



THE IMPACT OF AGEING

on the needs of people with
physical disability

2011

pdcn



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BACKGROUND

Population growth and life expectancy

Australia’s population is projected to grow from 21 million people in 2006 to between 31 and 43 million people in 2056 (ABS, 2009:1). In 2009, more than 2.9 million Australians(13.3% of the population) were aged 65 years or over compared with under 1.1 million (8.3% of the population) in 1971 (AIHW, 2010). By 2056 the age group 65-84 years is projected to grow to 6.4 million and the number of people aged 85 years and over is projected to increase to 1.7 million (ABS, 2009: 3).

In relation to population projections for New South Wales, the population is expected to grow to 9.1 million people by 2036 an increase of 33% on the 2006 population of 6.8 million. It is anticipated that three-fifths of this growth will be the product of natural increase (births minus deaths) and that two fifths will be the result of net migration. In addition, the State’s population is expected to increase so that the percentage of people aged 65 years and over is projected to rise from 13.5% in 2006 to 21.5% in 2036 (NSW Department of Planning,2008: 3).

Of the total population, the 2006 Census of Australia identified that 4.4 percent had a ‘need for assistance’ (ABS, 2006: 9) of which 61 percent were aged 60 years or more (ABS, 2008: 2) with twice as many women as men aged 80 years and over (ABS, 2008: 3).

In 2003, 3,958,300 people or 20 percent of the Australian population had a reported disability of whom 1.2 million (6% of the population) had severe or profound core activity limitations (ABS, 2004 in AIHW, 2010: 40). In 2009, 4,026,200 people (18.4% of the Australian population) had a disability and 3,487,200 people (16% of the Australian population) had a restriction or limitation in regard to communication, mobility and self-care or schooling or employment (ABS, 2009: 3). Thus there is a decline of 1.6% between 2003 and 2009. But, there are projections of an increase in the number of people with disability. It is projected that by 2030 the number of people with severe disability will increase to 2.3 million owing to growth in the population and ageing (AIHW, 2010: 40).

The Australian data also indicates that females expect to live longer with more years of disability. In 2003, 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 2009, there were 2.6 million carers who provided care to a person because of disability or old age, of which, 68% were women. Almost one third (29 percent) were primary carers and 20 percent of carers were more likely to be older than 65 years (compared to 12.7% percent of the total population) (ABS, 2009: 5, 10).

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

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 need for assistance in that more people with disability aged under 65 had higher need for assistance with self-care, communication and personal guidance. For all other activity restrictions, more 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 core activities, increased by 96,700 and most people (80,600) were aged 65 years and over (AIHW, 2008).

In 2009, the need for assistance for core activities (including self-care, mobility and communication) was fully met by family for half of all people with disability (56%). One fifth of assistance was provided by formal support (services), one fifth met by both formal support and family assistance, with a small proportion of people whose needs were not met at all (3%). In addition, around 40% of people with core activity limitations reported that their non-core activity needs were only partly met or not at all. Where needs were fully met it was likely to be provided by family members (Productivity Commission, 2011; 123)

In relation to unmet need, 86,900 people (37.9%) of people with severe or profound core activity limitation required assistance with personal care, 82,100 (20.6%) of this group required assistance with mobility; 46,700 (17.9%) required assistance with transport and 15,400 (14.2%) needed assistance with meal preparation.

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. Although most people with a severe or profound core activity restriction living in households were assisted by co-resident informal carers, 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. People with disability

aged under 65 were more likely to rely on a formal 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 ‘service transition’ of 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 carer (AIHW, 2000).

Need for assistance

In relation to the needs of people with disability, data from the 2006 Census indicate that people who require assistance (the same conceptual category as people with disability (ABS, 2003)) face barriers to essential services and goods.

In 2006, 5% of people in regional Australia needed assistance compared with 3.4% of people in major cities and 2.8% of people in very remote areas (ABS, 2006:4). This data raises interesting issues in relation to access outside metropolitan areas in terms of infrastructure for people with disability.

Housing

There are also differences in living arrangements. In relation to the living arrangements for people with disability, owing to shortage of private housing, supported accommodation and support for community living, people with disability under 65 years often remain in their parents’ home. Where this was not possible, they are often housed in residential aged care (AIHW, 2009a in Productivity Commission, 2010). The data shows that this was the living arrangement of almost 6,500 people with disability under 65 years at June 2010.

According to the data there are a high proportion of people who own their own homes across all age groups who need assistance- the lowest rate being for people aged 30-39 years. In addition, 10 percent of people who need assistance rented from housing authorities or co-operatives, community and church groups (ABS, 2006: 7).

Employment

In relation to employment, in 2010 around 31% of people with severe or profound core activity limitation were employed, compared to 54% of all people with disability and 83% of people without disability.

At all ages the participation rates of people who need assistance were lower than for the rest of the population. The highest participation rate was 31 percent in the 25-34 age groups. (ABS, 2006: 7, 8). People who need assistance were more likely to participate in part-time work and even though they belong to each of the major occupation groups they are twice as likely (31 percent) than people who do not (11 percent) to work at low-skilled jobs (ABS, 2006:8).

The Productivity Commission reported that only 28 percent of people with severe or profound disability were in the labour force, compared to 50 percent of people with disability and 83 percent of people without disability. Thirty-eight percent of the employment for people with disability was

part-time, compared to 30 percent for people without disability (2011b:2.4).

These figures show an under-representation of people who need assistance in the workforce and an over-representation of this group in unskilled labour. The Productivity Commission report indicated that only 66 percent of people with disability and almost half of people with severe or profound disability progress in their education past year 10, compared with 80 percent of the rest of the population (2011b:2.3,2.4).

Transport

People who require assistance are more likely to use buses, taxis, lifts with other drivers and use more combinations of travel to get to work than the general population. Only 39 percent of working people who need assistance drive themselves to work, compared with 68 percent of people without a need for assistance (ABS, 2006: 8).

In relation to need for transport in NSW, within Sydney 17.3% of people live less than 5 kilometers from their employment. Across NSW 19.5% live within 5km of their employment and 1.4% live 50 kilometres or more from employment (Drabsch, 2011:).

Social isolation

People who need assistance were half as likely as the rest of the population to be in couple families with their own children (13 percent compared with 26 percent) for each age group between 15 and 64. People who need assistance aged 25-44 were also much less likely to be in partner relationships (36% compared with 69%), with or without children, than those without need for assistance. Lone parents aged 65 years and over were more than twice as likely to need assistance (ABS, 2006).

These figures indicate that people with disability are less likely to be in partner relationships without or without children. It is apparent that for people with disability the potential for social isolation is much larger than that for the general population. The Shut Out report (Australian Government, 2009a in Productivity Commission, 2011b: 2.3) found that people with profound core activity limitation (a measure of the degree of impairment) were almost ten times more likely than the rest of the population not to access activities outside the home.

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 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 international literature.

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 conducted in 2008 found that although writers have seen ageing and disability mediated by the ‘medical model’ which associates disability with ‘impairment’ , ageing with ‘decline’ and both with ‘dependency’ (National Disability Authority, 2006) some have pointed to the interdependency of disability and ageing (Morris, 1999 in National Disability Authority, 2006) and have identified mutual concerns in the need for civic rights, mobility, transport, accessible housing and independent living (Priestley and Rabiee, 2002; NCAOP, 2005a in National Disability Authority, 2006). For these reasons, some writers have argued in favour of a social model of disability, in which impairment is separated from disability and the latter is socially constructed. In this way, barriers to access to services and rights in the public sphere preclude the social participation of people with disability (Barnes, 1998). These barriers include environmental factors.

One approach, termed ‘radical consumerism’ sees disability as largely a social construct, a product of both impairment and the environmental factors that prevent a person with a disability from living independently (De Jong, 1979: 242 in Barnes, 1998: 69).

The ‘ecological model’ suggests that the environment interacts with social factors to produce particular bio-physical conditions and social responses to impairment (Albrecht, 1992 in Barnes, 1998:71).

In relation to environmental barriers for people with disability, the literature emphasizes the importance of accessible, safe, well-designed built environments for optimal health (Jackson & Kochtitzky, 2001: Koplan & Flemming, 2000 in Clarke et al, 2009: 965). The literature also indicates that barriers in the built environment have consequences for participation in terms of social isolation (Debnam, Harris, Morris, Parikh & Shirey, 2002 in Clarke et al, 2011:1675) the ability to carry out daily tasks (Clarke & George, 2005: Keysor et al 2010 in Clarke et al, 2011: 1675) and can lead to entry to residential care (Cohen, Tell & Wallack, 1986; Gill, Allore & Han, 2006: Jette, Branch, Sleeper, Feldman & Sullivan, 1992 in Clarke et al, 2011: 1675). Such barriers can preclude leisure time physical activity (Rimmer et al, 2004 in Clarke et al, 2011: 1676) and result in a decreased likelihood of preventative health measures (Chevarley et al, 2006: Iezzoni, McCarthy, Davis & Siebens, 2000: Ramirez, Farmer, Grant & Papachristou, 2005 in Clarke et al, 2011: 1676).

Policy attempts to counter the effects of environmental factors, have focused 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 focus was on ‘livable communities’ which support home adaptation and universal design in home-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 focus of funding is on informal and community-based care to enable older people to remain in their own homes and on building assisted-living complexes (Bakker, 2005 in National Disability, 2006). Thus ‘livable communities’ assume ‘ageing in place’ and thus enabling the social integration of people who develop impairments (National Disability Authority, 2006).

In relation to accessible and appropriate housing, The Productivity Commission reported that people with disability are more likely to live in public housing than the rest of the population, with many in the private rental market or in their homes with mortgages (2011b:2.5) Eighty-one percent of people in private dwellings require assistance and are likely to be older people (ABS, 2006:7).

In relation to need for housing in NSW, one report identified 3.5 million private dwellings in NSW in December 2010. Two thirds of households in NSW are occupied by owners with or without mortgage, about one quarter of households rent their home privately and 5% rent through the State housing authority (Drabsch, 2011:20).

In relation to affordability, for owners with a mortgage, housing costs were an average 14% of gross income. In 2008/09 more than 146,000 dwellings were under social housing management (85% of which were public housing, 11% were community housing, 3% were Aboriginal Housing Office dwellings and 1% were crisis accommodation (Drabsch, 2011: 28).

In response to the indicators of high need for housing for people with disability, the NSW Government developed an accommodation scheme to complement existing accommodation. The scheme includes a range of accommodation models which vary from larger residential accommodation, to village or cluster models, villas, apartment, co-located accommodation and group homes. These models are to be supported by a variety of packages for residents which include: flexible packages, drop-in support and in-home or Attendant care support (DADHC, 2011).

The NSW Department of Ageing, Disability and Home Care (DADHC) together with the Department of Family and Community Services have undertaken community consultations on the operation of a Supported Living Fund which is intended to commence in 2012. The Fund is intended to provide an average amount of \$50 000 per person per annum to purchase a combination of existing disability support and mainstream services which will enhance existing support services and networks (DADHC, 2011). The NSW Budget 2011-12 allocated \$22.6 million to supported accommodation places with 100 Supported Living Fund packages (NSW Government, 2011).

Yet, people with disability face social barriers in relation to access to social and economic opportunity. The literature indicates that people with disability are at increased risk of living in poverty (Saunders, 2005: Stapleton, O’Day, Livermore & Imparato, 2006 in Wilkinson-Meyers et al, 2010: 1882) and are more likely to have lower incomes, as a result of lower paid jobs with fewer hours, little career opportunity and greater likelihood of unemployment (Barnes & Mercer, 2003 in Wilkinson-Meyers et al, 2010: 1882). One study found that among the costs related to disability was the opportunity cost of time thus the higher the level of unemployment and fewer vocational options open the greater the lack of opportunity for productive and rewarding use of time (Wilkinson-Meyers et al, 2010: 1888).

Thus while access to the built environment cannot be disregarded, the implications of the reduced financial resources of many people with disability have consequences for their financial security and even survival.

For this reason, the literature on financial resources for people with disability was examined.

One strategy outlined in both the Australian and international literature involved the payment of a cash benefit to individuals with disability so that they can purchase the necessary resources to meet their individual needs.

The literature from the USA focused on the cash benefit paid to individuals to choose services (Simon-Rusinowitz, 1999 in National Disability Authority, 2006; The American Association of Retired Persons, 2003). The European literature also referred to cash benefits for individuals to pay both external services and family members (AARP, 2003; 171-172; Wiener et al, 2003 in National Disability Authority, 2006).

An Australian study on individual cash benefits found that individualized benefits are portable, organized on an individual basis and are more likely to be used by people of working age with low support needs, across disability and disability support types (Fisher et al, 2010: 13). The study pointed to the literature which indicates that effective approaches to individual funding have emphasized consumer-driven and centred support which facilitates independent living in the community and is flexible in its organization (Leadbeater, Bartlett and Gallagher, 2008: 9 in Fisher et al, 2010: 26). The study found that although support is required for people to make an informed choices about individual funding (Fisher et al, 2010: 31) and there are potential difficulties in maintaining the quality of services chosen and integrating such a package of services, individualized funding is cost-effective, covers disability and management support and provides benefits for people with disability such as personal well-being, physical and mental health improvement as well as improved social participation through increased control, choice, independence and self-determination (Fisher et al, 2010: 58).

One Australian report indicates that support levels for people with disability are generally insufficient and inequitable. The report finds that currently the disability support system is underfunded and that existing funding does not reflect differences across states and territories in disability rates. In addition, the cost variations between states and territories do not adequately explain the difference between the need for resources among the states (Productivity Commission, 2011).

Despite attempts by NSW government to meet the shortfall through a focus on building the capacity of support in a number of areas such as respite, case management and accommodation and by Australian government through an increase in funding for the National Disability Agreement, the report finds that expenditure on disability by the States is growing faster than State revenue and projects funding remains the present level, and demand for supported accommodation increased, fewer people would receive support in the long-term(Productivity Commission, 2011).

The report concludes that structural change and a national disability scheme is required. Such change would involve the timely provision of support, the encouragement of employment for carers and streamlining of the data relating to the provision of support to people with disability (Productivity Commission, 2010).

These findings reflect the literature mentioned above in terms of flexible approaches to 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).

In response to this report, the Australian Government committed \$10 million to develop policy required to support the establishment of a National Disability Insurance Scheme; establish a COAG Council of Ministers to lead the reforms identified by the Productivity Commission and take steps to establish an Advisory Group which is intended to provide expert advice on strategies for reform and preparation for the launch of the Scheme (Press Release Office of the Prime Minister, 2011).

The NSW Government also responded to the report in the 2011-12 Budget through the allocation of \$2.8 billion dollars to DADHC to form the basis for individualized funding packages which are to be available to people with disability in NSW by 2013-14.

In the context of these issues, the findings explore the experiences of people with disability in relation to their assistance needs, their mobility and access to public space, services and facilities, appropriate accommodation, social activities, health and well-being, financial security and future concerns.

METHODOLOGY

The issues identified in the Literature Review informed the development of a survey conducted by the Physical Disability Council in 2008 (before the Global Financial Crisis) to investigate the impact of ageing on people with disability. The survey was undertaken again in 2011 to assess the impact of changes on people with disability in relation to ageing since 2008.

The literature review identified unmet need in relation to assistance, housing, social activities and medical services for people with disability as the literature identified barriers to necessary services and goods available in the public domain. For this reason, respondents were asked about their experiences and needs in relation to this aspects of their lives. In relation to environmental barriers 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.

161 people commenced the survey and 157 completed the survey. There were 85 (54%) from metropolitan areas, 22 (14%) from regional areas and 50 (32%) from rural areas. 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, health and financial security that are common to all versions of the survey. 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 10 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

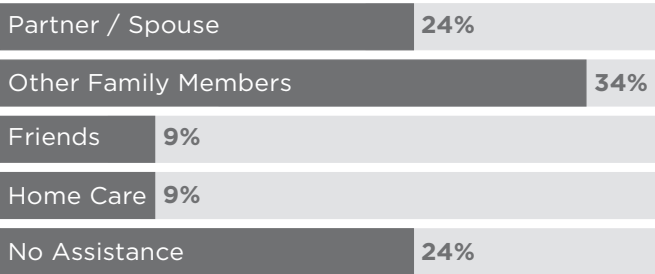
Overall, it became apparent there is overlap in need between older people with disability and older people with early onset disability. For this reason, the themes that emerge reflect the priorities and issues of both groups.

The case studies are included to 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 Eva, David, Margaret, Barbara and Simon. The concerns of older people with early onset disability are reflected in the case studies of Peter, Lorraine, Paul, Debbie and Mark.

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 (as in the case of Peter, David, Margaret, Mark and Simon): 24% by partner/spouse(as in the case of Paul, Debbie and Barbara) (a decrease of almost 6% since 2008), 34% by other family members (an increase of 23% from 2008), 9% from friends(as in the case of Simon) and 9% by Home Care. The remaining 24% received no assistance.*

Personal assistance provided by:



58.6% indicated that their needs for assistance were being met.

Some respondents expressed concern at the thought of their family member not being able to continue to provide assistance.

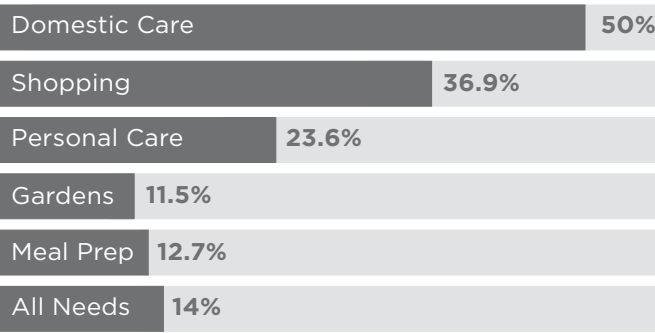
My needs are being met by Home Care and my daughter, but I feel that it will be too much for my daughter.

While my father is alive I manage OK with Home Care Service and relief carers.

As my mother is ageing she is less able to provide the level of care for me that she provided in the past. Extra hours of Attendant Care would relieve her of some of the care responsibilities she currently assumes, such as meal preparation, laundry, shopping and sundry ADLs.

Over 50% of respondents receive assistance with domestic care, 36.9% of respondents receive assistance with shopping, 23.6% receive personal care assistance, 11.5% receive assistance with lawn-mowing or gardening, 12.7% receive assistance with meal preparation and 14% of all respondents receive assistance for all their needs.**

Receives assistance with:



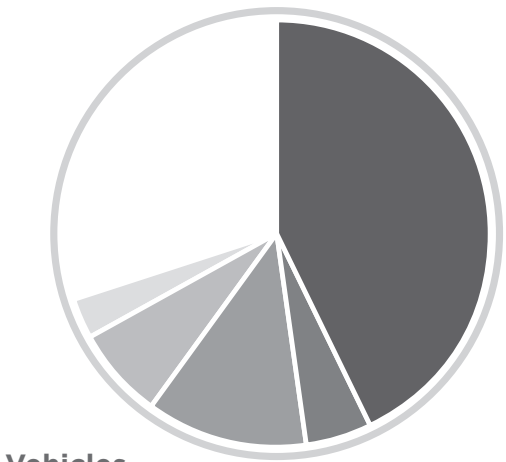
60% of respondents indicated that their needs have changed and 80.9% thought that their needs would change in the next 5 years.

Clearly, there are service implications arising from such a high proportion of people whose needs are not currently met and these are discussed later in the report.

* These are overlapping categories
** These are overlapping categories

MOBILITY

Respondents used a combination of forms of transport. 21% reported the use of wheelchairs and 6% also use scooters. These figures represent a decrease of 32% and 10% respectively since 2008. The same proportion of people (43 %) as in 2008 drive their own car and 5% are passengers in cars of family members. Wheelchair accessible taxis are used by 12% of respondents, accessible public buses by 7% and community transport by 3% - reflecting almost the same percentages in 2008.***



Vehicles

- Drive own car
- Passengers in family members car
- Accessible taxis
- Accessible public busses
- Community transport
- Not Specified

One respondent spoke of the need for assistance to meet the cost of necessary mobility aids:

needs not being met. Some respite care (in my home to give relative a rest. Appears as though I need an electric wheelchair as well as a manual wheelchair and mobility scooter...Cannot afford to buy an electric wheelchair on DES Pension and Aids +Equip. will not supply one because of the scooter.

As a large proportion of respondents in 2008 drove motor vehicles, respondents were asked about vehicle modifications. 47% of respondents had not modified their vehicle, 18% had modified their vehicle for wheelchair access, 9% had modified the seating arrangement in the vehicle and 8% had installed hand controls.

In addition, 30% of people intend to undertake vehicle modifications in the next 5 years.

It is apparent that there has been little change in mobility since 2008.

*** These figures are overlapping

ACCESS

In terms of access to a vehicle, 95% of respondents indicated they had access either to their own car or as a passenger. 40% of respondents could access public transport, 17% had access to taxis and 6% had access to community transport vehicles.

When a vehicle is not available 51% of respondents indicated that they had access to some form of public transport.

In relation to how easily people can access disabled parking, 35% of respondents reported the shortage of disabled parking spaces due at times to occupation by people who were not eligible.

66% of respondents reported no difficulty in access to facilities. Yet, 11% reported that access to the built environment was a priority.

Other respondents (as in the case of David, Margaret and Debbie) spoke of difficulties in accessing essential facilities and their community:

Footpaths, chairs in public too low, badly sloped ramps.

Access issue getting in and out of my home and in my local built environment.

Suggestions also involved widening and repairing street gutters and the pavement.

With regard to improvements in access to public transport some respondents could not access public transport at all. Other respondents commented on the need for buses to accommodate scooters or wheelchairs. Others commented on the need to increase the number of wheelchair accessible taxis. Other respondents suggested that there was a need for more community transport and wheelchair accessible public buses.

One respondent summarised her concerns:

I have reached that stage that I am far too afraid to use buses or trains – too many injuries. Taxis are an option, but I cannot afford the fees. I know my fear is an impediment for using public transport, but it is now TOTALLY in the “too hard basket”.

Another respondent commented on the need for the training of public transport staff on the needs of people with disabilities:

Bus drivers need training in understanding and respect for people with disabilities.

She also spoke of the need for more accessible transport available for longer hours.

Train stations need to be fully accessible, community transport needs to operate longer hours. It is one thing to be able to catch public transport but when you have to change to multiple services to get to one location it is beyond me. If out of my local area taxis are too expensive this is when transport should be available.

The need for train stations to provide access for wheelchairs:

Lifts needed to access platform train stations don’t always have the ramp and with the disease I need it.

The need for disabled taxis to accommodate larger wheelchairs

All disabled taxis should have minimum size standards to allow for extra height and depth of customized electric wheelchairs.

For people who used wheelchairs or scooters, there were concerns expressed about the need for local councils to maintain access to public transport.

Gutter ramps need work. Station is accessible but physical access to station is very steep from my location.

Bus stop considered unsafe raised tree roots hidden by dead leaves mud pool when it rains no shelter.

With regard to accessing services, 70% of respondents indicated that they had no difficulties with access.

Most of access issues identified are the same as in 2008 and thus the implications arising are discussed later in the report.

HOUSING

In terms of housing, 74% of people reported they are home owners(an increase of 41% since 2008), with 20% holding a mortgage on their home.

26% of respondents live in rental accommodation. In 2008, 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.

Despite 33% of respondents indicating that their accommodation needs had changed in the last 5 years, most people are satisfied that their accommodation meets their needs (74%).

Of the 26% who have unmet accommodation needs, some (like Mark) expressed the need for home modifications:

There are some stairs into and out of my house. This is a problem.

Over several years and with the support, I have attempted to have ramp access to my home – no luck so far – too awkward, too expensive or too much trouble. I have given up!!!

Some respondents indicated the need for more accessible and affordable accommodation:

The accommodation that I am currently renting needed to have modifications made to suit my needs. There is a shortage of wheelchair accessible housing in this community.

Others (like Eva) spoke of the need for more affordable, accessible and smaller accommodation:

House is too big for me, will have to downsize in the future.

It is apparent that despite the decrease in need for housing since 2008 there are still 1 in 4 people with disability who have unmet accommodation needs.

SOCIAL

Seventy percent of respondents found their social activities satisfying and 27% would like to increase the range and variety of these activities.

Analysis of the data indicated that social needs are largely met through a combination of activities.

Sixty percent of people participate in community organisations (compared to 16% in 2008. 58% belong to clubs. Fifty one percent participate in volunteer work (compared to 9% in 2008). Thirty four percent belong to hobby groups. Twenty three percent attend church groups (compared to 10% in 2008). Thirteen percent attend theatre, films or concerts. Twenty percent socialize with family members (compared to 22% in 2008), Thirteen percent have social contact with friends (compared to 17% in 2008) and 5% with work colleagues(compared to 8% in 2008). Four percent participate in educational activities.

However, it is of concern that 12% of respondents reported no social contact and 11% (an increase of 4% since 2008) only experience social contact with service staff.

Of particular mention for social activities are community organisations, and in particular, those for people with disability, clubs (such as Probus, retired veterans clubs, senior citizen clubs), hobby groups and church groups.

In relation to unmet need, 12% of people (like Peter, David and Mark) reported a need for companionship.

It became apparent that for some people, social isolation was linked to level of health. People with deteriorating medical conditions expressed regret at their inability to continue valued social activities.

In addition, people who lacked mobility (particularly vehicles) could not participate in social activities.

Currently not attending the Art Society I am a member of, due to my vehicle situation.

Mobility, in particular, driving a vehicle, provides access to social activities not only access to essential goods and services. Lack of access to a vehicle increases vulnerability to social isolation.

Friends do not want to be obligated to help. Many of mine still work full time and cannot find the time. So I lead an anti-social excluded lifestyle. My relative does not drive nor owns a car!.

The implications of social isolation for 33% of respondents are discussed later in the report.

HEALTH AND WELLBEING

In relation to how people view their current level of health and wellbeing, 37% regard their health as stable, 14% of respondents thought that their health is deteriorating and 2% rated their health as poor.

Forty nine percent of respondents thought that currently their access to health professionals was satisfactory and their health needs were being met.

Of the 51% of respondents who sought improvements, 19% thought that access to doctors or specialists could be improved and 16% reported that their health could improve.

Some respondents expressed concerns about their medical costs:

I had to really hunt around for a suitable GP and the one I finally found does not bulk bill so I hold off on visits. My ideal situation would be regular check ups, access to medication that does not cost \$230 per month...

Other respondents commented on the lack of relationships with doctors:

My old GP retired – have not found one yet who cares about the whole me.

Long term GP left community, now see various drs at medical centre – not satisfactory.

Better relationship with GP. Some specialists too expensive.

Others spoke of the difficulty in accessing doctors:

The ability to consult GP and specialists by phone when necessary to avoid lengthy trips especially when acutely unwell.

More medical services in our area.

There were also concerns expressed about the lack of expertise on certain conditions:

Mainly I'd like to know if my Post-Polio management is enough. Have put myself on waiting list at.. hospital for physiological assessment.

With regard to the past 5 years, 57% of respondents (like David) reported that their health needs have changed and 59% anticipate a further change in the next 5 years.

It is apparent that a large proportion of people have unmet health and medical needs and the implications arising are discussed later in the report.

FINANCIAL SECURITY

As the findings from the 2008 survey indicated that people were experiencing financial insecurity, people were asked again about their financial security post-Global Financial Crisis.

It was apparent from the survey that most people (like Peter and Paul) are concerned about the future in terms of financial security.

Fifty six percent of people feel financially insecure about the next ten years (almost double the proportion of 31% in 2008) with 52.2% of people financially insecure about the next 5 years (compared with 17% in 2008).

Timeframe	2011 (%)	2008 (%)
Feel financially insecure about the next 10 years	56%	31%
Feel financially insecure about the next 5 years	52%	17%

Clearly, the items of greatest expenditure indicate that people are experiencing financial difficulties, sometimes with the basic costs of living. This is discussed in detail later in the report.

Twenty five percent feel considerably insecure about the next 10 years and 14.6% feeling considerably insecure about the next 5 years.

Thirty one percent feel slightly insecure about the next 10 years with 37.6% slightly insecure about the next 5 years.

Only 31% feel secure about the next 5 years and 8% feel secure about the next 10 years.

Seven percent of respondents reported a need for financial assistance.

Some people required assistance with the cost of living:

Most helpful would be more assistance with rates as these keep going up but the amount of assistance has not increased since the mid-90s. Also I struggle with electricity have most of it taken out of my pension ahead of time which helps. Also I get dental assistance on an ECP and believe that is being removed which would be dreadful.

In relation to financial security, people were asked about their most significant expenses.

Respondents reported that currently their greatest costs are utilities (50%), 47% being electricity.

Home related costs accounted for 41% of expenditure. Of this proportion 13% is spent on mortgage and 6% on rent. Land and water rates represented 11% of significant costs. Eight percent reported home insurance. Twenty six percent reported car-related costs, 10% reported car insurance. Seventeen percent reported medication, Twenty two percent reported food. Doctors, specialists and hospital costs represented 14% of the greatest expenditure by respondents. Six percent of respondents stated that general living costs were their most significant expense.

As is apparent from the literature review, that both Australian and State governments have indicated that individual funding packages are under consideration for people with disability, respondents were also asked about how they would spend a one-off cash amount to improve their lives.

Nineteen percent of respondents stated they would buy equipment to improve their health/mobility, 13% would spend the money on home modifications, 11% would purchase a vehicle. Nine percent would purchase housing, 6% would have a holiday and 1% would undertake vehicle modifications.

FUTURE CONCERNS

Finally, people were asked about their concerns, expectations of the future and changes that could impact on their lives in the next five years.

People expressed concerns about the loss of independence (23%):

The more independence is lost, the more pressure is left to everyone else, currently I still contribute to society and am still useful.

I wonder if I am going to be able to do what I enjoy.

that their health is deteriorating (18%):

That I’ll be housebound because of ill-health and unable to drive.

Gradual physical decline.

that they experience financial insecurity (15%):

If my wife does not support me who is going to pay my accommodation and other things.

Not having enough money to support myself.

Health and income. Medical expenses – cost of living.

about entry to residential care (11%):

Having to go into a nursing home.

I do not want to go to a nursing home. I would rather die.

about losing their carer (10%):

How will I cope when/if my partner pre-deceases me.

Who will help me when my father is not around as my mother is in a nursing home.

Caring for myself if my wife wasn’t able to care for me.

about getting older (1%):

When I get older & I can’t look after myself.

As carer and self are ageing there is a risk of further illness (stroke or heart attack) resulting in further disability.

Some respondents spoke of their social isolation:

The need for a companion pet (I have just had to part with my dog) would give me someone to look after and more meaning in my life.

Live alone – widowed.

Live in companion or regular visitation.

People also spoke about the need for future accommodation and support need:

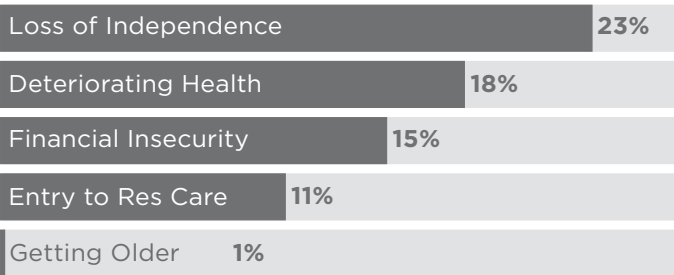
Concern in regard to possible nursing home accommodation needed in the future.

Fifty four percent of people anticipated a change in their lives in the next five years.

Thirty three percent of respondents fear this change as deterioration in their health, 8% identified the change as losing their carer, financial insecurity or ageing and 4% are anxious about changes in current health care arrangements.

Clearly, these concerns reflect the potential impact of ageing on the lives of people surveyed and are discussed in the next section.

Future concern:



DISCUSSION AND CONCLUSION

It was apparent in 2008 that a large proportion of people who were receiving assistance from family members, particularly spouses/partners depended on the health of family members to meet their needs. Thus, people receiving assistance from family and their carers were both likely to require assistance in the future from both personal care and health care professionals.

In 2011, 24% of respondents receive no assistance and 43% indicated that their needs for assistance were not being met. Of particular note was the finding that the needs had changed for 60% of people surveyed. It is worth noting that only 50% of respondents received domestic assistance and 24% received personal care assistance. It is also interesting to note that family member or spouses/partners account for 58% of the assistance provided. As indicated later in the discussion, there are resources implications in terms of all types of assistance for people whose spouses/partners or family members are themselves ageing and will be unable to provide care in the future, given that 90% of respondents anticipate a change in their needs in the next 5 years.

It was also apparent in 2008 that most people attributed their mobility to their access and ability to drive their own vehicle. In this way, they retained 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.

In 2011, the proportions have not significantly changed except for a decrease in the use of wheelchairs and scooters. It is interesting to note that 35% of vehicle owners had undertaken modifications and that 30% intend to undertake modifications in the next 5 years. Given the high proportion of self-drivers questions were asked about access to parking space for people with disability. It is of concern that 35% of respondents found existing spaces inadequate and several commented on the illegitimate use of such space by non-disabled drivers. Clearly, there are implications in terms of increasing and monitoring the use of disabled parking spaces.

Given that the literature review identified barriers to the built environment, it was interesting to note that 66% of respondents reported no access difficulties to the community and facilities, with 11% reporting this as an unmet need. It was also apparent in the previous survey that people who do not drive 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. Most of these needs were also identified in 2011, with respondents commenting on the need for access to public transport, particularly to wheelchair accessible taxis, wheelchair accessible buses and trains.

It was also apparent in 2008 that the degree of mobility also determined 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. This is also the case in 2011. The lack of accessible public transport and accessible infrastructure still has implications for both local and state levels of government.

Regarding social needs in 2008, the high number of people who live alone indicated that there are a substantial proportion of people who are vulnerable to social isolation if they lose mobility. In 2011, 70% of respondents are satisfied with their social activities, 27% would like an increase and 23% have no social contact except for formal and informal carers. As mentioned above, mobility provides access to social activities as well as essential goods and services. The social isolation experienced by 33% of respondents and the fear of losing significant partners/spouses/family members was expressed by respondents.

In 2008, 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. In 2011, it is encouraging to note that 74% of people are satisfied with their accommodation. Yet, the concerns expressed by the 26% who have unmet needs reflect the issues raised in 2008.

In 2008 it was apparent that health care needs were being addressed, but there were concerns about future health need and areas in health care that are issues for an ageing population.

In 2011, 51% of people feel that access to health professionals could be improved. Of particular concern was the lack of ongoing relationships with GPs and difficulties in access to doctors in rural areas. The current shortage of medical professionals in regional and rural areas was noted in 2008. It is still a concern that there is a shortage of particular areas of medical expertise. The education of professionals and the provision of specialised clinics suggested in 2008, could meet this need.

In addition, it was apparent in 2008 that pensions were insufficient to meet the rising cost of living and that people who were working felt concern about meeting the cost of living when they retire. In 2011, the financial insecurity generated by the impact of the Global Financial Crisis resulted in greatly increased financial insecurity both in the short and long term.

People surveyed identified the greatest expenditures arose in relation to the cost of living and in particular, utilities (electricity). The introduction of the Carbon Pricing Scheme in 2012 has implications in terms of the cost of energy and thus in the cost of all related items. The proposed cost of living increase was estimated at 1.1% in 2010-11 (Australian Government, 2008: 17-2). However, the Australian Government has indicated that most households will receive compensation in the form of tax cuts and family benefits. For people with disability, it is intended that the assistance provided will cover the cost of the average price impact and for some cover in excess of the average price impact (Australian Government, 2011:1). A White Paper on Carbon Pricing (2008) indicated that the estimated impact of carbon pricing would be from 1.1% for part-pension and self-funded retiree households, to 1.3% for sole parent pensioner households, 1.4% for single pensioner households and 1.2% for married pensioner households across income and salary groups (Australian Government, 2008: 17-3). In addition, the Australian Government increased the pension payment by 2.5% from 1 July 2010 (Australian Government, 2008: 17-9). Yet, as is evident from the data and findings of this survey, people with disability are still experiencing financial difficulty in meeting their energy costs. There are clearly implications in terms of resources for people who require energy to manage their disability.

Other expenditures identified by respondents included: the costs of mortgage and rent, land, water and insurance rates and vehicle maintenance costs. Of particular concern was the expenditure on medication, food and medical costs all of which are not subsidized. As the White Paper estimated that the impact of Carbon Pricing would be 1.1% when the scheme is introduced, there are also implications in terms of financial assistance for people with disability to cover the carbon-pricing-associated costs of these items as well.

In terms of potential expenditure for individual funding resources, respondents indicated that a one-off payment would be used by 19% to purchase necessary equipment, 13% to modify housing, 11% to purchase vehicles (and thus mobility) and 9% to buy housing. The remainder opted for holidays and vehicle modifications.

Given that the NSW Government has already committed funding to Individual funding packages, it is hoped that the availability of such packages is extended to enable people with disability to cover both their essential costs and their needs.

In relation to concerns about the future, people feared the loss of their independence through ageing or deterioration in their health. Some people fear financial insecurity at a time when their needs increase. Some people fear the loss of a family or spouse/partner carer both in terms of assistance required and social contact. Some people fear nursing home entry and others fear the lack of residential care if required.

In conclusion, it was evident that many concerns raised in 2008 are still not addressed in terms of access to transport, the built environment, community and facilities. While the findings reflect an improvement in access to housing, there is still one in four people who require appropriate housing and the same issues as in 2008 are relevant. It is also evident that people surveyed are much more concerned about their financial security than they were in 2008, particularly in relation to meeting their changing needs. People are largely satisfied with social activities but it is of concern that a large number of people are socially isolated and fear such isolation in the future. It is also apparent from the distribution of the case studies representing people with both late and early-onset disability 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 that were identified by the Productivity Commission for future kinds of services that are needed by people ageing with early-onset disability as well as late-onset disability, 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 which provide accessible transport, housing and access to health and social services together with informal and formal assistance arrangements that enable people to remain independent in their own homes. In addition, the Productivity Commission identified the need for co-ordination between the different levels of government to address the issues that provide barriers to access in the public domain.

The findings confirm the needs identified in the literature review and indicate that there are still barriers to access which prevent the social inclusion of people with disability of all ages.

APPENDIX A

Case studies

- 1

Eva is an older person with late-onset disability who manages to live independently with domestic assistance, community-based home maintenance and modification and a little help with her garden from her neighbor. Eva drives her own car and owns her house but would like to downsize to a smaller more accessible home. Eva has a busy social life volunteering, being a member of clubs and seeing her friends.
- 2

Peter is an older person with early-onset disability. He requires family help to do all domestic work and personal assistance as well as shopping. As most of Peter’s friends work full-time he is socially isolated – a situation which is exacerbated by the lack of a vehicle and inaccessible public transport. Peter cannot afford the necessary modifications to his bathroom. He feels socially excluded financially insecure and thinks that his only option is to enter a nursing home.
- 3

David is an older person with late-onset disability who receives assistance from an older relative with domestic work, personal care, shopping and meal preparation. David is unable to access community facilities or services and requires full assistance at home and with transport. He is also unable to access social activities owing to his medical condition.
- 4

Margaret is an older person with late-onset disability, who is now a widow. She receives assistance with all domestic work and personal care from both Home Care and her daughter.

Margaret has great difficulty in access to facilities in her community as they are not wheelchair accessible and is unable to use public transport. Her social activities are restricted to her family and a community organisation.
- 5

Lorraine is an older person with early-onset disability. She receives assistance with domestic work. She can drive and is able to access facilities in the community. Lorraine is a member of her Church group and attends exercise and hobby classes.
- 6

Paul is an older person with early-onset disability who receives assistance from his wife with all domestic tasks and personal care. Paul is concerned about deterioration in his health and financial viability. He is also worried about the impact of his increasing needs on his wife.
- 7

Debbie is an older person with early-onset disability who receives full assistance with personal care, domestic care and shopping from her husband. Debbie only has partial access to facilities in her community as it is not all wheelchair accessible. Debbie drives and has an active social life as a member on various committees as well as spending time with friends.
- 8

Mark is a younger person with early-onset disability. He receives assistance from his mother and brother. Mark is unable to use the stairs in his parent’s home and is also unable to drive. Thus his social activities are restricted to service staff and medical appointments.
- 9

Barbara is an older person with late-onset disability who receives assistance with heavy chores from her husband. Sam. As Sam can drive, Barbara is able to access her community and facilities, attend Church and participate in volunteer activities.
- 10

Simon is an older person with late-onset disability who receives assistance with domestic work and transport for shopping. As he does not drive, he is reliant on friends and his daughters for transport. Simon uses a scooter for mobility and is able to use public or community transport. He participates in a variety of social activities such as exercise classes, choir and church activities as well as spending time with his family.

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Physical Disability Council of NSW
Ordinary People Ordinary Lives

St Helens Community Centre
3/184 Glebe Point Rd. Glebe 2037

T: (02) 9552 1606
1800 688 831(freecall outside
the Sydney metropolitan area)

E: Admin@pdcnsw.org.au

F: (02) 9552 4644

National Relay Service

TTY users:
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for (02) 9552 1606

Speak and Listen users:
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for (02) 9552-1606