

CONTENTS

BACKGROUND	2	METHODOLOGY	9
Population growth, ageing and life expectancy.....	2	THEMES EMERGING FROM THE DATA	10
Data on disability	2	PERSONAL ASSISTANCE	10
Types of assistance required	2	MOBILITY	11
Need for assistance	2	TRANSPORT	12
Source of assistance.....	3	HOUSING	13
Family and or spouse/partner providers	3	ACCESS TO HEALTH AND WELL-BEING.....	14
Paid assistance	3	FINANCIAL CONCERNS.....	15
Housing	3	CONCERNS ABOUT THE FUTURE	16
Financial issues	3	DISCUSSION AND CONCLUSIONS	18
Social participation	3	REFERENCES.....	22
LITERATURE REVIEW	5	APPENDIX: CASE STUDIES OF PEOPLE WITH PHYSICAL DISABILITY.....	24
Access of people with disability to housing.....	5	IMPLICATIONS FOR POLICY AND PRACTICE	26
Access of people with disability to transport	6	IMPLICATIONS FOR POLICY AND PRACTICE.....	.Error! Bookmark not defined.7
Social inclusion of people with disability 7			
Financial resources.....	8		

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BACKGROUND

Population growth, ageing and life expectancy

The Australian population is growing and ageing, with longer life expectancy.

According to the Australian Bureau of Statistics (ABS) the estimated population in Australia in September was over 23, 600 000 people (ABS, 2014: Population Clock). In 2013, the population of New South Wales was estimated at 7, 465,500. The 2014 figure represents an increase of 1.5 percent since 2012 (ABS, 2013: Australian Demographic Statistics).

The latest data also indicates that the proportion of people in Australia aged 65 years and over increased by 4 percent between 1972 and 2012 and the proportion of people aged 25 years and under fell by 13 percent (AIHW, 2013: 4) reflecting an ageing population.

In addition, life expectancy rates increased from 82.8 years in 2001-3 to 84.3 years in 2010-12 for females and from 77.8 years to 79.9 years for males for the same period (ABS, 2014).

Data on disability

The data on disability also reflect these trends.

Data from the 2012 Survey of Disability, Ageing and Carers (SDAC) indicate that 4.2 million Australians (18.5 percent of the total population) have a disability (ABS, 2012: 1), of which 3.3 million people (14 percent of the total population) are aged 65 years and over (ABS, 2012: 1). This is an increase of 0.1 percent since 2009.

The data also indicated that the proportion of people with a severe or profound disability has slightly increased between 2009 and 2012, as has the proportion of people with a mild disability, but the proportion of people with a moderate disability has slightly decreased (ABS, 2012: 1).

Types of assistance required

In 2012, in Australia, 60 percent of all people with disability and around 42 percent of older people required assistance with at least one activity because of disability or age (ABS, 2012: 1).

Data on the types of assistance required indicated that, in 2009, 38 percent of people with severe or profound core activity limitation required assistance with personal care, 21 percent of this group required assistance with mobility, 18 percent required transport assistance and 14 percent required assistance with meal preparation. In 2012, the data indicated that people with disability of all ages reported that their assistance needs were most likely to be health care or property maintenance (29 percent) and least likely to be communication (6.8 percent) or meal preparation (8.7 percent). In addition, females were more likely to receive help with household work, mobility and transport, than males.

Need for assistance

The data also indicated the level of need for assistance.

In 2009, around 40 percent of people with core activity limitations reported that their

needs were only partly met or not at all (Productivity Commission, 2011: 123).

In 2012, although most people with disability received some assistance, one third reported unmet need. Older people were more likely than other people with disability to report that their need for assistance had been met (64 percent compared with 58 percent) while 2 percent of each group reported that their needs were not met at all (ABS, 2012: 2).

Generally, people with increasing impairment reported that their needs were not fully met (less than half of people with a profound disability).

The need for assistance for older people differed according to gender, with almost half of older females reporting a need for assistance compared with one third of older males. Thus it is apparent that older females are more likely to have unmet need.

Source of assistance

Family and or spouse/partner providers

In terms of the source of assistance, the data indicated in 2009 that the needs of half of all people with disability were fully met by family members. Twenty percent was provided by paid services and 20 percent provided by a combination of paid services and family assistance (Productivity Commission, 2011, 123).

Primary carers were more likely to be the partner of their recipient and one in five were aged 65 years and over. The data also indicated that 14 percent of children provided care for a parent and 13 percent of carers provided care for a child. Sixty seven percent of primary carers were caring for a parent who did not live with them (ABS, 2012:1).

The data indicate that primary carers were significantly more likely to have a disability (one third) and males were more likely to have disability than females (45 percent compared with 34 percent) (ABS, 2012: 1).

Paid assistance

The most common sources of paid assistance were private commercial organisations (37 percent) and government organisations (30 percent) (ABS, 2012:1).

Housing

According to the 2006 Census data, a high proportion of people with disability owned their own homes. Ten percent of people with disability rented from housing authorities or cooperatives, community or church groups (ABS, 2006:7).

In 2012, 45 percent of people with disability lived in a private dwelling, 5 percent lived in supported accommodation and 3 percent lived in other non-private dwellings (ABS, 2012: 2).

Financial issues

The financial pressures on people with disability are evident in the data which indicated that over 800,000 people with disability of working age were in the two lowest quintiles for income in 2012 (ABS, 2012: Table 8), and over 947,000 people with disability of all ages received their income from a government pension or allowance (ABS, 2012: Table 8).

Social participation

In 2006, people who needed assistance were half as likely as the rest of the population to be in couple families with their own children (13 percent compared to 26 percent), and those aged 25-44 were much less likely to be in partner relationships (36 percent compared with 69 percent) than people without a need for assistance. In addition, lone parents aged 65 years and over were twice as likely to need assistance (ABS, 2006).

However, the data indicated that people with disability have moderate levels of social

participation. In 2012, people with disability were less likely to have participated in at least one activity outside their home in the preceding 12 months (ABS, 2012: 1).

In addition, 35 percent of people with increased impairment and 49 percent of people with mild to moderate impairment participated in sports activities, 42 percent of people with increased impairment and 50 percent with moderate impairment attended movie or events and 22 percent of people with increased impairment and 30 percent with moderate impairment attended sporting events as spectators (ABS, 2012: 1).

The data also indicated that the level of participation decreased with age and level of impairment. So that, in 2012, one third of people aged 65 years and over did not participate in any social or cultural activities outside their home in the preceding 12 months. This proportion increased to 51 percent for older people with profound or severe impairment (ABS, 2012: 1).

From the preceding data, it is apparent that the rate of disability is increasing with the ageing of the population. In addition, there is an overlap between the needs of older people and people with early onset disability in terms of type of assistance required, source of assistance and financial issues. It is also apparent that less than half of all people with disability live in private housing and that the level of social participation decreases with age and increasing impairment.

In order to better understand this overlap and the needs of people with physical disability living in New South Wales, this study examines, among other factors, the type and source of assistance, housing, social and financial needs. However, prior to exploring the findings from the 2014 Survey on the Impact of Ageing on People with Physical Disability, the literature on ageing and disability was examined.

LITERATURE REVIEW

In line with the data, the literature indicated the emergence of a nexus between ageing and disability (Ruiz et al, 2012; Washko et al, 2012) which will affect the demand for long term services and supports (LTSS) provided in community settings as people with disability and older people share a desire to 'age-in-place' (Washko et al, 2012).

Various studies have investigated the factors that contribute to the well-being of older people with disability: health, housing and education (Wilson, 2006 in Chen, 2012: 331); participation in the labour market (Pierson, 2002 in Chen, 2012: 331), family and social relations (Allen et al, 2003 in Chen, 2012: 331), social participation (Madamipour, 2003 in Chen, 2012: 331), social mobility (Ou, 2008 in Chen, 2012: 331) and household finances (Burchardt et al, 2002 in Chen, 2012: 331). For these reasons, these factors are examined in this study.

A number of principles for a long term support system (LTSS) for people ageing with disability are also outlined in the literature. These include sustainability, self-determination or consumer-centred focus, community integration and inclusion, prevention, shared accountability and co-ordination and transparency (Ruiz et al, 2012: 131).

Access of people with disability to housing

The literature seems to indicate that people with disability are more likely than people without disability to experience difficulties with housing.

The literature pointed to the extent of disadvantage experienced by people with

disability, many of whom are public housing tenants (Productivity Commission, 2013) and indicated the need for increased availability of public housing for people with disability (Australian Government, 2009).

The literature also pointed to the link between homelessness and chronic health problems (Henwood et al, 2013). Another study focused on the relationship between the homelessness of adolescents and young adults with traumatic brain injury and found that these young people were more likely to report mental health diagnoses, substance use, suicidality, victimisation and difficulties with activities of daily living (ADL).

For these reasons, the 2014 survey enquired whether people had ever experienced homelessness.

There is also literature on the impact of an ageing population on housing, health and social care. One UK study found that home and the wider neighbourhood influence the health and well-being of older people. The study recommended housing, physical and social infrastructure which could accommodate the changing needs of people as they grow older and the increase in services to support older people's housing choices and housing options (Communities and Local Government, 2008 in Buckner et al, 2013: 127). The report also pointed to the significant role of housing in enabling people to maintain their independence in terms of home modification to existing properties and specialist housing which also provides assistance for older people with disability (Buckner et al, 2013).

Another study from the US points to the need for ageing-friendly communities with affordable and accessible housing that offers opportunities for social integration and interaction which do not rely on vehicle dependence (Scharlach and Lehning, 2013). It emphasises the need for ageing-friendly communities which offer: continuity in terms of ability to participate in existing activities

and interests; compensation or the ability to meet basic health and social needs regardless of disability; connection which involves opportunities to develop and maintain social relationships; contribution which enables people to participate and have an influence on their social environment and challenge which enables people to develop new interests and activities (Lehning, Chun and Scharlach, 2007; Scharlach, 2009 in Scharlach and Lehning, 2013:111) which it argues comprise the elements of social inclusion (Scharlach and Lehning, 2013).

Given the importance of housing to maintaining independence, the housing and home modifications needs of people with physical disability are examined in the 2014 survey.

Access of people with disability to transport

In terms of social inclusion, access to transport has been related to improved functional health status and a higher degree of autonomy, which in turn may reduce the demand for societal support (Hakamies-Blomqvist, Henriksson & Heikkinen, 1999 in Sjodin et al, 2012).

UK studies in the area of transport access found links between income poverty, transport disadvantage, poor access to key services and social exclusion (see for example Church et al. 2000; TRaC 2000; Lucas et al. 2001; Kenyon 2003; Kenyon et al. 2003; Hine and Mitchell 2003; Hodgson and Turner 2003; Raje' 2004 in Delbosc & Currie, 2011) and US studies on transport access have focused on the links with social inequality.

Barriers to public transport (buses, trains, taxis, aircraft and ferries), private individual transport and community transport prevent access to education, employment, health services, social events and leisure pursuits which creates social exclusion for many

people with disability (Hesier, 1995; Alsnih and Hensher, 2003; SEU, 2003 in Wilson, 2003: 6). For this reason, access to private and public transport is examined in the 2014 study.

One Australian study explored the access of low income earners in Western Sydney. The authors examined the differences between the travel and activity patterns of socially excluded groups and the average population in the Melbourne region (Currie et al. 2007; Currie 2010; Currie and Delbosc 2010a, b in Delbosc & Currie, 2011).

Other studies have measured barriers to access for particular groups of people or characteristics such as income, employment status, car ownership or health (Delbosc & Currie, 2011) in terms of the ease with which people can access travel modes, levels of car ownership, licensing rates or public transport services for either individuals or for a given area (Hine, 2004; Hurni, 2005; Currie, 2009 in Delbosc & Currie, 2011:171).

Research on drivers with disability has largely focused on adaptations to vehicles, transport safety (Henriksson, 2001 in Wilson, 2003; 44) and the problems experienced in urban areas, arising from the increasing distance of parking from amenities, the lack of provision of accessible parking spaces, inconveniently located parking spaces, illegitimate use of accessible parking spaces and a lack of wheelchair ramps (DPTAC, 2002a; Mori, 2000 in Wilson, 2003: 44; Marini, Bakhta and Graf, 2009; Withers and Hampton, 2003). These aspects are also examined in the 2014 survey.

The literature indicates that there is a need for the regular monitoring of pathways and pedestrian areas, paved surfaces, car parking, bus stops, taxi ranks, access to and within transport-related buildings, facilities within transport buildings, lighting, signage and information as well as consideration of access needs outside urban areas and consultation

and training (Oxley, 2002). There is discussion of access to the built environment in this study.

It is apparent from these studies and the data that driving a private vehicle is an important aspect of personal mobility and social access for people with disability yet there are significant social and environmental barriers as well as issues surrounding private vehicle access and usage. For these reasons, this study investigates the vehicle ownership, modifications made and access to public transport of people with physical disability.

Social inclusion of people with disability

As indicated in the literature one aspect of social inclusion involves social integration. It has also been defined as covering a variety of social and economic factors (Sen, 1998 in Giambona and Vassallo, 2013: 271) and interpreted as the ability of an individual to participate in the basic political, economic and social activities of a given society (Chakravarty and D'Ambrosia, 2006; Bellani and D'Ambrosio, 2011 in Giambona and Vassallo, 2013: 271).

The European Commission defines social inclusion as a process which ensures that people at risk of poverty and social exclusion gain opportunities and resources essential to participate fully in social and cultural life and enjoy the normal standard of living and well-being in the society in which they live (European Commission, 2004: 10 in Giambona and Vassallo, 2013: 271). Eurostat has three levels of indicators of social inclusion: people at risk of poverty after receiving social benefits, severely materially deprived people in terms of resources and living standards; people living in households with very low work levels (less than 20 percent of their capacity) and early school

leavers namely people with low levels of education (Giambona and Vassallo, 2013).

It is apparent from the literature and data that people with disability are at risk of social exclusion.

As mentioned earlier, 'ageing-friendly' communities (Scharlach and Lehning, 2013) facilitate the ability of individuals and groups to participate fully in the benefits of society. In particular, in relation to access to resources, such as goods, services, power and control (Cass, Shove and Urry, 2005; Marsh and Mullins, 1998 in Scharlach and Lehning, 2013: 113) by providing social integration; social support and access to resources (2013). The authors consider social inclusion not only pertaining to individuals, but also to communities in which they live so that the environment is a factor in consideration of social inclusion and points to the need for the accumulation of social capital (Bourdieu, 1986: 248 in Scharlach and Lehning, 2013: 115). In addition, community social capital comprises community or organisational features that engender mutually beneficial social interaction among members of a community (Scharlach and Lehning, 2013).

Initiatives for the social inclusion of people with disability in Europe include the 'Europe 2020' strategy to achieve sustainable and inclusive growth in its member countries and to obtain high levels of employment, productivity and social integration (Giambona and Vassallo, 2013: 269)

In Australia, the social inclusion of people with disability in social and community life is underpinned by the United Nations Convention on the Rights of Persons with Disabilities and the Council of Australian Governments' (COAG) National Disability Strategy 2012-2020 (ABS, 2012) which was ratified by the Australian Government in 2008 and endorsed by COAG in 2011 (AIHW, 2013).

The policy of social inclusion also defined many of the initiatives of the former Labor

Government as well as those of the current NSW government. Even though the current Coalition Government does not identify social inclusion as a priority, it endorses the principles behind the National Disability Insurance Scheme, which are based on a philosophy of social inclusion.

In addition, both the Australian and NSW government have committed to the Disability Inclusion Act 2014, which replaced the former Disability Services Act 1993. According to the Family and Community Services, Ageing, Disability and Home Care, this Act has the role of committing the NSW Government to making communities more inclusive and accessible for people with disability now and into the future when the NDIS is operating across NSW (2014). The aims of the Act include: acknowledging human rights, promoting the independence and social and economic inclusion of people with disability, enabling choice and control, setting up safeguards and, where practicable supporting the United Nations Convention on the Rights of Persons with Disabilities (FACS, 2014)..

It is apparent from the foregoing literature that social inclusion encompasses many aspects of people's lives in terms of access to social participation, housing, the built environment, health and welfare services, infrastructure and financial resources. These aspects are examined in the 2014 survey.

Financial resources

In relation to financial resources for people with disability, the National Disability Insurance Scheme (NDIS), which is expected to be implemented in all states by 2016, was introduced in the Hunter region of NSW from July 2013 (NDIS, 2014)..

It is interesting to note that the 2014/15 Commonwealth Budget committed \$4.3 million towards the preparation of the NDIS in 2014/15 and \$600,000 in 2015/16. In addition, the National Disability Specific Purpose Payments (SPP) which is provided to

the States to support disability services has been allocated \$1.398 million in 2014/15 and \$1.454 million in 2015/16, \$1, 513 million in 2016/17 and \$1, 580, 300 in 2017/18 (Budget Paper no. 3, 2014: 3).

From 2013/14 there has been no funding allocated to assist the States with pension concessions, public transport concessions or services for veterans under the National Partnership on Home and Community Care (Budget paper no.3 2014, 5, 6).

As the literature indicated that people with disability experience financial pressures and difficulties, the financial resources and levels of financial security are explored in the 2014 survey.

In summary, it is apparent from the literature review that many of the issues that affect the lives of people with early onset disability also influence the lives of older people with disability. In addition, it is apparent that the definitions of social inclusion involve access to both social and economic areas of life. It is also apparent that people with disability experience barriers to housing, transport and financial resources. For these reasons, this study investigates these areas as well as: mobility, access to facilities, services and the community, social participation, household finances, health and the future concerns of people with physical disability in NSW.

METHODOLOGY

Following on from the 2008 and 2011 surveys, the 2014 survey aims to investigate the impact of ageing on people with physical disability 6 years after the Global Financial Crisis.

The literature review identified unmet need in relation to assistance, housing, transport and infrastructure. The literature review also pointed to the importance of access to all areas of life such as social and economic participation, infrastructure, the built environment and suitable housing. For these reasons, participants were asked about their experiences and needs in relation to these aspects of their lives and whether they had ever experienced homelessness. Another two questions were added which explore the financial resources of people with physical disability. In addition, people were asked about their anticipated needs and individual concerns.

The 2014 survey was distributed by the PDCN in metropolitan, regional and rural areas of New South Wales. The survey was made available online, using QuestionPro digital software and as a Word document from the PDCN website. Most of the questions were open-ended, which allowed for qualitative analysis of the findings. The data was used to

create a data base using SPSS statistical software. This data enabled the calculation of frequencies and the statistical computation of various variables discussed in the findings section.

A total of 268 people started the survey and most completed. Analysis of the sample indicated that the sample was representative for all variables, except for the following owing to insufficient responses: additional assistance required; 5 year projected needs; access to facilities; needs met in relation to facilities; accommodation needs in 5 years and need for other social activities. Thus, statistical analysis was undertaken for all except these variables (see discussion of the findings) but the statistical frequencies of all variables was calculated. The data in the findings, cited from the SDAC 2012, focuses on New South Wales.

The findings address each area of need to identify themes and issues which are then discussed and conclusions drawn about the extent of access to essential goods and services and the extent to which people with physical disability in NSW are socially included.

THEMES

EMERGING FROM THE DATA

It became apparent from the findings that many of the issues that affect the lives of people with early onset disability also impact on the lives of older people with disability the following themes reflect the issues, concerns and needs of both groups.

To illustrate particular themes, case studies (Meg, Greg, Tim and Paul) have been drawn from the data to represent both people with early onset disability, and older people with disability.

GEOGRAPHICAL LOCATION

The data from the survey indicated that most respondents (58 percent) live in metropolitan areas, 25 percent in regional areas and 17 percent live in rural areas of New South Wales.

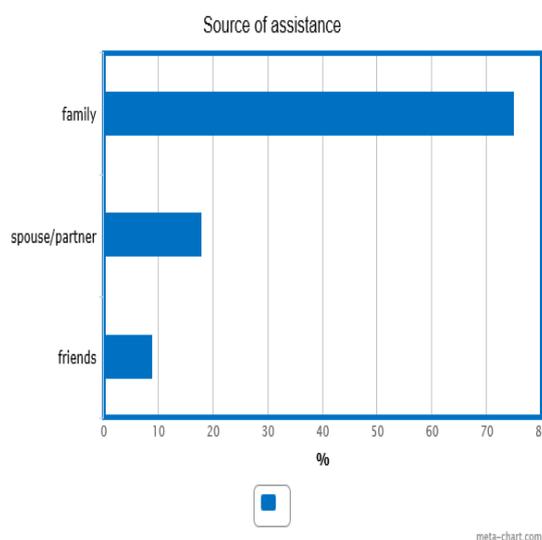
PERSONAL ASSISTANCE

Source of assistance

According to the SDAC, 35 percent of people with reported disability living in NSW received assistance from a partner, 26 percent received assistance from a child, 17 percent received assistance from a parent, 14 percent from another relative and 11 percent received assistance from a friend or neighbour (ABS, 2012)

The findings from the 2014 survey indicate however that most people (75 percent) like Meg receive assistance from family members, 18 percent of respondents in NSW like Paul (a decrease of 6 percent since 2011) receive assistance from a spouse/partner and as in

2011 less than 10 percent receive assistance from friends.¹



With regard to paid assistance, in NSW: one third of people with disability received assistance from service providers; one third received assistance from Government; and over one third received assistance from private commercial organisations. However, just over one fifth received assistance from private non-profit organisations (ABS, 2012).

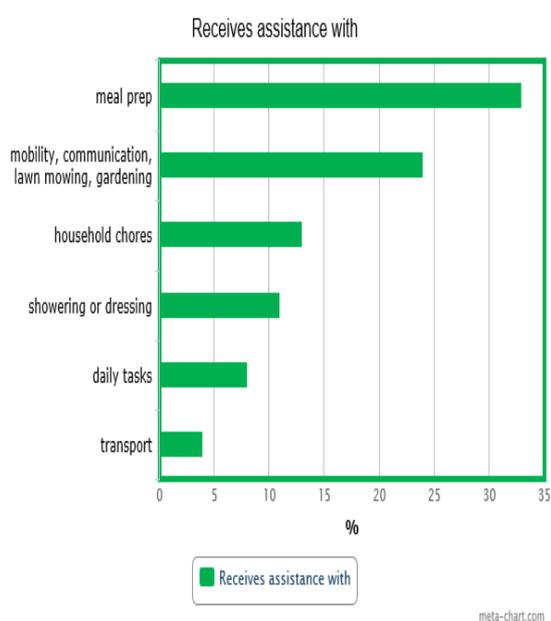
Type of assistance

In relation to the type of assistance received, the data indicated that most people (76 percent) receive assistance with mobility, 61 percent with health care, 55 percent with transport, 48 percent of respondents receive assistance with self-care or household chores; 45 percent with property maintenance, 40

¹ These are overlapping categories

percent receive assistance with cognitive or emotional tasks; 24 percent with reading or writing tasks; 27 percent received assistance with meal preparation and 22 percent receive assistance with communication (ABS, 2012)².

Results from the 2014 survey indicate that one third of respondents receive assistance with meal preparation (an increase of 19 percent since 2011) ; 8 percent of respondents (double the proportion of 2011) require assistance with all daily tasks; 13 percent of respondents have assistance with household chores; 11 percent receive assistance with showering or dressing; 24 percent receive assistance with mobility or communication or social support or lawn mowing/gardening and 4 percent receive assistance with transport³.



In relation to need for additional assistance, 28 percent of people require personal care; 16 percent require cleaning and 12 percent need lawn mowing/gardening, home maintenance and meal preparation respectively, 8 percent require shopping and transport and 4 percent need home modifications.

Only 11 percent of respondents reported unmet need and 15 percent of respondents

² These are overlapping categories

³ These are overlapping categories

anticipated that their needs would change in the next 5 years. When asked about their changing needs, some people like Meg:

Expect needs to change in the next 5 years as she becomes less mobile.

Other people like Tim:

feel that ageing may lead to increasing needs in the next 5 years.

Whereas others like Paul:

think needs are increasing and even though regarded as met, anticipate a need for more personal care within 2 years.

MOBILITY

In relation to mobility, almost 60 percent of people in the 2014 survey believed their mobility would decrease in the next 5 years.

With regard to travel, the ABS data indicate that 28 percent of people with disability were passengers in a vehicle in their last journey, 13 percent drove their own vehicle, 7 percent used public transport and 8 percent walked (ABS, 2012: Table 23).

In the 2014 survey almost one third of respondents either drove their own car or used a wheelchair (a decrease of 14 percent and increase of 8 percent respectively since 2011). Just less than one quarter were passengers in other people's vehicles (compared with 5 percent in 2011). There was no significant change in the proportions of people who used public transport (6 percent compared with 7 percent) community transport (7 percent compared with 3 percent and mobility scooters (7 percent compared with 6 percent) in 2011. However, only 2 percent of respondents used accessible taxis in 2014 compared with 12 percent in 2011. This difference could be due to the rising

costs of accessible taxis and is discussed later in the report⁴.

Close to 60 percent of drivers in the 2014 survey had undertaken hand control modifications to their vehicles (an increase of 46 percent since 2011), 18 percent had installed a wheelchair hoist and 6 percent had installed tail gate openings, (24 percent compared with 18 percent in 2011), 6 percent had installed hand brakes or modified pedals in 2014. In addition, as in 2011, 30 percent of people intend to undertake vehicle modifications in the next 5 years.

When private vehicles were not available 41 percent of people used accessible buses, 37 percent used accessible taxis, 10 percent used trains, whereas 7 percent relied on lifts from friends or neighbours and 5 percent used community transport⁵.

It is apparent that the only marked changes were in the decrease of the number of people driving their own vehicle or using an accessible taxi since 2011. In addition, a large proportion of people use accessible buses or taxis when their vehicle is not available. These points are discussed later in the report.

TRANSPORT

In relation to Improving access to transport, over 40 percent of people in the 2014 survey reported a need for more accessible buses, almost a quarter reported the need for assistance with public transport, just over 10 percent indicated a need for more accessible taxis and accessible bus stops, 7 percent reported a need for more taxi vouchers, 5 percent required more accessible train stations and 2 percent of people reported a need to improve the pedestrian pathways.

⁴ These are overlapping categories

⁵ These are overlapping categories

ACCESS TO COMMUNITY, SERVICES AND FACILITIES

In terms of access to the community, the 2014 survey indicated that almost 30 percent of people accessed the community using their own vehicle or a wheelchair, 22 percent of people were passengers in a vehicle, 20 percent relied on accessible public transport or service provider transport or a mobility scooter or accessible taxis.

Respondents were also asked about their access to facilities. The findings from the 2014 survey indicate that 38 percent of people require paid assistance to access facilities in their area, 17 percent obtain access through the assistance of friends, 8 percent use accessible taxis and 4 percent use a wheelchair to access facilities. Twelve percent of people use accessible shopping centres, 8 percent only use facilities with accessible parking such as medical centres.

In relation to improving access to facilities, 26 percent of respondents reported the need for accessible shopping centres, and 21 percent reported a need for more accessible parking spaces like Meg:

who can easily access the community and facilities but finds that parking is difficult due to high traffic levels. Sometimes she is not able to park near her home.

15 percent reported a need for accessible buildings:

Lots of places are difficult for me to access, too many stairs

an accessible built environment:

I can still drive but accessing the streetscape in a manual chair is very difficult for me. Need assistance in negotiating curb ramps and steep incline and footpaths. I cannot access my local shops from my home independently in the wheelchair. Because of the terrain and old

infrastructure it is also difficult and dangerous in an electric wheelchair.

9 percent reported the need for more community transport.

Specifically in relation to people with disability who are drivers, over three quarters of respondents indicated a need for more accessible parking spaces, with 3 percent reporting this need at entertainment venues. Fourteen percent of people experienced difficulties with parking owing to the misuse of accessible parking and 8 percent reported difficulties with parking at times of heavy traffic.

In relation to access to services, almost 50 percent of people only accessed services with assistance, 15 percent reported the need for accessible services and 8 percent reported access only with accessible taxis which are costly:

private taxis are far too expensive – even with a voucher

State rail would be much cheaper if I was able to access the discounted fare available to people on a Commonwealth disability pension. As I am a State superannuation pensioner I am not eligible.

Another 8 percent reported the need for more accessible buses like Greg who noted:

access to the community is time restricted due to public transport not being fully accessible i.e. all buses not wheelchair accessible and not all train stations are accessible. He can also access facilities if they are accessible. He feels that all buses could be wheelchair accessible but the one hour between services dictates when he can go out. Making the station accessible would ease that restriction.

When asked about unmet need for services, 14 percent reported a need for increase in the amount of services available, 9 percent reported barriers in accessing services and 6 percent reported a need for affordable services, 3 percent reported a need for a funding package for services. Finally with

regard to facilities 3 percent reported a need to increase access.

HOUSING

According to the 2012 SDAC, 30 percent of people with reported disability are home owners with a mortgage, 25 percent are home owners without a mortgage, 10 percent of people rent their homes from the State or Territory Authority, 21 percent rent from commercial landlords, 4 percent live in boarding homes, 8 percent live rent-free and 2 percent live in other arrangements (ABS, 2012: Table 7).

The findings from the 2014 survey indicate that 78 percent of respondents were satisfied with their accommodation (an increase of 4 percent since 2011). However, 11 percent required home modifications for access:

rooms to small and doors to narrow corridors to narrow

I have less than 1 cm each side of my wheelchair

7 percent required home maintenance and just 3 percent were experiencing financial issues with accommodation, namely, the need to downsize:

(we) are considering down-sizing to make maintenance easier.

the need for financial assistance to access affordable housing:

I can't pay the mortgage on my measly Centrelink allowance. I am in danger of the bank selling the house in the near future. I have no other accommodation option besides homelessness for myself and family that I can see.

and 2 percent of people reported that they had experienced homelessness.

In relation to anticipated need for changes to accommodation in the next 5 years, 42 percent anticipated the need to undertake home modifications for access, 30 percent foresaw the need to downsize, 21 percent predicted the need to modify for mobility, and 7 percent anticipated the need for a single storey home.

ACCESS TO HEALTH AND WELL-BEING

The SDAC examined medical access of people with disability. The data indicate that 93 percent of people with reported disability had seen a general practitioner in the past 12 months, 55 percent had seen a medical specialist, 48 percent saw a dental professional, 48 percent had either visited a hospital department or been admitted and 65 percent had received co-ordinated medical care in the past 12 months.

In the 2014 PDCN survey people were asked about their health and well-being. As in 2011 almost forty percent of people regard their health as stable, 24 percent reported declining health (an increase of 10 percent on 2011), 15 percent reported decreasing mobility, 13 percent reported increasing impairment and 9 percent reported constant pain.

When asked about the next 5 years, 39 percent foresee increasing impairment, 22 percent anticipate declining mobility, 17 percent fear declining health, 11 percent anticipate the need for full time support and 6 percent foresee increasing pain.

People also reported on their health needs. Fifty two percent see their health needs are met (an increase of 3 percent), 15 percent would like increased access to medical generalists and specialists (a decrease of 4 percent since 2011):

Will probably need more access to spinal specialists

8 percent reported a need for access to allied health professionals:

Would like access to other services but care plan only allows 5 visits. Such as OTs - waiting list too long through hospital

6 percent indicated that less pain would improve their lives:

I believe my ideal health could be having a lot less pain.

and 2 percent reported a need for free dental care.

Even though 8 percent reported a need for greater understanding of disability by general practitioners, 4 percent reported good relationships with medical generalists and specialists.

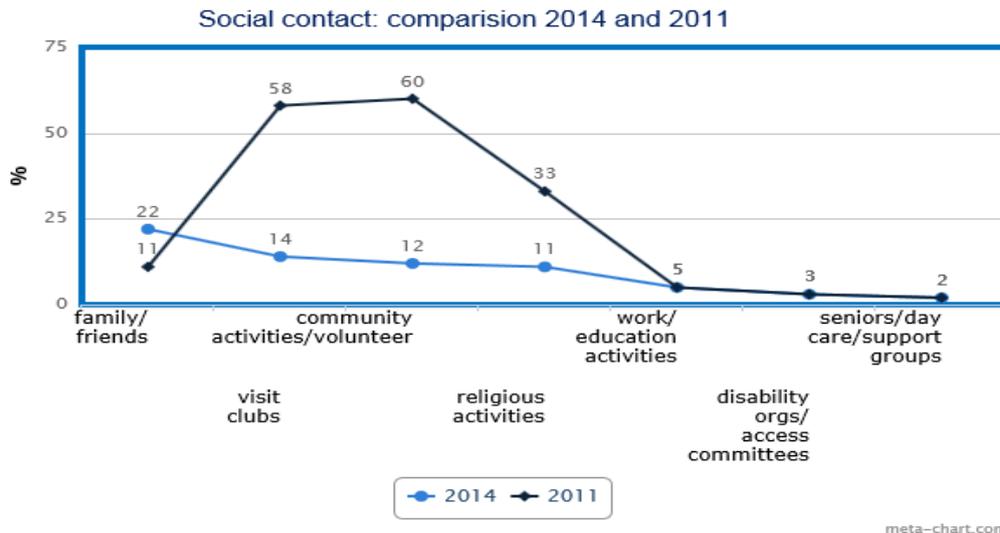
SOCIAL INCLUSION

According to the SDAC, 88 percent of all people with reported disability had contact with friends or family at home with 80 percent reporting visiting family and friends in the past 3 months. Sixty eight percent visited restaurants or clubs, almost a quarter (24 percent) reported social activities with hobby groups, 25 percent were involved in Church activities and 16 percent were volunteers.

Seventy three percent of people with reported disability had visited a public venue in the past 12 months such as galleries, museums, cinemas, theatre etc., 15 percent had visited a botanic, animal or marine park, 48 percent of people had participated in sport or physical exercise and 15 percent had visited sporting events in the past 12 months.

Twenty four percent had active involvement with community groups in the past 12 months and 11 percent participated in civic or governance groups (ABS, 2012). Twenty seven percent would like more sporting activities, 23 percent would like to join hobby groups, 11 percent would like more inclusive community activities, 8 percent would like to join social clubs and 4 percent would like to join disability organisations, educational activities, volunteer work or access social media. It is interesting to note that only 6 percent of people reported a need for social support.

The findings from the 2014 Survey indicate that 22 percent of people had contact with family or friends (an increase of 11 percent since 2011), 14 percent visited clubs (a



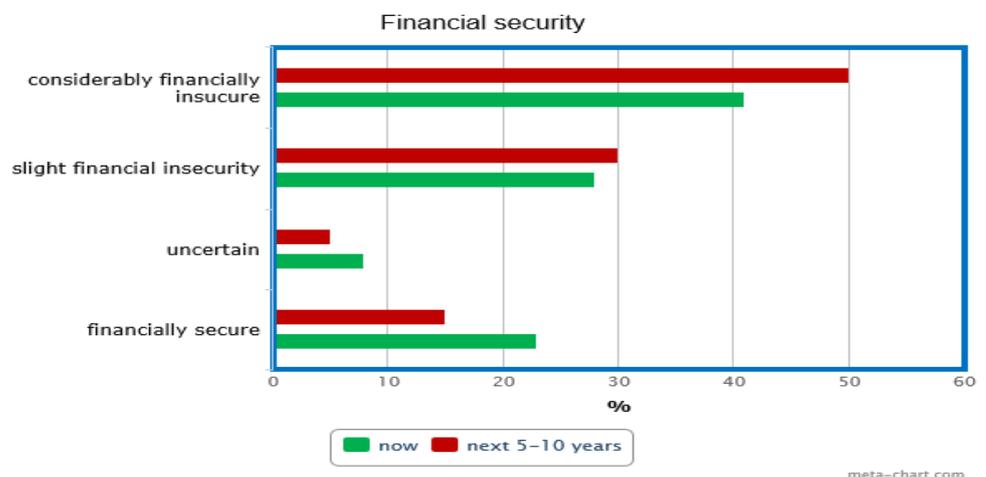
decrease of 44 percent since 2011), 12 percent participated in community activities or volunteer work (compared with 60 percent and 51 percent in 2011), 11 percent were involved in religious activities (a decrease of 12 percent since 2011).

As in 2011, 5 percent had social contact involving work or educational activities, 3 percent were involved in disability organisations or access committees or visited entertainment venues, whereas 2 percent were involved in seniors groups, day care groups or support groups respectively. Eighty one percent of people found these activities satisfying⁶.

FINANCIAL CONCERNS

In relation to financial security, 41 percent of people feel considerably financially insecure, 28 percent feel slight financial insecurity, 8 percent are uncertain and only 23 percent feeling financial secure.

In relation to the future, almost 50 percent feel considerably financially insecure about the next 5 to 10 years (a decrease of 6 percent), however, 30 percent feel slight financial insecurity (an increase of 5 percent since 2011), 5 percent are uncertain and 15 percent are financially secure (an increase of 7 percent since 2011).



⁶ Overlapping categories

In relation to unmet need, 20 percent of people reported experiencing financial difficulties. Some experience difficulties with the cost of living on a pension:

I live on the age pension. That means that there is seldom enough money. I am lucky in that I neither drink alcohol nor smoke, so I do not have those expenses. The pension provides for living on the barest minimum. It isn't much fun, let me tell you.

Some people who worked worried about losing income:

Mother with dementia; lack of finances because husband's pension seriously cut because I work full time.

lack of support once my son marries and worsening of my condition

lack of money if I stop working but also not being able to access services while my husband and I (both disabled continue to work)

For the first time, in the 2014 survey, people were asked about their main source of income. Almost 50 percent received the Disability Support Pension, 27 percent received the Aged Pension, 9 percent received subsidised equipment, 6 percent received subsidised health care and 3 percent received the Attendant Care Package, Carer's Allowance or Community Access.

Sixty five percent of people reported the Australian Government as the financial provider, 21 percent regarded the NSW government as the source of their financial assistance, 6 percent received assistance from friends and family and 2 percent regarded their local health service or their partner/spouse as the source of financial assistance.

When asked about their most significant expenses, as in 2011, over 40 percent reported mortgages/rates/fees, 16 percent reported

utilities (an increase of 5 percent since 2011), 12 percent reported food (a decrease of 13 percent since 2011), 6 percent reported vehicle maintenance or equipment maintenance (a decrease of 20 percent since 2011), 5 percent reported medical expenses, medicine (a decrease of 26 percent since 2011) or home maintenance and 3 percent reported insurance (a decrease of 7 percent since 2011).

People were also asked to specify how they would spend a one-off cash grant. Forty percent of people would spend it on equipment (an increase of 21 percent since 2011), 16 percent would purchase home modifications (13 percent in 2011), 14 percent would purchase housing (an increase of 9 percent since 2011), 10 percent would purchase a vehicle (as in 2011), 6 percent would purchase a gift for their family, 4 percent would buy a holiday or swimming pool/spa and 2 percent would purchase a live-in carer, computer equipment or clothing.

CONCERNS ABOUT THE FUTURE

Respondents were asked about their greatest future concerns.

One person expressed the main concerns.

I'm worried due to employment and age, and I'm worried about cognition or ABI impacting / stopping employment income; I'm worried about losing my home; worried about being a burden on my kids; worried about becoming suicidal due all the problems returning .. worried about losing independence; worried about losing the ability to self-manage/direct.

In particular, twenty three percent of respondents fear declining health, 18 percent



fear financial difficulties or loss of independence, 10 percent fear entry to residential care, 8 percent fear changes to subsidised services, 7 percent fear rises in the

cost of living, 5 percent fear social isolation, 3 percent fear losing their partner/spouse or their current assistance provider and 2 percent fear they will not access affordable accommodation.

DISCUSSION AND CONCLUSIONS

It is apparent from the data from 2011 and 2014 that most people received assistance from family members. In 2014, 20 percent of people received assistance from partners/spouses. These findings are similar to those from the SDAC 2012 survey.

In relation to the type of assistance received, about 8 percent of respondents received assistance with all tasks in 2014, compared with 4 percent in 2011. Eleven percent of people receive personal care. Assistance with household chores and meal preparation accounted for 43 percent of respondents, compared with 23 percent in 2011. Only around 10 percent receive assistance with mobility or transport. However, almost two thirds of respondents in 2014 believed their mobility would decrease in the next 5 years.

These data seem to reflect the importance of mobility assistance indicated in the 2012 SDAC and have implications for government in terms of mobility assistance services and subsidy for equipment.

However, overall there is a decrease of 29 percent since 2011 in the number of people reporting unmet need.

In the 2011 survey the importance of vehicles was reflected in the data which indicated that 95 percent of respondents had access to a vehicle (their own or as a passenger). In 2014, 55 percent of people had access to a vehicle. An increased number of people (51 percent in 2014 compared to 40 percent in 2011) can access public transport. In addition, 37 percent use accessible taxis (when their vehicle is not available) compared with 17 percent in 2011 and a similar proportion (6 percent compared to 7 percent in 2011) use community transport. In addition, the

number of people using a wheelchair increased by 8 percent since 2011.

Clearly, the decrease in the number of people driving or being passengers in a vehicle together with the large increase in the number using taxis and public transport and the moderate increase in wheelchair users have implications for government in terms of availability and cost of accessible public transport and accessible taxis. It also, arguably, reflects an older population which is less inclined to drive.

In relation to drivers with disability, almost two thirds of drivers in the 2014 survey had undertaken hand control modifications (an increase of almost 50 percent since 2011). The proportion of modifications for wheelchair access and storage also increased by 6 percent since 2011 to 24 percent. The proportion of people who intended to undertake vehicle modifications in the next 5 years remained stable in 2014 at around 30 percent. Clearly, people who drive are increasingly modifying their vehicles which arguably reflects the decreasing mobility of people with physical disability. In addition, quite a few people expressed their fear of decreasing mobility which has implications for both increasing the availability of accessible public transport and community transport. This finding is supported by the data which indicate that accessible public transport was used by most people when private vehicles were not available. The large proportion who use accessible taxis has implications in terms of the cost and availability of taxi vouchers.

A T-test was applied to the variables of access to public transport, access to private transport, access to parking and rate of

satisfaction with social participation with a significant result at the 95 percent interval of confidence. This finding indicates the importance of accessible public transport as well as the availability of adequate accessible parking to participation in social activities.

In 2011, 66 percent of respondents could access facilities. In 2014, fifty five percent of respondents require assistance to do so.

As in 2011, respondents in 2014 pointed to the need for more accessible parking spaces, accessible buildings and built environment. People also experienced difficulties with parking due to the misuse of accessible spaces and the volume of traffic at peak times. These findings indicate a need for the planning and regulation of accessible spaces at facilities such as shopping centres, entertainment venues, medical centres etc.

In 2011, 70 percent indicated no difficulty in access to services. In 2014, almost 50 percent of people required assistance to access services and reported barriers to access and affordability of services, as well as the need for increased services. It is apparent that there are implications for government in terms of availability, affordability and support for services provided to people with physical disability.

In 2011 almost three quarters of the sample reported home ownership. In 2014, almost 80 percent of people in the 2014 survey were satisfied with their accommodation. However, there is an expressed need for home modifications for access and mobility in 2014. In addition, the 2014 survey enquired about the experience of homelessness and 2 percent of respondents indicated they had been homeless. In 2011, 25 percent of people had unmet accommodation needs. In 2014 some people expressed the need to downsize and for financial assistance to find accessible housing. These findings are similar to those of 2011 and indicate the need for affordable, accessible housing. In addition, there are

implications for government in terms of subsidised home modification services.

In 2011 and 2014 people were asked about their health and wellbeing. The same proportion of people (40 percent) saw their health as stable but there is an increase of 10 percent since 2011 in the number of people reporting declining health. In addition, people reported decreasing mobility, increasing impairment and constant pain. These issues are reflected in the responses of people about the anticipated changes in the next 5 years. In both 2011 and 2014 about half of all respondents consider that their health needs were met. However, the proportion of people who suggested improvements in access to medical expertise decreased by 4 percent since 2011. Whereas in 2011, people pointed to concerns about medical costs, difficulties in access to doctors, the lack of relationships with doctors and lack of medical expertise on certain conditions, the focus in 2014 was also on the lack of medical expertise about certain conditions but also on increased access to medical expertise and allied health professionals and a need for pain management.

A T-test was applied to the variables of health and well-being and access to services and the community. The result indicated a significant relationship at the 95 percent interval of confidence. This finding reflects the importance of good health to enable people to access, among other things, services and the community.

Thus, it seems that access to general practitioners and specialists has improved since 2011, yet there is still a need for access to allied health professionals. There are also implications for medical generalists in terms of training about certain impairments and conditions.

In 2011 as in 2014, most people reported that their social activities were satisfying. As in 2011, the data indicate that social needs are met through a combination of activities. In

2014, more people (increase of 11 percent since 2011) had contact with family or friend and fewer people (decrease of 44 percent since 2011) visited clubs, participated in community activities, volunteer work (a decrease of 48 percent and 39 percent since 2011), and religious activities (decrease of 12 percent since 2011). The proportion of people who had social contact involving work, educational activities, disability organisations, seniors group, day care or support groups was stable between 2011 and 2014.

It is also interesting to note that around one quarter of respondents would like more sporting activities or to join hobby groups but less than 12 percent of people would like to participate in more community activities, social clubs, disability organisations, educational activities or volunteer work. In addition, only 6 percent of people in 2014 reported a need for social support.

These data seem to indicate that people are less inclined to participate socially outside family and friends and supports the SDAC data which indicates that older people with increased impairment are less likely to seek social participation. A T-test was applied to the variables of type of personal care and social participation. The result was significant at the 95 percent interval of confidence. This reinforces the finding that personal assistance needs are related to social participation and that increased needs lead to less social participation. A second T-test was applied to the variables of access to services and social participation with a significant result at the 95 percent interval of confidence. This finding points to the importance of adequate funding for services for people with disability as service provision impacts on other areas of life such as social participation.

A third T-test was applied to the variables of accommodation needs met and social participation with a significant result at the 95 percent interval of confidence. This finding indicates the importance of accessible

affordable housing to people with disability in terms of enabling them to participate in among other things, social activities.

In relation to financial security the level of financial insecurity and security has decreased across the board. Yet, people are still concerned about financial issues.

In 2011 the focus of concern was the cost of living and the need for financial assistance. In 2014 people are experiencing financial difficulties, some of whom receive a pension. Other people who are employed are concerned about losing income if they need to stop working.

These concerns reflect a continuing concern with the global financial situation and its implications for younger people with disability who work and older people with disability who receive a pension.

For the first time in 2014, people were asked about their main source of income. Half of the people in the survey receive the Disability Support Pension whereas 27 percent receive the Aged Pension. Less than 10 percent receive subsidised equipment, health care, Attendant Care Packages, Carer's Allowance or Community Access. There are implications for government in terms of the dissemination of information about the availability of subsidies and allowances for people with disability.

Most people were aware of the source of their income. Sixty five percent reported the Australian government as the financial providers, 21 percent reported the NSW government and less than 10 percent reported assistance from family, friends, partner/spouse or local health service.

As in 2011, people were asked about their most significant expenses. Most people reported mortgage/rates/fees, and utilities, but there was a decrease in the number of people who reported vehicle or equipment maintenance, medical expenses, food, home maintenance and insurance since 2011).

As in 2011, people were asked about how they would spend a one-off grant. Most people in 2014 as in 2011 would spend it on equipment, home modifications, housing, a vehicle or holiday. Less than 10 percent of people in 2014 would spend it on vehicle or equipment maintenance, medical expenses, home maintenance and insurance reflecting the same priorities as in 2011.

People were also asked about their future concerns and changes that could impact on their lives in the next 5 years,

People generally expressed concern about declining health, financial difficulties or loss of independence and for some entry to residential care. Yet, unlike 2011, some people were very concerned about the financial implications for their services of the NDIS scheme in terms of losing existing services and benefits. Other people fear changes to existing subsidised services as a result of policy changes. Some people expressed financial concerns, others fear social isolation when the partner/spouse or current service provider is not available to help them and some fear that they will not access affordable accessible accommodation or become homeless.

Overall, these concerns are similar to those expressed in 2011. However, there are implications for government in disseminating information about the NDIS and how it will affect existing services and service packages.

In terms of social inclusion, it is apparent that there are still barriers to access for some people with disability in terms of service provision, access to public transport, the built environment, facilities and the community. In addition, some people are still experiencing difficulties in obtaining affordable and accessible housing. Even though most people are satisfied with their social participation, there has been a decrease in the level of social participation as people with disability age. In terms of access to health services, there are still some barriers to certain types of

medical expertise. Even though people are less concerned about their financial security, there are concerns expressed about the prospect of unemployment for those who work and financial difficulties with living costs for those people who receive pensions.

Clearly, even though people with physical disability are expressing an increased sense of social inclusion, for some people financial hardship and the loss of independence through declining health or mobility and increased impairment remain a source of concern.

In conclusion, it is apparent from the data that both people with early-onset disability and older people with disability face barriers to social inclusion. Even though people seem more satisfied with their housing and medical services, some people still face barriers to affordable housing, services and certain medical expertise. Even though people seem less concerned about their financial security in 2014 than in 2011, and are largely satisfied with their social activities, their concerns reflect continuing barriers to certain areas of social and economic life. The nexus between disability and ageing identified in the literature review has implications for governments in terms of increasing the access for people with disability to public transport, the built environment, community, facilities, and for some, housing and health and other supports and services.

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APPENDIX: CASE STUDIES OF PEOPLE WITH PHYSICAL DISABILITY

Meg

Meg is an older person, who receives assistance from her son. Meg is not able to walk long distances or lift and carry heavy items. Her son helps with some heavier tasks around the house.

Meg feels her needs are being met, but expects her needs to change in the next 5 years as she becomes less mobile. She can easily access the community and facilities but finds that parking is difficult due to high traffic levels. Sometimes she is not able to park near her home.

Meg also has access to the services she requires but feels her mobility in 5 years will decline. She owns a vehicle, which has had no modifications and does not anticipate them in the next 5 years.

When her car is unavailable, Meg uses a taxi or bus.

Meg's accommodation needs have not changed over the past 5 years and feels they are being met.

Meg likes to visit with friends and finds that her social needs are met.

She anticipates further changes to her well-being in the next 5 years and has no other unmet need that may impact on her life.

Meg is self-funded and does not receive any financial assistance or support. Her most significant expenses are strata fees and electricity. Her biggest concern about the future is whether her savings will last.

Paul

Paul is an older person with a disability who lives with his wife who assists with all help needed for personal care, but can do most things for himself. He receives no outside assistance at all, except when his wife is away, when he uses Aged Care through the xx Community Church. Paul thinks his needs are increasing and even though he regards his needs as met, he anticipates he will need more personal care within 2 years.

Paul drives his own vehicle but can use the bus and train to travel. His vehicle has been modified to include hand controls, seat dock, auto rear door and ramp. He can access the facilities in his area but is concerned that development in the local area will take away council parking. Paul feels that an accessible bus closer to home would improve his mobility. He is able to access the services he needs but anticipates his mobility will decrease in the next 5 years.

Paul's accommodation needs are met. He has an extensive network of friends and is involved in several Council committees. He is a committee member and trainer at the local senior's computer club and is also a member of a book club.

Paul describes his general health and well-being as good but thinks that he will probably need more access to spinal specialists in the next 5 years.

He receives an Aged Pension, Mobility Allowance and has applied for Enable. Paul's most significant expenses are his wheelchair, vehicle and modifications as well as accommodation when he travels. If given a one-off opportunity he would purchase an electric bed. His greatest concerns about the future centre on the possibility of insufficient personal care to keep him out of a nursing home. He sees himself just getting older and wearing out in the next 5 years.

Greg

Is a younger person with a disability, who does not require assistance with personal care. He does not think his mobility will change in the next 5 years.

Greg drives his own car and has had modification to the tail gate opening for wheelchair access and storage. He anticipates that he will need hand controls in the next 5 years. Occasionally he is a passenger in the cars of friends or family. He finds that parking is fairly easy but at peak hours it is hard to find enough accessible car spaces as people without disability use the accessible spaces. If Greg's car is not available he uses the buses as the local station is not accessible. Greg feels his needs are being met but he expects his needs to change in the next 5 years.

Greg finds that access to the community is time restricted due to public transport not being fully accessible. He feels that all buses should be wheelchair accessible as currently a non-accessible bus can make a 2 hour difference to when he can travel. He also thinks more stations need to be accessible.

Greg is mostly able to gain access to services he needs. He can also access facilities if they are accessible. Greg's accommodation needs have not changed over the past 5 years and are being met.

Greg's social activities involve work and involvement with various Councils and peak bodies in the disability/transport sector. He is satisfied with these activities. He regards his current level of health and well-being much the same as it has been but feels it would improve with better access to the community.

Greg does not receive financial assistance for services or supports. His most significant expenses are the mortgage and his 2 kids. Greg would spend one-off grant on a good wheelchair. Greg's biggest concerns about the future involve the federal and state governments. .

Tim

Has assistance with personal care, housekeeping including meal preparation and shopping, as well as with transport and social support. He feels that currently all his needs are being met. However, he feels that ageing may lead to increasing his needs in the next 5 years.

Tim has difficulty accessing the community, and accesses facilities with the aid of a carer and a wheelchair. Tim drives his own car which has no modifications and he anticipates no modifications in the future. He feels there are not enough disabled or parking spaces.

Tim does not have access to public transport as there is none in his local area. He does not have access to any other form of transport if his car is not available. He would like to see public transport in his area, and he has difficulty sometimes in access to the services he requires. Tim is unsure about whether there will be any decline in his mobility in the next 5 years.

Tim's accommodation needs have not changed in the past 5 years and are met as long as he can continue to live in his own home. He enjoys social outings like lunch/ shopping and finds them satisfying.

Tim describes his current level of health and well-being as satisfactory. He has access to a community nurse if required. He anticipates no changes in the next 5 years. Tim receives the DSP and feels that his most significant expenses are utilities, council rates and car expenses. If given a one-off grant he would purchase a new car.

Tim's greatest concerns about the future involve the NDIS as he currently receives an Attendant Care package and is worried that it might be cancelled or replaced by something which is not suitable for his needs especially as they relate to ageing. He wonders whether he will still receive quality and quantity of disability care after he reaches the age of 65.

IMPLICATIONS FOR POLICY AND PRACTICE

- Increased funding for individual funding packages
- Increased funding for mobility assistance services
- Provision of accessible infrastructure such as accessible buildings, footpaths, curbs.
- Increased number and availability of taxi vouchers
- Increased number of accessible buses, bus stops and train stations
- Increased assistance provided to people with disability using public transport
- Increased number and monitoring of accessible parking spaces
- Planning for and provision of accessible infrastructure at facilities
- Funding for affordable, accessible housing and subsidy for home modification to existing housing
- Dissemination of information about NDIS and impact on existing services