes membership of a music group, attendance at Church, playing golf, croquet and painting. Her progressive disability and associated costs have recently led her to resign from providing volunteer transport and she is unable to join a group of painters who meet in the next town or visit friends who live in the next town.

Her progressive physical impairment and limitations as well as worsening health leave her with little energy and increased fatigue. Helen has little support from her local doctor who does not understand her disability, and has no access to specialists. In addition, the waiting times for her GP involve 4-6 weeks for an appointment and even longer period for a specialist. Helen fears that she will need increasing help with household tasks which she will be unable to afford and that she will need to relocate owing to her inability to climb stairs in the house.

Margaret is an older person with early onset disability who lives in her own home in a metropolitan area and works. She lives alone and is visited by her three sons.

She needed assistance with housework, yard work, care modifications, ramp, wheelchair and electric scooter all of which were provided by Margaret's income and the financial support of her employer.

However, Margaret has experienced a marked decrease in mobility and physical strength over the last five years, and worries that she will need to leave her job and thus lose the income necessary to maintain the house, the modifications needed to make her house wheelchair accessible and the vehicle.

Margaret's deteriorating physical strength has also affected her social life. She has had to resign presidency of a social group and now the only social contacts she enjoys are family and work related.

Margaret also experiences difficulty in accessing medical support as doctors' surgeries are not adequately wheelchair accessible and will require wheelchair access to all health professionals in the

future. Margaret anticipates that she will need help at home and funds for her mobility equipment when it needs to be replaced. Her greatest concerns are social isolation as a result of financial difficulties and the inability to afford essential aids and transport.

Arthur is an older person with late onset disability who lives in a regional area. He requires assistance with dressing, walking, meals, washing and transport, all of which are provided by his wife. Arthur's health is deteriorating and he fears his wife will not be able to meet his increasing needs as her health is also deteriorating.

Arthur has limited mobility and needs wheelchair accessible transport. If his wife cannot drive him he must ask a friend as the local community transport is difficult to access and local taxis and buses provide a limited service.

Arthur lives in his own home with his wife and now needs modifications made to the bathroom and toilet as well as a ramp to the house. He also requires affordable yard maintenance.

Arthur has difficulty gaining access to public hospitals, clinics and doctors as they are located in different areas. He would greatly benefit from home visits from the nurse, occupational therapists and doctors as well as increasing funding for equipment that he needs for mobility and health.

Arthur's social life is limited by lack of access and mobility. He has been involved with a pensioner association, a support group, Probus and Computerpals. However, owing to lack of access he can no longer attend the latter two clubs. As a result Arthur misses social interaction as people tend not to keep in contact. Arthur would like more support in the form of newsletters and phone enquiries about his welfare as well as consideration of access and mobility limitations on his social life.

Arthur fears loss of mobility, thus requiring a wheelchair, nursing care or supported aged care. He also worries about the cost of such services and facilities and whether they are available.

David is an older person with late onset disability. Five years ago, he cared for his wife, who has since passed away.

He now requires assistance with showering (which he receives from Home Care) dressing and meal preparation (which he receives from his daughter who works).

David has had to recently hand in his license and now needs to rely on his daughter for transport for shopping, appointments, and other services.

David lives alone and relies on his daughter's visits at night for company. She also takes him out on the weekend and keeps him in touch with his old friends. David feels isolated and lonely.

His health is deteriorating and he fears loss of mobility and greater need for assistance.

David greatest anxieties are becoming more frail, that something will happen to his daughter and that he may have to leave his home.

Eva is an older person with late onset disability who lives in the metropolitan area. She requires assistance with meals, personal care, continence, medication, dressing, showering and wound dressing. These needs are mostly met by her daughter.

Eva's daughter and son-in-law came to live with her in the family home to provide assistance.

Eva has no mobility, except for 'patient transport' or ambulance. Consequently, she relies on the social contact arising from her relationships with her daughter, son-in-law, husband, nephew and the visits from the community nurse, a case worker and the local doctor.

Eva feels that despite struggling for many years, she is now coping. She fears having insufficient money to survive and that should her needs become more than her daughter can manage she will need to enter a nursing home.

DISCUSSION AND CONCLUSION

It is apparent from the foregoing that a large proportion of people who are currently receiving assistance from family members, particularly spouses/partners depend on the health of family members to meet their needs. Thus, people receiving assistance from family and their carers are both likely to require assistance in the future from both personal care and health care professionals.

It is also apparent that most people attribute their mobility to their access and ability to drive their own vehicle. In this way, they retain access to the necessary services and goods available in the public domain, be it through paid employment, shopping for goods, medical and dental services and access to leisure and social activities. However, people with their own vehicles noted the lack of available parking for disabled drivers in essential services such as shopping and medical centres.

It is also apparent that people who do not have this form of mobility experience considerable difficulty in attempting to gain access through public transport, accessible and non-accessible taxis and existing infrastructure such as footpaths, seating, accessible toilets.

The degree of mobility also determines access to social activities and thus people who are not mobile are restricted to community transport and public transport which as noted by many people are inadequate owing to the lack of bus services and accessible buses, particularly in regional and rural areas but also in urban areas. For some people, the rail service is also inaccessible. The lack of accessible public transport and accessible infrastructure has implications for both local and state levels of government.

Regarding social needs, the high number of people who live alone indicates that there are a substantial proportion of people who are vulnerable to social isolation if they lose mobility.

The need for home modification was identified by some people who wish to remain in their family home. Accessible housing was identified by quite a number of people who lived in their own homes and whose needs have changed and thus require smaller accessible housing or home modifications to existing houses. Some people expressed their concern about the lack of aged care housing and the high cost of such housing when available.

This clearly has implications for the type of housing that will be required as the population ages as well as in the immediate future.

Although it is apparent that currently health care needs are being addressed, there are concerns about future health need and areas in health care that are issues for an ageing population. The current shortage of medical professionals, particularly in regional and rural areas, is of concern to a population whose health needs are increasing as they see their health deteriorating. Particular areas of medical expertise are also of concern, where education of professionals and the provision of specialized clinics could address this need. In the health care system, there is currently inadequate training of medical and nursing staff in the needs of people with disability in the hospital system and this need is reflected in the concerns expressed by people who may require hospital care in the future. The high costs associated with disability and the necessary medical care is also an issue for many people, particularly those dependent on pensions.

In terms of financial security, it is apparent that pensions are currently insufficient to meet the rising cost of living and that people who are currently working feel concern about meeting the cost of living when they retire, particularly in relation to housing and necessary modifications and maintenance of a vehicle. In addition, people expressed anxiety about their increasing needs, associated with ageing and progressive disability, in relation to the adequacy of funding for health, personal care, housing services and facilities and aged care housing in the future.

As is apparent from the case studies of Helen, Margaret, Arthur, David and Eva, their stories reflect the issues surrounding and barriers to essential goods and services. These barriers, in turn, impact on other areas of their lives. In this way older people with disability, like Helen, Margaret, Arthur, David and Eva, are, in fact, experiencing limitations on their participation in society. Clearly there is a need for barriers to such essential goods and services to be addressed to achieve their social inclusion.

From the findings, it was evident that there is overlap between the needs of older people with disability and older people with early onset disability which reflect the 'common agenda' identified in the literature review. This overlap has implications for the kinds of services that are needed, the relationship between the different service agencies and the models of service delivery.

The literature review identified the need expressed by people of all ages with impairment for independent living in 'livable communities' which provide accessible transport, housing and access to health and social services together with informal and formal assistance arrangements that enable people to remain in their own homes.

The findings of this survey reflect those of the AIHW report in that given the ageing of the Australian population and the increased life expectancy of people with disability in the population, there is an increasing need for home and community care, health, transport, private and public housing stock.

The need for sustainable long term care and support, rehabilitation equipment, the provision of care for people with high and complex needs and flexibility in the provision of more and different community care services is also reflected in these findings.

In this way, the different levels of government can address the issues that provide barriers to access in the public domain, preclude livable communities and the empowerment of people with disability in the future.

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APPENDIX A Case studies

1 David is an older person who has a lot of health problems and requires assistance with showering, dressing and preparing meals. He is helped with showering by Home Care and by his daughter for the rest. Five years ago David cared for his wife who has passed away.

2 Bill is an older person who is housebound and who requires increasing assistance. He lives alone and receives help from support workers.

3 Helen is an older person who experienced early onset disability and has suffered from strokes more recently. Helen requires Home Care assistance to do vacuuming and housework and personal care when she is unwell as she has no family members living in her area. She lives in a rural area.

4 Rita is an older person who experienced early onset disability and whose mobility is decreasing. She receives help from Home Care but requires assistance with transport and she neither walks nor drives. Rita lives in a rural area.

5 Elaine is an older person who experienced early onset disability and who receives help from her husband. She uses aids for mobility and can drive herself. Elaine lives in the Sydney metropolitan area.

6 Margaret is an older person with early onset disability who lives alone (visited by her three sons) and who currently is employed. Margaret drives but is concerned about the cost of car maintenance when she retires. She lives in the Sydney metropolitan area.

7 Bruce is an older person with early onset disability who receives assistance with personal care from a nurse and with all his other needs from his parents who are in their seventies. He belongs to DARTS which provides social interaction as well as assistance with some of his transport needs. Bruce lives in the Sydney metropolitan area.

8 Derek is an older person who receives assistance from Home Care three times a week and his wife but who now requires daily assistance. Derek is concerned that his wife will no longer be able to care for him. Derek lives in a regional area.

9 Paul is an older person with early onset disability who requires assistance with transport, general care and gardening which is provided by his wife. Paul is experiencing decreased mobility. Paul lives in a regional area.

10. Mathew is an older person with early onset disability who requires high levels of care and who is currently in respite care awaiting extended care. He has limited mobility and can no longer drive. Mathew has his own house which is situated in the Sydney metropolitan area.

11. Susan is an older person who requires assistance with dressing and who receives help from her family. She lives in the family home but has limited access to parts of her home. Susan lives in metropolitan Sydney.

12. Kevin is an older person who receives assistance from his 79 year old wife and who requires assistance with housework. Kevin still drives and lives in the family home but requires financial assistance to maintain the house. He lives in metropolitan Sydney.

13. Patrick is an older person with early onset disability and who requires assistance with personal care and transport. He lives in an aged care hostel in a regional area and would prefer to live with younger people.

14. Arthur is an older person who requires assistance with personal care and transport and who receives assistance from his wife. He is concerned that she will be unable to meet his increasing needs and would prefer assistance from Home Care and with transport. Arthur lives in a regional area.

15. Phillip is an older person who requires assistance with personal care and transport who receives help from his wife. Phillip is concerned that they both need Home Care and transport as his needs are increasing and his wife's health is deteriorating.

16. Eva is an older person who is housebound and requires assistance with almost all her needs. Help is mostly provided by her daughter. Eva fears that her increasing needs may lead to her entering a nursing home when her daughter cannot continue to care for her at home.