THE PRODUCTIVITY COMMISSION INQUIRY INTO A NATIONAL DISABILITY LONG TERM CARE AND SUPPORT SCHEME

Draft NSW Government submission August 2010

NSW GOVERNMENT

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EXECUTIVE SUMMARY

It is estimated that one in five people in NSW have a disability. In 2006, approximately 1,248,400 people (18.3%) reported having a degree of disability of whom it is estimated that 387,700 people have a severe or profound disability of which half are under the age of 65.

This Submission acknowledges the pressures and demands, and complex funding and service delivery arrangements, across and between the different levels of government that currently characterise specialist disability support services.

Access to services and supports for people with a disability in Australia currently sits within a multi-layered arrangement of specialist disability support and mainstream services, as well as the natural support mechanisms available through carers, families and broader community interactions. This complexity is further compounded by the arrangements or responsibilities between differing levels of government, i.e. the intersection between the Australian Government role in employment and income support and the States and Territory Governments with responsibility for specialist disability services.

Demand for services is projected to reach levels unsustainable within current government resources. The factors driving the demand growth for specialist disability services are:

- increasing numbers of people with a disability
- achievements of the medical, health care and therapeutic communities
- decreasing capacity of families/carers to provide support
- changing community expectations.

Real growth rates of 8–10% a year are projected. Over the medium to long term, existing funding structures cannot meet this cost. An additional revenue source needs to be explored to ensure a sustainable system into the future.

This Submission proposes that a national disability service system funded by a disability insurance scheme (via a Medicare type levy) and administered by a single level of government has the potential to provide long term, sustainable outcomes for people with a disability.

The design of a new national disability service system presents an opportunity to reset and rebalance the contributing components into an integrated system and to remove artificial impediments created by differing layers of government control.

The benefits that could be realised include:

- Meeting the need for support and care for people with a disability

- Equity between all people with an existing disability and those who acquire a disability in the future
- Providing certainty to people with a disability and their carers
- Responding to the future demands on the formal care system with the ageing of the population
- Partnership between funded supports, informal support and community based activity and infrastructure
- System integration of the current disparate elements to eliminate gaps and duplication of services
- Clear accountability and responsibility, and quality services whilst minimising costs of administration and red tape
- Eliminating cost shifting between levels of government.

This Submission highlights that the above benefits can only be realised where there is one level of administration of the system for people with a disability in order that specialist disability services are not further segmented.

The NSW Government has a preference for State based administration within a national framework. This has the benefit of leveraging established administrative systems and infrastructure and experience in direct service provision as well as the intersections with and support from other vital state services especially health and education and reform initiatives already being progressed at a national and State/Territory level.

Also outlined in detail are a number of key proposals required to make up a national disability service system including financing, governance, design, and principles underpinning such a system. In summary the key proposals include:

Financing

1. Institute a well designed social insurance scheme
2. Fund the scheme via a Medicare type levy, as well as incorporating existing funding from all levels of Government (including the Commonwealth Disability Support Pension and Carer Allowance Schemes).

Governance

3. Establish a national disability service system, including all funding, purchasing and policy responsibility, to be undertaken by one level of government
4. Operate a contracted service model with services predominantly provided by the non-government sector within a quality standards framework.

Design

5. Establish broad based coverage in terms of eligibility and services provided
6. Introduce incentives to ensure cost containment

Principles

7. Incorporate key principles such as needs based assessment; person-centred approaches; whole of life early intervention; maintaining the role of mainstream services; supporting families and carers; and cultural inclusiveness.

This Submission sets out the current demographics of the population of people with a disability in NSW, the services and supports currently available as well as current Government commitments to service expansion and development, demand management and national reform directions.

The NSW Government Submission concludes by identifying the economic and social benefits that a national disability service system has the potential to deliver for all Australians living with a disability.

The NSW Government will consider the Draft Report of the Productivity Commission and will provide further comments as appropriate to support the development of a national disability service system and disability insurance scheme, including consideration of demand issues, transitional costs and the contributions of the various levels of government.

A number of government agencies have been involved in the preparation of this submission:

- Department of Premier and Cabinet
- NSW Treasury
- Ageing, Disability and Home Care
- NSW Health
- Lifetime Care and Support Authority
- NSW Trustee and Guardian
- WorkCover NSW
- Department of Education and Training
- Transport NSW
- Department of Justice and Attorney General.

Note for the purpose of this submission names used in case studies are fictitious.

List of Recommendations

Recommendation 1 **55**

The Productivity Commission consider the establishment of a national disability service system based on a social insurance model, financed with a Medicare-like levy together with redirection of existing State, Territory and Australian Government funding.

In developing the model, the Productivity Commission could consider other social insurance schemes within Australia and internationally.

Recommendation 2 **56**

Any Disability Insurance Scheme should be inclusive of existing disability funding from Australian, State and Territory Governments and complement existing compensation schemes where these are not appropriate for inclusion into the national scheme.

Recommendation 3 **61**

A national disability service system to be administered by one level of government.

Recommendation 4 **61**

The Productivity Commission undertake further analysis to identify a governance structure for a national disability service system that maximises direct benefits for people with a disability, provides the framework for effective and efficient administration, and considers issues of current jurisdictional responsibilities.

Recommendation 5 **66**

All people with a disability currently receiving a service or support from a State or Territory or Australian Government funded disability service should be deemed eligible for the new national disability service system.

Recommendation 6 **66**

The Productivity Commission consider the possibility of broad coverage with regard to eligibility and scope of supports available.

A broad based approach does not include financial capacity assessment or means testing at the point of determining eligibility.

Modelling consider the costs and benefits of including all people with a disability who require long term care and support.

Recommendation 7 **66**

The Productivity Commission consider mechanisms to quantify and cost the potential offsets or savings to other systems, such as health, through a broad approach to service provision under a new national disability service system.

Recommendation 8 **72**

Cost modeling of a disability insurance scheme to include consideration of opportunities to maximise private contributions within a universal national disability service system.

Recommendation 9 **73**

In developing a national disability service system, the Productivity Commission consider incentives to ensure cost containment including building system integration, establishing a consumer driven services market, encouraging participation in employment and establishing a system that encourages independence and self reliance.

Recommendation 10 **73**

The Productivity Commission consider inclusion of strategies that build effective partnerships with the non-government service sector, enhance workforce capability and establish integration with aged care service systems.

Recommendation 11 **81**

A national disability service system to be based on the principles of:

- **Needs based assessment**
- **Person centred approaches**
- **Whole of life early intervention and prevention**
- **Sustaining the support of family and carers**
- **Mainstream services and community support**
- **Culturally appropriate services.**

Recommendation 12 **81**

The Productivity Commission explore a comprehensive variety of needs based assessment tools to identify an appropriate mechanism for effective assessment and determination of what level, and how, supports will be provided.

Recommendation 13 **81**

The Productivity Commission, in consultation with Aboriginal people, determine how a national disability service system can best meet the individual needs of Aboriginal people with a disability, at the same time as supporting unique Aboriginal community responses.

Recommendation 14 **83**

The Productivity Commission conduct economic and financial modeling that considers the potential broad economic and social benefits in the assessment of the feasibility of a national disability insurance scheme and a national disability service system.

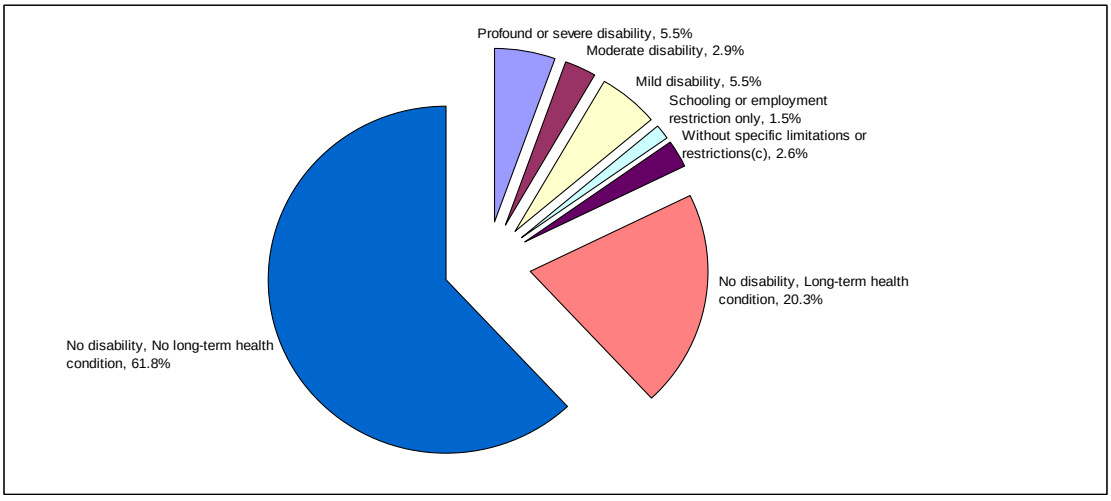
1. DISABILITY IN NSW

It is estimated that one in five people in NSW have a disability. The vast majority of people with a disability live in the community and go about their everyday lives requiring little or no support. In 2006, approximately 1,248,400 people (18.3% of the population) reported having a degree of disability[1].

In addition, approximately one in five people in NSW has a long term health condition which has lasted, or is likely to last, for at least six months but that does not result in an impairment or restriction on the person's everyday life.

Approximately 387,700 people (5.5%) of those with a disability in NSW have a severe or profound disability and about half of these are under the age of 65. While most of the people with a severe or profound disability live independently or with family, some require assistance to participate in education, work and community living.

FIGURE 1: Proportion of the population with a disability or long term health condition



Source: Australian Bureau of Statistics (ABS): *Survey of Disability, Ageing and Carers* 2003

Levels of Disability

People have a disability when they experience a limitation in one or more of the core activities of daily living - communication, mobility and self care. The four levels of limitation are classified as:

- *Profound: the person is unable to do or always needs help with communicating with others, walking or using a mobility aid or self care including personal care and toileting.*
- *Severe: the person sometimes needs help with a core-activity task; has difficulty understanding or being understood by family or friends; or can communicate more easily using sign language or other non-spoken forms of communication.*
- *Moderate: the person needs no help but has difficulty with a core-activity task.*
- *Mild: the person needs no help and has no difficulty with any of the core-activity tasks, but uses aids and equipment; cannot easily walk 200 metres; or cannot walk up and down stairs without a handrail.*

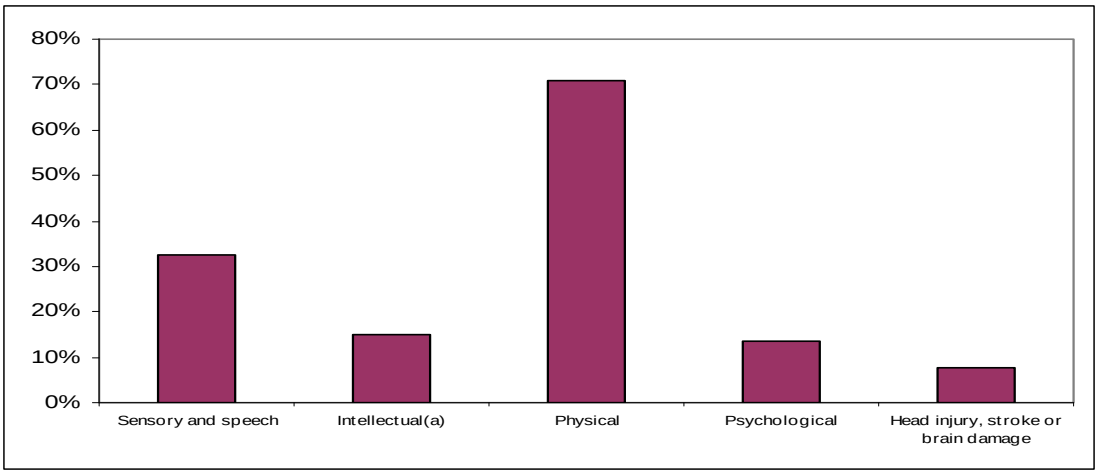
Source: ABS: Survey of Disability, Ageing and Carers (SDAC) 2003.

[1] ABS: *Survey of Disability, Ageing and Carers,* 2003.

Types of disability

The predominant type of disability in NSW is physical (over 70% of all people with a disability). The next largest group is sensory and speech impairment (32%). People with an intellectual disability make up only 15% of those who identify as having a disability. However they are the predominant group requiring support from the specialist disability service system.

FIGURE 2: Proportion of people with a disability by primary disability group

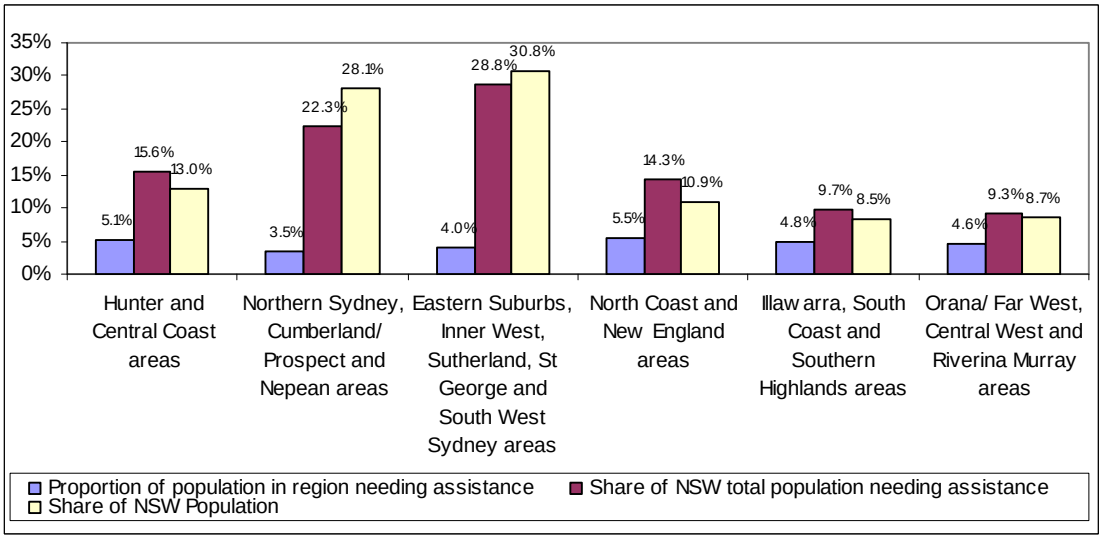


(a) 'Intellectual' may include learning or cognitive disabilities.
(b) Total may be greater than the sum of the components as persons may be counted in more than one disability group.
Source: ABS: *Survey of Ageing Disability and Carers (SDAC)* 2003

Location

The geographic distribution of the population of people with a need for assistance[2] differs to the general population distribution in NSW.

FIGURE 3: Distribution of people with a need for assistance in NSW



Source: ABS: *Census of Population and Housing* 2006

[2] Need for assistance refers to people who need assistance in one or more of the three core activities: mobility, self care and communication because of a long-term health condition, a disability or old age. It is conceptually similar to people with a profound or severe limitation in core activities defined in the ABS: *Survey of Disability, Ageing and Carers*.

Figure 3 shows the two Sydney metropolitan areas have a lower share of the population of people in need of assistance in comparison to their share of the total NSW population. For example, the Northern Sydney area contains 28.1% of the NSW population but only 22.3% of people who require assistance. Overall, the metropolitan areas contain 58.9% of NSW population but only 51.1% of the NSW population of people needing assistance.

In contrast, the other areas have higher proportions of the population of people needing assistance than their total population share. This increase is most significant in the Hunter/Central Coast and North Coast/New England areas[3]. The proportion of people needing assistance in these geographical areas is partially explained by the inclusion within these numbers of people with a disability associated with ageing.

Appendix A contains further detail of the distribution of people with a disability in NSW. The maps, drawn from the ABS Census 2006, show the distribution and proportion of people with a need for assistance in NSW. Need for assistance refers to people who need assistance in one or more of the three core activities: mobility, self care and communication because of a long-term health condition, a disability, or old age[4]. It is conceptually similar to people with a profound or severe limitation in core activities defined in the Survey of Disability, Ageing and Carers.

Labour Force Participation

A report of a national inquiry into employment and disability by the Australian Human Rights Commission found that people with a disability face higher barriers to participation in employment than many other groups in Australian society[5].

In NSW, for people of working age (15-64 yrs), the participation rate of people with a disability (who have a need for assistance) is significantly lower (18%) than for people without a disability (75%). Younger people with a disability (15-44 years) have a relatively higher labour force participation rate of 26% compared with older working age (45 -64) people with a disability (10%)[6].

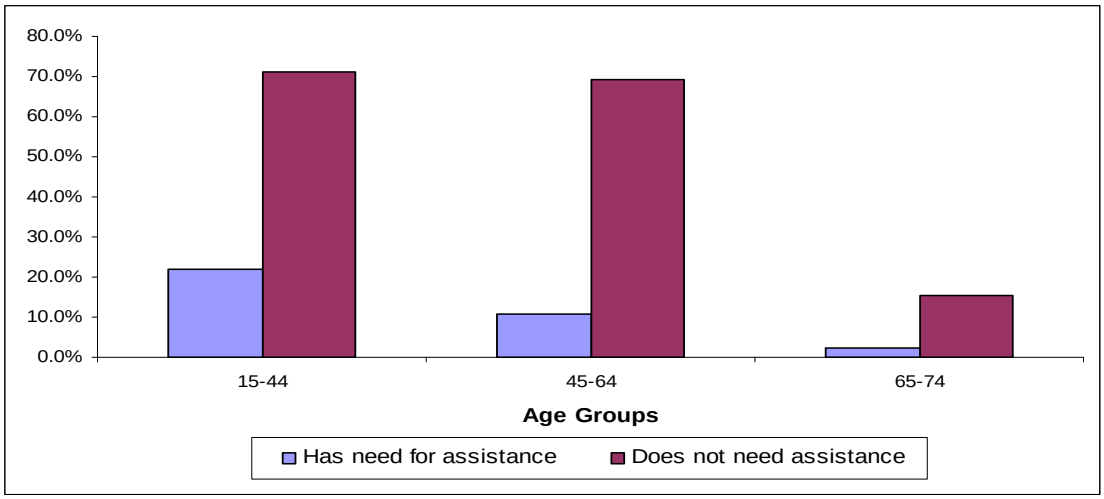
[3] ABS: *Census of Population and Housing 2006.* Note: the Census collected information on people with a need for assistance in core activities such as communication, mobility and self care because of a long-term health condition, disability or old age. While this is conceptually similar to definitions in the ABS SDAC 2003, Census data is an underestimation of disability prevalence due to the collapsed nature of the questions and different collection methodology.

[4] However, due to the collapsed nature of the questions and different collection methodology, the Census underestimated the disability prevalence. The profound/severe disability rate from SDAC is 5.5%, compared to 4.5% of need for assistance rate in Census 2006. ABS recommends its use mainly for comparing people with a disability across different areas.

[5] Australian Human Rights Commission: *People with disability in the open workplace*, 2005

[6] ABS: *Census of Population and Housing,* 2006*.*

FIGURE 4: Labour force participation rate by need for assistance, total population, NSW



Source: ABS: *Census of Population and Housing* 2006

In addition to the individual and family benefits, improved social and personal outcomes for people with a disability, there is a strong economic imperative to maximise workforce participation by all Australians. However, people with a disability who have a need for assistance face a range of barriers to participation in employment.

Corresponding to this, in 2006, the unemployment rates of people with a need for assistance were much higher than for the rest of the population.

People with a disability, when in employment, were more likely to work part time than full time. Only one in three people with a need for assistance worked full time, compared to two in three people without a need for assistance. People needing assistance were more than twice as likely to work less than 15 hours a week as those not needing assistance.[7]

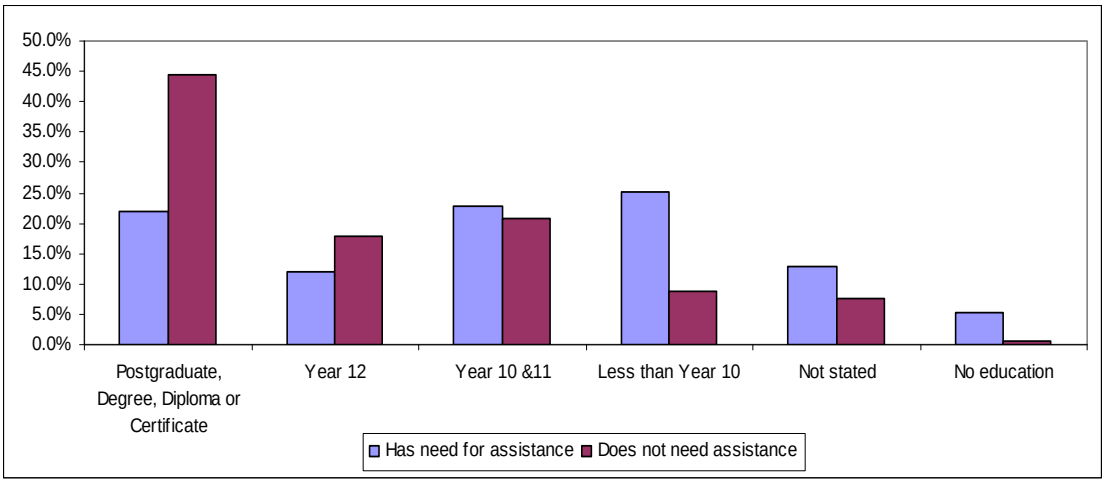
Education

There is an important relationship between educational outcomes for people with a disability and their future economic security and contribution as workers and taxpayers.

As with employment, people with a disability in need of assistance face barriers to educational achievement. The 2006 Census data showed that the likelihood of continuing education after Year 12 for people needing assistance was much lower than for the rest of the population in NSW. Only 21% of people aged 15–64 years with a need for assistance had an educational qualification above Year 12, compared to 45% for those without a need for assistance. People needing assistance were much more likely to have no education (5%) due to their disability, which is significantly higher than for people who did not need assistance (0.8%) (Figure 5).

[7] ABS*: Census of Population and Housing,* 2006*.*

FIGURE 5: Distribution of highest educational level by need for assistance, persons aged 15-64, NSW



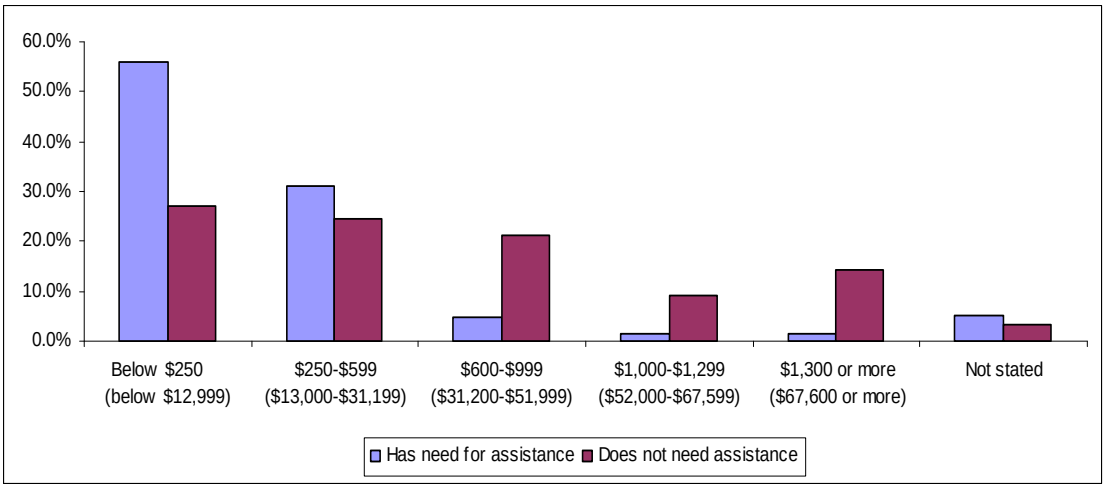
Source: ABS: *Census of Population and Housing* 2006

Income Security

The individual incomes for people with a need for assistance are significantly lower than for the general population. In NSW, in 2006, the median individual income was $238 per week for people needing assistance, compared with $461 for the general population. This income gap was largely a reflection of the lower labour force participation rate, shorter working hours and the lower skills and educational levels of people with a need for assistance.

Over half (56%) of those aged 15-64 with a need for assistance earned less than $250 per week, compared to 27% for people without a need for assistance. At the other end of the income range, only 1.5% of people with a need for assistance received an income of $1300 or more per week, significantly lower than the rest of the population (14%)[8].

FIGURE 6: Distribution of weekly income by need for assistance, persons aged 15-64, NSW



Source: ABS: *Census of Population and Housing* 2006

[8] ABS: *Census of Population and Housing,* 2006

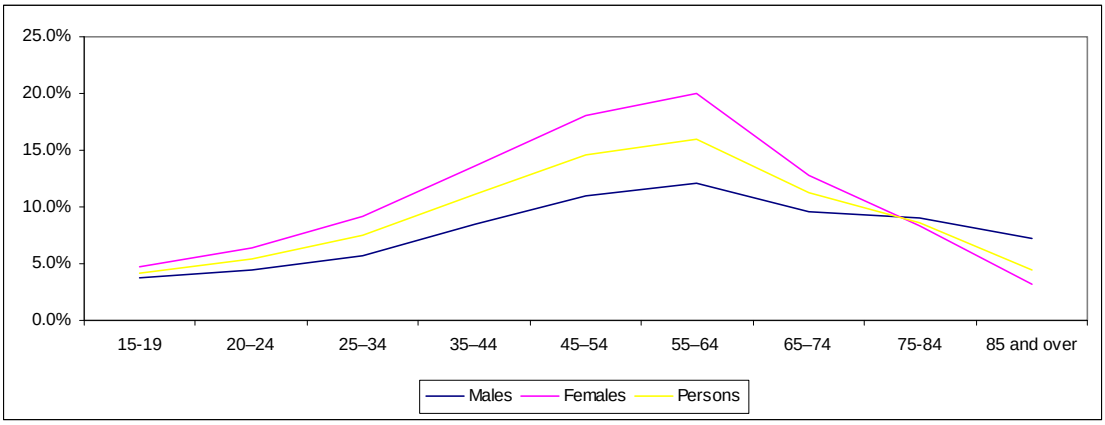
Carers

In 2006, over 540,000 people in NSW were providing informal support to family members (or others) with a disability, a long term illness or related problems. Nearly half of the people who provided assistance in NSW were aged 50 years and over and 62 per cent were female[9].

The 2006 Census data revealed a strong relationship between providing assistance and age. As people age, they are more likely to provide unpaid assistance until they reach 65. After 65 the likelihood of being the primary carer or providing assistance decreases. For both men and women, those in the age group 55-64 had the highest rate of providing assistance (12% for men and 20% for women) (Figure 7).

People aged between 45 and 64 years comprised 31% of the population aged 15 years and over, however, they accounted for nearly half of those who provided assistance (Figure 7).

FIGURE 7: Proportion of people in each age group who provided assistance, NSW



Source: ABS: *Census of Population and Housing* 2006

The geographical distribution of people who provided assistance to people with a disability was more consistent with the distribution of the general population than that of people with a need for assistance. More than 55% of people who provided assistance lived in Sydney metropolitan areas, compared to 59% of the general population and 51% of people with a need for assistance.

[9] ABS: *Census of Population and Housing.* NB. Data only refers to people 15 years and older.

2. LEGISLATION

A range of legislation and legal instruments – at the International, Commonwealth and NSW levels – govern both the operation of the disability service sector and how all people or organisations are required to respond to people with a disability.

The *UN Convention on the Rights of Persons with Disabilities* aims to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms for people with a disability, and to promote respect for their inherent dignity.

The Convention, signed by Australian Government in March 2008, signifies a commitment to eradicate the obstacles faced by people with a disability. The Convention provides details on the explicit rights of people with a disability and a code for implementation.

NSW Legislation

NSW legislation relating to people with a disability and the provision of services to people with a disability includes:

- *Disability Services Act 1993*. This Act provides for the funding and provision of disability services and sets out terms and conditions under which non-government organisations may receive funding.
- *Home Care Service Act 1988*. This Act established the Home Care Service of NSW, and provides the framework for the management and direction of the Service.
- *Youth and Community Services Act 1973*. This Act provides for the licensing of residential centres (licensed boarding houses) for people with a disability.
- *Anti-Discrimination Act 1977*. This Act prohibits discrimination, on grounds including disability, in places of work, the public education system, delivery of goods and services and other services such as banking, health care and property.
- *Guardianship Act 1987.* This Act provides for the guardianship of people with a disability and the establishment of the Guardianship Tribunal and the Public Guardian.
- *NSW Trustee and Guardian Act 2009.* This Act covers financial management for people with a cognitive impairment and is the instrument by which the Mental Health Review Tribunal and Guardianship Tribunal makes its financial management orders.

- *Community Services (Complaints, Reviews and Monitoring) Act 1993*. This Act is administered jointly by the Minister for Community Services, the Minister for Ageing and the Minister for Disability Services. The Act provides for the resolution of complaints about community services and programs.
- *Community Welfare Act 1987*. This Act established the Disability Council of NSW to monitor government policy implementation.
- *Carers (Recognition) Act 2010*. The aim of this Act established a Carers Charter to recognise the role and valuable contribution that carers make to our community.

NSW legislation, policies and programs currently comply with all immediately applicable obligations under the UN Convention and substantially achieve implementation of the progressively realisable obligations under the Convention.

Commonwealth Legislation

Commonwealth legislation relating to people with a disability and the provision of services to people with a disability includes:

- *Disability Services Act 1986.* Provides a comprehensive framework for the funding and provision of support services for people with a disability, including the types of services that can be funded.
- *Disability Discrimination Act 1992.* Provides protection for everyone in Australia against discrimination based on disability. The Act gives the Minister power to formulate standards in relation to any area of discrimination covered under the Act, including education and transport.
- *Social Security Act 1991.* An Act to provide for the payment of certain pensions, benefits and allowances, and for related purposes. The *Act* also refers to the Social Security (Special Disability Trust) legislative instruments. Special Disability Trusts are discussed under “Private Investment” further in this submission.
- *Income Tax Act 1997.* This Act is applicable in relation to direct payments to people with a disability as it may be necessary to obtain rulings from the Australian Tax Office and Centrelink that the payments do not count as personal income for the purposes of income tax or pensions.
- *HACC Act 1985.* The Act relates to funding and provision of home and community care services. The Act provides the framework for a range of support programs to assist frail older people, younger people with disability, and their carers, to enhance their independence in the community and avoid their premature or inappropriate admission to long term residential care.

3. SUPPORTING PEOPLE WITH A DISABILITY IN NSW

In 2006, there were approximately 1,248,400 people in NSW who reported having a degree of disability. Approximately 387,700 of these people reported having a severe or profound disability. The majority live, work and interact as part of their local community, accessing mainstream services and supports, and the informal support networks of their families, carers and friends.

State, Territory and Australian Governments provide services that assist people with a disability to access and remain in their community including:

- Education
- Employment services
- Home and Community Care services
- Health services
- Lifetime Care and Support Scheme
- Workcover
- Housing.
- Residential Aged Care
- Transport
- Criminal Justice system.

The NSW Government also offers a number of concessions to make a range of goods and services more affordable to people with a disability. These services and concessions assist the majority of people with a disability to live full lives within their community.

A small proportion of people with a disability and their families require support provided through the specialist disability service system (as described in Section 4 - Specialist Disability Services in NSW). This group may include:

- People who do not have informal support networks able to meet all their needs
- People with a severe or profound disability
- People with a mild or moderate disability who, due to their specific circumstances or disability, require specialist services
- People where the benefit of a low level early intervention approach may prevent escalation to higher levels of need later in life.

Education

In 2008, over 1.1 million students were enrolled in NSW schools with almost two thirds of these students enrolled in NSW Government schools[10]. These students attended more than 2,100 government, and over 900 non-government, locations throughout the State including pre-schools, primary schools, central schools, high schools, colleges and specialist schools.

[10] Productivity Commission: *Report on Government Services,* 2010.

In 2009, there were more than 32,500 students enrolled in special education services or in special education programs in NSW. This included enrolment in regular classes with additional support, in support classes in a regular school, or in special schools.

More than 76% of students with a disability or additional learning needs are supported in government schools in NSW. In 2009, this included support for over 15,000 students with moderate to severe disabilities in regular classes and over 17,500 students with a disability in over 2,000 support classes in regular and special schools.

Students with a disability in NSW Government schools are supported through a wide range of means. In addition to special classes and schools, this may include, for example, changes to teaching and learning programs and activities, modifications to premises and classroom environments, additional support from specialist teachers and school learning support officers (formerly known as teachers aides), technology support and adaptive equipment and professional learning programs for teachers.

School enrolment and support options for students with a disability in NSW government schools are informed by parent choice as espoused in the Commonwealth *Disability Discrimination Act* (1992) and related Disability Standards for Education (2005).

CASE STUDY[11]

The Therapy Transition to School program is one initiative by the NSW Department of Employment and Training to give younger children with a disability a good start at school.

The program works with families and uses therapy tailored to the needs of the individual child to help them develop skills and independence to a level where they can attend school.

A four year old boy was referred to the program after his family became concerned about his behaviour. Through the program he was diagnosed with autism and moderate intellectual disability. As a result of the support provided to them through the process of diagnosis, information about the impact of the diagnosis on their son, and the assistance given to develop and maintain a structured environment at home, the family and school work together to assist the young boy to develop his skills. He has made a successful transition to a support class in a mainstream school.

In 2009, over 5,600 students with a disability also participated in the TAFE NSW School to Work Program and over 1,000 students with a disability were in TAFE NSW delivered Vocational Education and Training (VET) courses for the Higher School Certificate[12].

[11] NOTE: All case studies are based on real people but use fictitious names.

[12] NSW Department of Education and Training, *Annual Report,* 2009.

In 2008, almost 430,000 students participated in publicly funded VET courses in NSW. These courses were provided throughout NSW by both government training providers such as TAFE NSW and by private Registered Training Organisations receiving government VET funding. Approximately 37,000 of these students (8.7%) identified as having a disability[13]. TAFE NSW provides a range of supports to students with a disability including in-class tutorial support, note-takers and interpreters, exam modifications, adaptive equipment, access and mobility support and special programs and courses[14].

Employment Services

People with a disability at times need assistance/support to secure and retain employment. The Australian Government is responsible for the provision of specialist employment services for people with a disability, funding both open employment and Australian Disability Enterprises. Open employment services assist people to obtain or retain paid employment in the open employment market. Australian Disability Enterprises (ADE) are organisations that employ people with a disability as the predominant workforce within a specific commercial business field of their agency.

In NSW in 2007-08, over 29,000 people with a disability (21.5% of the potential population) accessed Australian Government employment services - 73 % of employment service users received open employment services and 27% received ADE services. The profile of employment service users for NSW was broadly similar to the profile for Victoria, Western Australia, Tasmania and the Australian Capital Territory[15].

Patterns of use of employment services by primary disability group varied between the employment programs. Almost one third (31%) of open employment service users nationally indicated that their primary disability was a psychiatric disability, 27% indicated a physical disability and 16 % reported that their primary disability was an intellectual disability. This contrasts with Australian Disability Enterprises where 70 % of users had an intellectual disability as their primary disability and 19% indicated a psychiatric disability[16].

The NSW Government also funds a Transition to Work Program. The program provides fixed term (up to two years) support to assist school leavers with a disability to develop skills that will help them move into employment, vocational education and training, or higher education.

[13] Productivity Commission: *Report on Government Services,* 2010.

[14] TAFE NSW: *Policies and Procedures,* 2010.

[15] Productivity Commission: *Report on Government Services 2010.*

[16] Australian Institute of Health and Welfare: *Disability Support Services 2007-08.*

CASE STUDY[17]

Nick is a young man who has an intellectual disability. Upon completing Year 12 he entered the Transition to Work (TTW) program to prepare him for future employment.

Nick worked with a TTW provider to decide his future goals and to put in place strategies to reach them. He wanted to work in an office. The TTW provider worked with Nick to ensure the he had the proper training and skills to achieve his goals. Nick also participated in work experience with an employer in his desired field.

The TTW service provider was so impressed with Nick, his eagerness to work and what he brought to their organisation that he is now permanently employed with them. Nick was initially employed for 2-3 hours a day performing general office tasks but has been so happy and successful in his position that he now works full time doing accounts payable data entry.

CRS Australia provides vocational rehabilitation services to people who have had an injury, or developed a health condition, resulting in a disability that affects their capacity for employment. These services provide rehabilitation support to people with a disability receiving income support payments from Centrelink, with assistance to get a job or return to their job.

Home and Community Care Services

The Home and Community Care (HACC) Program is a jointly funded Australian, State and Territory Government Program providing community care services to frail older people, younger people with a disability, and their carers. The Program provides funding for services that support people who live at home and whose capacity for independent living is at risk, or who are at risk of premature or inappropriate admission to long term residential care.

In NSW, the HACC program is administered by Ageing, Disability and Home Care (ADHC). In 2010-11 almost $650 million has been allocated for HACC services in NSW. Basic maintenance and support services provided under the HACC Program aim to assist with 'tasks of daily living' and enhance quality of life. Services include domestic assistance, personal care, social support, meals, and transport.

In 2008-09, over 48,000 people with a disability in NSW under the age of 65 years accessed a range of support services funded under the HACC Program with individual clients receiving over 100,000 separate services. Over 7000 of these clients accessed both a specialist disability service and a service under the HACC Program[18].

[17] NOTE: All case studies are based on real people but use fictitious names.
[18] ADHC: *NSW Disability Services National Minimum Data Set 2008-09.*

Health Services

The NSW Government supports the provision of high quality, consistent and equitable access to health services for all people living in NSW. Currently, almost one-third of the entire NSW State budget is invested into health services. In 2010-11 this represents $16.4 billion.

NSW Health recognises that a range of health services, from access to mainstream through to highly specialised and targeted services, are involved to promote fairness and opportunity for children and people with disability to access the health services they need. Specialist services include areas such as brain injury, mental illness, spinal cord injury and developmental disabilities.

NSW Health services have a strong community health focus with specialist clinical streams such as the state-wide Brain Injury Rehabilitation Program and the state wide Spinal Cord Injury Service. Initiatives such as the NSW Agency for Clinical Innovation (formerly known as the Greater Metropolitan Clinical Taskforce) have established clinical networks that address issues such as transition from paediatric to adult services and equity of access to clinical services across the state.

In addition to the services directly provided through health agencies, NSW Health also funds service provision through the non-government sector such as therapy services, as it is acknowledged that non-government organisations play an important part in delivering services.

Acquired Brain Injury (ABI)

Interventions and support needs for people with ABI vary according to critical transition points when service provision can have a significant positive long-term impact for an individual. Appropriate service provision can ameliorate potential problems that may lead to higher support needs in the future.

The provision of services to people with ABI across government agencies can be complex. Service entry requirements, eligibility criteria and prioritisation of services are different across agencies.

A priority for NSW has been to improve how people with an ABI access and receive services, this includes linking acute, rehabilitation, transitional and home living. An interagency agreement has been developed between NSW Health, Department of Human Services (Ageing, Disability and Home Care & Housing NSW), and the Lifetime Care and Support Authority. The agreement outlines the roles and responsibilities of the key agencies involved in the provision of services, and agencies whose clients are significant potential users of ABI services, particularly at the interface between health and disability services.

Mental Health Services

The level of mental illness and disability in the community is rising across Australia. Reasons for this change are not well understood, but most likely include a mix of broad social changes including a decrease in social supports and social capital, increasing socio-economic inequality, and change in patterns and rates of drug and alcohol use.

Mental illness and disorders are significant causes of disability and disease over the average lifespan. Mental illness and disorders can have a severe impact on a person's life, and on that of their family, reducing their quality of life and their social and economic participation.

NSW Health aims to provide optimal clinical treatment and rehabilitation and support services in order to prevent relapse or the recurrence of symptoms and maintain optimal functioning to promote recovery. Ongoing mental health promotion, reduction of risk factors and the enhancement of protective factors are all relevant. Services aim to assist people with a mental illness to have control and choice over their lives in planning how and where they might live and work.

The NSW Mental Health budget in 2009-10 was $1.171 billion, with more than $1 billion allocated to Area Health Services to provide core mental health services, including family and carer support programs, rehabilitation services, supported accommodation services and partnerships with non-government organisations (NGO).

In addition, funding is also provided to NGO's to provide services or advocate for improved services, and to research institutes and universities to assist in research and services development opportunities.

Refer to Appendices E and F for

- *Information regarding NSW Health initiatives improving access to health services for people with a disability, and*
- *Additional statistical information regarding the incidence of mental health issues in NSW.*

Program of Appliances for Disabled People

People who need aids and equipment in NSW can access them from a variety of methods which include:

- Short term equipment loan pools operated by hospitals or Area Health Services
- Equipment loan pools specific to non-government organisations. An example is the Motor Neurone Disease Equipment Loan Pool, which provides equipment for people whose function is changing and need to access different equipment quickly as their condition deteriorates

- Statewide programs such as the Program of Appliances for Disabled People (for people with a permanent or long term disability) and the Artificial Limb Service.

NSW Health is currently implementing a range of initiatives to improve access to the statewide aids and equipment programs. These initiatives include significant administrative and quality reforms to consolidate a fragmented system of multiple programs operating in different locations, into a single, streamlined service where the provision of aids and equipment, including artificial limbs and home respiratory devices, is coordinated by one entity.

EnableNSW was established in 2007 as part of Health Support Services to reform and administer the NSW Health programs that provide aids and equipment (assistive technology) to people with a disability living in NSW. These programs provide assistive equipment in the areas of mobility, self care, communication and respiratory support. The programs are:

- Program of Appliances for Disabled People (PADP)
- Prosthetic Limb Services (formerly the Artificial Limb Service)
- Home Respiratory Program (consisting of the Home Oxygen Service and the Adult & Children's Home Ventilation Programs).

These programs have a total budget of more than $54 million in 2010-11 and will provide assistance to approximately 20,000 people.

Significant improvements are being achieved through quality improvement initiatives and business reforms to the programs and EnableNSW is continuing to work towards a single integrated statewide service that provides consistent, fair and timely access to services.

NSW Health has also established a statewide Specialised Equipment Essential for Discharge Program which provides timely access to essential equipment for eligible people who have sustained a newly acquired catastrophic spinal or brain injury so that they can be discharged from hospital. This program has a similar target group as the NSW Lifetime Care and Support Scheme (see below) and the two agencies have collaborated to develop common equipment prescription processes.

Lifetime Care and Support Scheme

The Lifetime Care and Support Scheme provides treatment, rehabilitation and care services to people with brain injuries, spinal cord injuries, amputations, burns and blindness resulting from motor accidents. It is funded through a levy on motorists through the compulsory third party (CTP) insurance. The levy is calculated to meet the lifetime costs of each participant entering the Scheme in that year.

Approximately 150 people enter the Scheme each year as an "interim" participant. After two years each participant is then assessed to determine if they continue to meet the eligibility criteria for lifetime participation. Approximately 120 participants have become lifetime participants in the Scheme since its inception in 2006.

As at 25 January 2010, there were 339 participants in the Lifetime Care and Support Scheme. The overall participant group included 298 adults and 41 children less than 16 years of age. Of the 339 participants in the Scheme, 266 had sustained a traumatic brain injury (78%) and 69 had sustained a spinal cord injury (20%). Some participants had sustained both a brain injury and a spinal cord injury. There were also 3 participants with multiple amputations and 1 participant with burns. Of the 339 participants, 236 were male (almost 70%) and 103 were female.[19]

WorkCover

WorkCover NSW works with NSW employers, workers and the community to continually improve workplace safety, return to work outcomes and security for injured workers. WorkCover NSW provides workers compensation and occupational health and safety services to assist employers meet their workplace safety and workers compensation obligations.

All employers in NSW are required to have a workers compensation policy to cover their employees in the event of a work related injury. Some employers are licensed by WorkCover NSW to self-insure if they are able to meet relevant occupational health and safety, injury management and financial standards.

Where a worker suffers a workplace injury the NSW workers' compensation system focuses on rehabilitating and returning the worker to suitable, safe and durable employment at the earliest possible time. I n the event of a workplace injury, an injured worker has a statutory entitlement to weekly payments, medical and related treatment costs, lump sum compensation for permanent impairment and the costs of rehabilitation to return to work where required.

Where a worker suffers a disability as a result of the workplace injury the benefits available under the Scheme may extend to home and vehicle modifications, appliances and aids and workplace modifications to accommodate the disability and facilitate return to work. Vocational retraining, on-the-job training and placement in employment which take account of the disability are also available.

[19] Lifetime Care and Support Authority: *E-news – 16 February 2010* - accessed 20 July 2010 at http://www.lifetimecare.nsw.gov.au//ENews.aspx

With the exception of weekly benefits, all worker entitlements are paid for life or until the workplace injury is fully resolved, thereby reducing the impact on public disability and health care funding. Weekly benefits cease one year after the worker reaches retirement age.

Thirty claimants in the WorkCover Scheme who were injured in motor vehicle accidents associated with their employment have been accepted for interim care for a period of two years with the Lifetime Care and Support Scheme. WorkCover NSW and the Lifetime Care and Support Authority have developed a memorandum of understanding to ensure coordinated management of "shared" claims and clear communication between all parties.

After the two year interim acceptance, workers will be assessed for ongoing Lifetime Care. If ineligible, responsibility for ongoing management of all aspects of the claim will return to the workers compensation insurer.

The benefits available to workers who sustain a severe injury that results in permanent impairment and disability are equivalent to those available to participants in the Lifetime Care and Support Scheme.

Housing

Affordable housing and housing security through ownership or through tenure, if renting, is important for all people.

However, home ownership in NSW for people under 65 years is lower for those people with a disability (57%) compared with those people without a disability (69%)[20]. This is similar to the national pattern and reflects the lower rate of employment and lower income levels of people with a disability.

In NSW, in 2006, 13.5 % of the population of people with a disability rented from State housing authorities, housing cooperatives, community or church groups compared with only 4.1% of the general population[21].

An important correlate of lower level of home ownership and lower income is the difficulty people with a disability have in making modifications to their housing to improve their access, functioning and independence.

Housing NSW provides housing assistance for people with a disability through a number of initiatives such as the Housing NSW Special Assistance Subsidy Program. This provides rental assistance that subsidises the rent of eligible clients with a mental or physical disability, helping them to rent in the private market.

[20] ABS: *Census of Population and Housing 2006.*

[21] ABS: *Census of Population and Housing 2006.*

In 2008-09, 1133 households were assisted under this program at a cost of $7.65 million. Housing NSW also has an ongoing program of modifications to existing and new state owned dwellings to house people with mobility related disabilities. Modifications include hand-rails and ramps for physical access and minor alterations to kitchens and doorways. In 2008-09, $5.16 million was spent on disability modifications in 1910 public housing dwellings[22].

Housing and Accommodation Support

People with a range of levels of psychiatric disability are also supported through the Housing and Accommodation Support Initiative (HASI) - an innovative partnership program between Housing NSW, NSW Health and the non-government sector which provides housing linked to clinical and psychological rehabilitation services. This program demonstrates the benefits and importance of coordinated care.

HASI provides stable and secure accommodation linked to services (accommodation support, clinical care and rehabilitation) to assist people with significant functional impairment as a result of a mental illness or disorder.

HASI recognises the interdependence of stable housing, accommodation support services and clinical mental health services. The specific aims of the Program are to:

- Provide people with ongoing clinical mental health services and rehabilitation within a recovery framework
- Assist people to participate in community life and to improve their quality of life
- Assist people to access and maintain stable and secure housing
- Establish, maintain and strengthen housing and support partnerships in the community.

HASI demonstrates the benefits of a partnership approach in facilitating improved outcomes and community participation for people with a mental illness. The joint aims of all partners of HASI include:

- Providing more efficient and effective co-ordination of care for consumers
- Exploring and enhancing the interface between specialist mental health services (both acute & rehabilitative), General Practitioners and the non-government sector in NSW
- Enabling and facilitating stable housing outcomes for all HASI consumers
- Facilitation of consumer, family and carer participation.

[22] Housing NSW, *Annual Report,* 2008-09

HASI is based on working holistically and tailors services to the needs of the individual. The development and ongoing review of an individual care plan is central to ensuring that people receive the services that best meet their needs as these change over time. HASI support ranges from very high (up to 8 hours per day, 7 days per week) to low (up to 5 hours per week).

There are currently 1096 funded HASI packages across NSW with an annual budget of approximately $35 million. NSW Health estimates that the HASI program currently meets approximately 50% of demand for this type of service.

CASE STUDY[23]

After being in and out of institutions for long periods for the past 17 years, Joan, a middle-aged woman, has finally regained her independence through HASI.

Joan was unable to live in supported accommodation previously because of mental health problems. Her lack of living skills and history of aggression meant Joan could not access community services such as Home Care. Over the last six months, a HASI service provider has spent time with Joan helping her in developing social skills and, according to her key worker, Joan is now 'more independent'.

'Joan has begun a one-on-one TAFE course on computers and reconnected with her family after seven years of separation. At Easter, Joan caught an interstate bus to visit family and now speaks with them once a week. The six months she has remained in her home is the longest period of time she has had out of hospital for many years.' (Accommodation Support Key Worker)

The Disability Housing and Accommodation Support Initiative (DHASI) is a similar joint initiative with Ageing Disability and Home Care (ADHC) for people with a disability with complex housing needs. DHASI aims to assist people with a disability to access social housing and yet live relatively independently with the support required to maintain their tenancy and well being. DHASI provides affordable rental housing with drop-in support. There are currently 50 people being supported under this initiative.

Residential Aged Care

In June 2010, there were over 2300 people with a disability under 65 years of age living in residential aged care facilities in NSW. Of these people, 304 were under the age of 50 years[24].

[23] NOTE: All case studies are based on real people but use fictitious names.

[24] Australian Government Department of Health and Ageing – *Data Cube - June 2010*

The Younger People in Residential Aged Care Program is a national program (administered by ADHC in NSW) that aims to assist people with a disability aged under 65 years (initially targeting those under 50 years) to live in the community or in their own home. The Program objectives are to:

- Assist younger people with a disability move out of residential aged care facilities
- Divert entry for younger people at risk of inappropriately entering a residential aged care facility
- Enhance delivery of disability services to younger people with a disability who continue living in a residential aged care facility

As well as Residential Aged Care, a number of people with a disability are also supported by community based aged care services. In June 2008, 600 people, in NSW, aged under 65 years were receiving Community Aged Care Packages (CACP), Extended Aged Care at Home (EACH) Packages or EACH Dementia packages[25].

Transport

Access to transport is vital for people with a disability, their families and carers to enable full participation in community life. The NSW Government is continually improving the accessibility of public infrastructure, transport services and information. The NSW Government is working to improve access for people with a disability through wheelchair accessible taxis, rail and buses.

People with a disability, because of mobility issues and lack of transport options, use taxis more than the population as a whole. There are 775 wheelchair accessible taxis in NSW, which is 11.6% of the fleet, and an increase of 64.2% since July 2005. The average pick up time for wheelchair accessible taxis in Sydney has also improved by 37.9% since 2004.

The NSW Government has an ongoing commitment to making trains accessible to people with a disability. As at August 2010, 121 City Rail Stations were accessible and all new rail carriages offer enhanced facilities including wheelchair spaces, priority seats for less mobile passengers, colour-contrasted doors and handrails, and audio and visual destination information.

As a result of initiatives to improve access to public buses for people with a disability 55.1% of buses in the Sydney Metropolitan area and 31.2% of buses in the Outer Metropolitan area are wheelchair accessible. These buses have stepless low level floors for easy boarding, large brightly coloured handrails, wide doors /aisles and allocated space/seat for the less mobile passengers.

[25] AIHW: *Residential Aged Care in Australia 2007-08*, *Aged Care Packages in the Community 2007-08*

The entire Sydney Ferries fleet is wheelchair accessible, as are 23 wheelchair accessible ferry wharves in Sydney Harbour (pending tidal and safety conditions).

Transport for Health is a program provided by NSW Health to assist people living in the community to travel to and from non-emergency health-related services. Transport for Health includes:

- Community transport
- Inter-facility transport
- Isolated Patients Travel and Accommodation Assistance Scheme (IPTAAS) subsidy scheme
- Statewide Infant Screening-Hearing (SWISH) travel reimbursement scheme.

Criminal Justice System

There are a significantly higher percentage of people with an intellectual disability in the prison population than there is in the general community. There are also significant numbers of people in the criminal justice system with mental health disorders, physical disabilities and sensory impairments. In 2008-09 1,265 offenders were referred for a disability assessment[26.]

Recent studies focusing on young people in NSW indicate that approximately 13% of those in custody[27] and 11% on community orders[28] could have an intellectual disability. This is much higher than the percentage of people with an intellectual disability in the general population.

A range of services are provided to assist people with a disability in contact with the criminal justice system in NSW.

Corrective Services NSW provides:

- A specialist State-wide Disability Services (SDS) Unit provides a number of services to meet the additional support needs of offenders with disability under its management in both custody and in the community. This includes specialist disability advice and consultation to staff and external stakeholders and state-wide training of staff. SDS undertakes identification and assessment of offenders, sourcing and provision of equipment for offenders with physical or sensory disabilities, and the development of policies, procedural guidelines and directives to facilitate the integrated delivery of services and programs as well as preparation of referrals to ADHC and other agencies.

[26] Corrective Services NSW, *Annual Report 2008-09*, page 30

[27] NSW Department of Juvenile Justice, *NSW Young People in Custody Health Survey: Key Findings Report* 2003

[28] Kenny, D.T., Nelson, P., Butler, T., Lennings, C., Allerton, M., and Champion, U. *NSW Young People on Community Orders Health Survey 2003-2006: Key Findings Report.* The University of Sydney, 2006

- Corrective Services NSW also operates Additional Support Units which house offenders who, because of their disability, require placement outside the mainstream correctional system.
- A Community Restorative Centre (CRC) provides transition and family support services to parolees with a mental health issue or intellectual disability for the first six months after release. In this time a case plan is set up to assist the client access mainstream services.

Through NSW Juvenile Justice, work is underway with the Intellectual Disability Rights Service to improve support to young people and victims of crime who have an intellectual disability. This will focus on inter-agency promotion, education and training.

Justice Health operates the *Statewide Community and Court Liaison Service* within 21 of the 148 active local courts across NSW, targeting defendants with mental health difficulties and provides mental health assessments and reports to inform decisions by magistrates relating to defendants with mental health problems. The *Adolescent Court and Community Team* operates in five out of the seven children's courts in NSW and targets young people appearing before the court.

The NSW State Debt Recovery Office has conducted a two-year *Work and Development Orders* pilot scheme which provided eligible people, including those with intellectual disabilities, cognitive impairment or mental illness, with the opportunity to carry out identified activities (such as health/mental health/drug and alcohol treatment; education and life skills courses) in lieu of paying fines owed to the State Debt Recovery Office.

Private Investment

In addition to services and supports provided by governments, there is a vast array of privately operated services that individuals may access independently and purchased through private financial capacity. These services provide a complement to government facilitated services and support. Additionally government may further foster opportunities for private investment or co-contributions to care and support responses. A number of initiatives across Australia provide opportunities for private investment aimed to assist people with a disability to live independently in their own homes and communities.

Special Disability Trusts were introduced by the Australian Government in 2006 as part of a package of measures to assist families wishing to make private financial provision for the current and future care and accommodation requirements of a family member with a severe disability. The NSW Government, in June 2010, passed measures which included the exemption of Special Disability Trusts from duty payable on the establishment of a trust and on transfer of property to these trusts. It is anticipated that these measures will remove an impediment to the establishment of Special Disability Trusts by the families and carers of people with a disability in NSW.

4. SPECIALIST DISABILITY SERVICES IN NSW

While the majority of people with a disability lead full lives independently in the community or with the support of mainstream community services, a proportion of people with a disability and their families require formal specialised assistance.

The objective of the specialist disability services system in NSW is to enable people with a disability to live at home and participate fully in the community with minimal formal supports. Where this is not possible, the priority is to support people with a disability in a way that is not overly restrictive or intrusive, enables community engagement, meets contemporary standards and is sustainable in the longer term.

NSW Government Funded Services

In 2008-09, the NSW Government spent over $1.38 billion to support more than 50,000 individuals through the specialist disability service system. People with a disability were supported through a range of services including:

- Community living/accommodation support: in-home support; group homes; large residences and attendant care.

  These programs support people with a disability to live in the community or in their own home and can range from minimal drop in support and assistance with tasks such as personal care or domestic assistance to intensive support delivering 24 hour care.
- Respite: flexible respite and centre based respite.

  These services provide planned short-term and time-limited breaks for families and other unpaid care givers of children and adults with a disability in order to support and maintain the primary care-giving relationship. Support aims to provide a positive experience for the person with a disability, including the opportunity to mix with other people.
- Community support: early intervention and prevention; intensive family support and therapy.

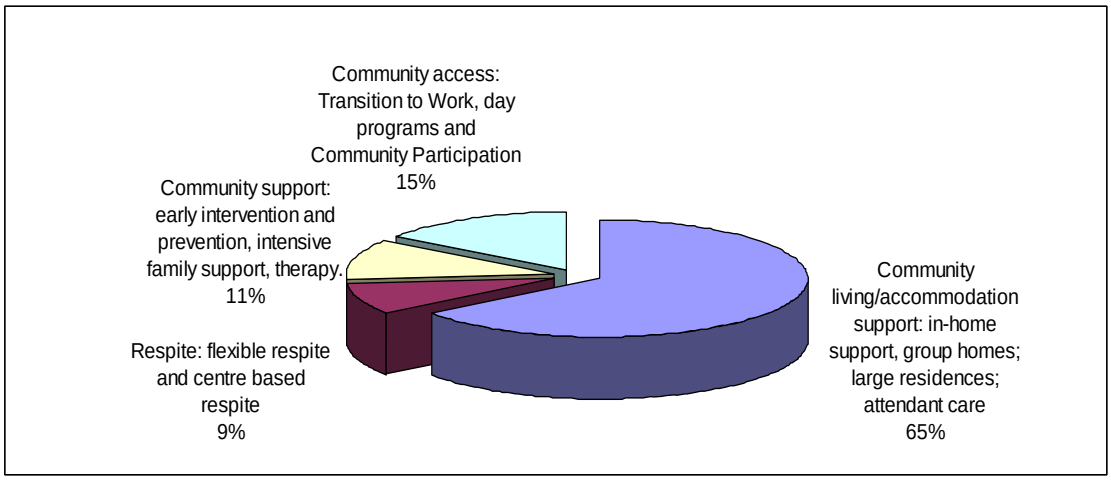
  A range of supports and activities provided to increase the individual strengths and skills of a person with a disability. These services also promote resilience and access to mainstream services to ensure disability has the least possible impact on the individual's capacity to live a normal life and participate in community life.
- Community access: Transition to Work; Community Participation and day programs.

  These programs aim to assist people with a disability to develop the skills they need to work towards their goals, increase their independence and participate as valued and active members in the community. This includes programs to access and participate in the community including support to improve employment outcomes.

A full list of the disability service types funded in NSW is at Appendix C.

Over half of all disability funds (65%) invested by the NSW Government were allocated to Community Living/Accommodation Support, particularly to Group Homes, however this investment only supported just under 16% of all NSW service users (Figures 8 and 9).

FIGURE 8: Proportion of funding invested by service type – 2008-09

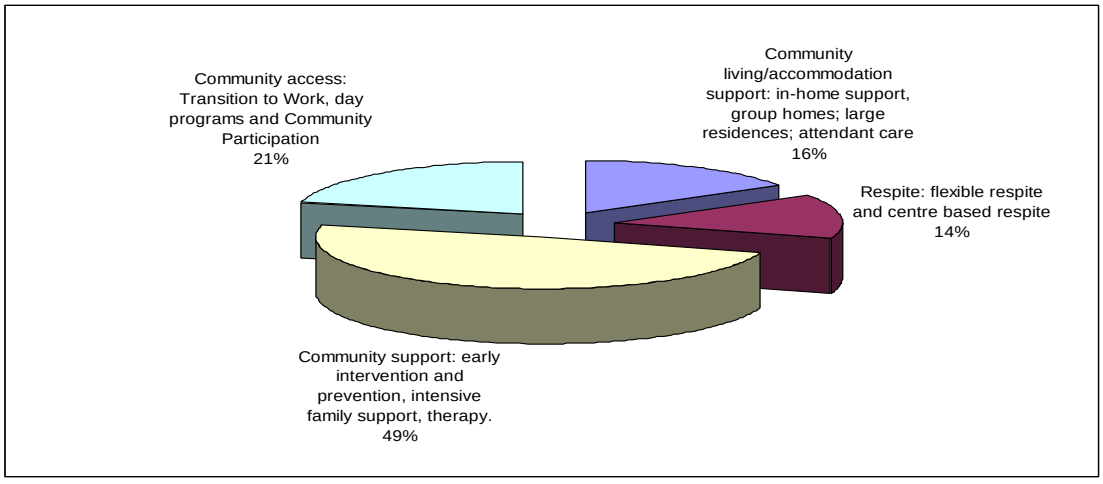


Source: ADHC: *ADHC Annual Report 2008-09*

Community Access services, which include the Transition to Work and Community Participation programs, received 15% of all funding and this funding supported approximately 21% of service users.

Almost 50% of service users accessing specialist disability services in NSW accessed community support services – early intervention and prevention, intensive family support and therapy services. Approximately 14% of service users accessed respite services.

FIGURE 9: Service Users by service type in NSW – 2008-09



Source: ADHC: *ADHC Annual Report 2008-09*

The NSW Government also provides a number of targeted services for particular population groups:

- The Boarding House Reform Program (BHRP) was established to improve the standard of accommodation and support to residents of Licensed Residential Centres (LRC). The key services provided to people under BHRP include personal care, community integration activities comprising skills development, social and recreational activities, primary and secondary health care and escorted medical and dental transport.
- The Criminal Justice Program was established to provide accommodation and support services for people with intellectual disability exiting the criminal justice system.
- Younger People with a disability in Residential Aged Care Program aims to assist people with a disability aged under 65 years (initially targeting those under 50 years) to live in the community or in their own home.

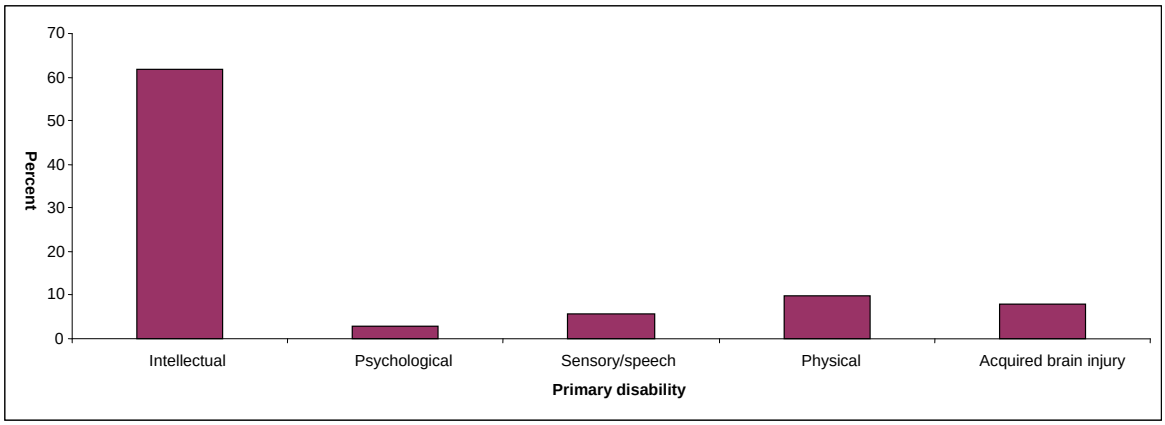
Service Users

Although the predominant type of disability in NSW is a physical disability (Figure 2), the formal service system is primarily accessed by people with an intellectual disability (Figure 10). People with a physical disability make up only 10% of those accessing formal specialist disability support services.

This can be explained by the effect of the different disability type on a person's functioning capacity and on the level of need for ongoing specialist support services.

The majority of people with a physical disability require only adaptive equipment and low level support services.

FIGURE 10: People accessing formal specialist disability services by primary disability type, 2008-09



Source: NSW ADHC – *NMDS – NSW 2008-09*

Service Providers

In NSW services are delivered both directly by ADHC and through funding to local government, community not-for-profit organisations, and private for-profit organisations. ADHC funds over 450 non-government organisations (NGO) to provide services to people with a disability.

A snap shot (based on disability funds in 2009-10) of the financial investment by ADHC in the NGO sector according to the amount of disability funding allocated to the provider organisation is outlined in the table below.

Table 1: NSW funded specialist disability services 2009-10

Level of Funding	No. of Providers	%	Total Funds (million)	% of Total Funds
>$5 million	46	10%	$536.8	61%
$0.5 – $5 million	188	41%	$303.1	34%
<$0.5 million	222	49%	$42.3	5%
Total	**456**	**100%**	**$882.2**	**100%**

This table shows that 10% of funded NGO (46 providers) each receive over $5 million per annum. This group receives 61% of the disability funding allocated by ADHC to NGOs. By contrast, 49% of NGO (222 providers) receive only 5% of the total allocated funding.

The providers with higher levels of funding are likely to deliver services across most service types and across a number of regions. The smaller providers tend to deliver services of only one type and, usually, to a more localised community level only.

Stronger Together

In 2006, in response to increasing demand on, and community expectations of, the disability service system, the NSW Government launched *Stronger Together: A new direction for disability services in NSW 2006-2016.*

This 10 year plan responded to the need for an alternative approach and action in a number of areas:

- The demand for services is increasing each year. It was recognised that more services had be provided but also in ways that provided services more efficiently.
- Services needed to be designed around the individual, their family and circumstances instead of a ‘one size fits all’ approach.
- The service system had to become more flexible and responsive to people’s changing needs as they move through their life stages. It also needed to become more transparent.

- A greater range of accommodation options were required to recognise people's life stages and the possibility that they might have differing accommodation needs over the course of their lives.
- There was need for innovation and continuous improvement in the way people with a disability are supported in the community.

The NSW Government invested $1.3 billion in *Stronger Together* for the first five years of the Plan. This has seen significant resources directed towards the 'front end' of the services system to support families and carers, with a focus on preventing or delaying the entry of people with a disability to high-cost specialist accommodation solutions.

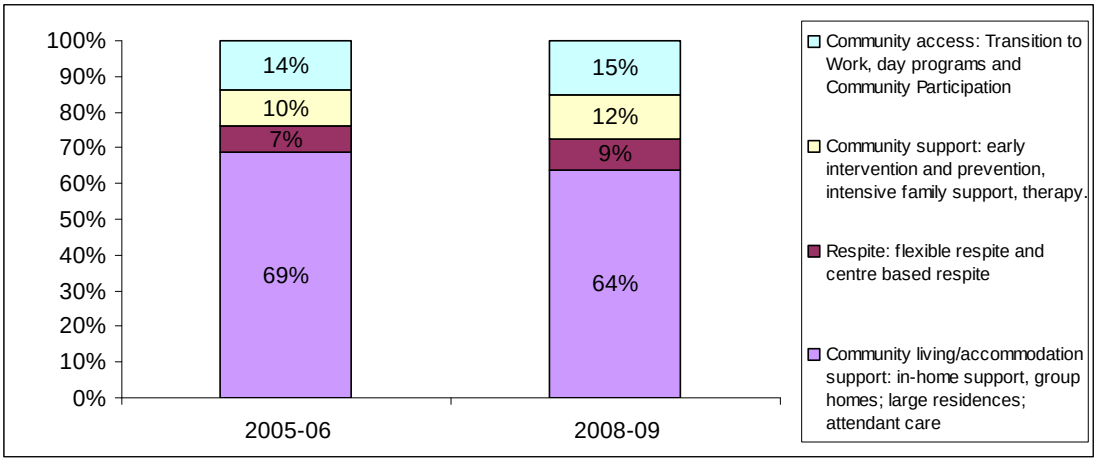
As a result of these interventions, the disability services system in NSW is less dependent on reactive, high-cost models of support.

The achievements have been significant. During the first four years of *Stronger Together* over 20,000 additional people have received support such as early intervention and family support, therapy, day programs and respite.

The real and tangible benefits of *Stronger Together* are being realised in the experiences of people with a disability and their families. For instance, more people with a disability are entering employment and further education. To date, the investment has enabled the Government to shift the service system approach to reach a greater proportion of the target population with planned and sustainable solutions and to begin to address the substantial backlog of unmet need.

Figure 11 compares the mix of disability services funded in NSW in 2005-06 and 2008-09. I t shows that a much greater proportion of NSW investment in disability services is being used to support people in the community in equitable and sustainable ways.

FIGURE 11: Comparison of NSW disability service investment; 2005-06 and 2008-09



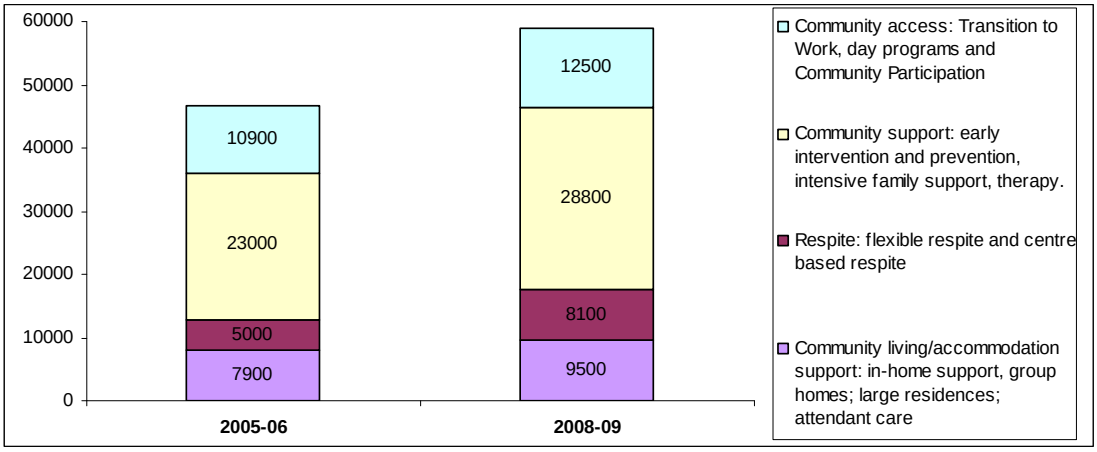
Source: ADHC: *ADHC Annual Report 2005-06, ADHC Annual Report 2008-09*

In 2008-09, 36% of the NSW specialist disability services budget was invested in community based support, compared with 31% in 2005-06.

A corresponding decrease (from 69% to 64%) occurred in the proportion of investment for higher cost solutions such as supported accommodation.

Figure 12 compares the number of people accessing different service types in 2005-06 and 2008-09. It shows that the total number of service users has increased for all service types, particularly for community support and respite services where the number of service users increased by 25% and 62% respectively.

FIGURE 12: Comparison of service users accessing NSW disability services; 2005-06 and 2008-09



Source: ADHC: *ADHC Annual Report 2005-06, ADHC Annual Report 2008-09*

NOTE: Clients may use multiple services and may, therefore, be counted more than once in the above figure.

Stronger Together has brought about significant new capacity and introduced reforms that broadened support options for people with a disability and their families and carers and expanded the range of flexible support models to target support to different stages of a person's life. It has worked in three main areas: strengthening families; community inclusion and improving the system's capacity and accountability.

Achievements under *Stronger Together* include:

- Community inclusion
  - People's life skills and participation in the community maximised
  - More people with a disability enabled to access employment or further education.

- Strengthening families
  - Families struggling and at risk of breaking down receive tailored, short-term one-on-one support
  - Families have improved access to respite due to increasing capacity across a range of services resulting in a reduced number of blocked respite beds

  - Aboriginal families in New England and Mid North Coast can now access specialist services designed to meet their cultural needs.

- Accommodation and alternative support
  - A wider range of accommodation options available
  - Better options for young people in, or at risk of entry to, residential aged care
  - Additional intensive in-home support packages through the Attendant Care Program
  - Assistance for people with a disability to avoid homelessness.

Between 2005-06 and 2009-10, the number of disability service places increased by over 29,000[29]. The focus of these additional places occurred at the lower cost early intervention and prevention services designed to support people to develop skills and resources to fulfil their individual potential. This investment reduced the system's reliance in high cost accommodation responses.

Stronger Together has assisted NSW to begin to address changes in demographics and other demand drivers which impact on the sustainability of the disability service system.

Further discussion of the demand drivers and the pressures being exerted on the service system are examined in the following section.

[29] Some clients are accessing a number of services and therefore a number of service places.

5. DEMAND DRIVERS

Actuarial work completed on the demand and supply of specialist disability services in NSW predicts that demand for disability services is growing at the rate of approximately 8-10% per year.

The actuarial work has shown that although the reforms put in place by the NSW Government from 2006 under *Stronger Together* have made a significant difference in refocussing the service system towards early intervention and prevention, these changes cannot fully alleviate demand. Long-term growth in the demand for specialist disability services in NSW is estimated at levels not sustainable within current financial investment.

Demographic changes are putting increasing pressure on the disability service system. These changes reflect the increasing number of people with a disability, decreasing availability of informal carers and an ageing population. The service system is finding it increasingly difficult to meet the needs of people with a disability, their families and carers.

In a recent speech to the Sydney Institute, the Parliamentary Secretary for Disabilities and Children's Services, the Hon Bill Shorten MP, noted that there are about 1.5 million Australians with a severe or profound impairment, half of whom are less than 65 years.[30] The Australian Institute of Health and Welfare estimates there will be 2.3 million people with a disability by 2030. It was noted that the disability system is reliant upon the unpaid work of primary carers.

Many of the carers are ageing and increasingly unable to shoulder the burden of caring for their adult children with a disability. Mr Shorten indicated that the cost of supporting people with a disability is predicted to increase by 66% over the next ten years – to $10 billion a year in current dollar terms (the Australian and State and Territory governments currently spend $6 billion on care and support for people with a disability under 65 years). This amount is only for support services - governments actually spend around $23 billion a year on the total disability welfare system.

This is unsustainable growth that cannot be addressed simply by increased funding. It needs a new approach.

Alternative revenue sources need to be considered to address disability budget pressures and effectively meet the needs of people with a disability in NSW. Without a long-term commitment to build a funding base that can match the diverse and growing needs of people with a disability, there is a significant risk that the service system in NSW will become increasingly less effective in meeting the needs of people with a disability, their families and carers.

[30] The Hon Bill Shorten MP, Parliamentary Secretary for Disabilities and Children's Services, *Speech at the Sydney Institute*, July 2010

The consequence of not addressing enduring shortfalls in the system coupled with the growing need for services has the potential to compromise outcomes for people with a disability, their families and carers, not to mention substantially increase costs to Governments in the longer term.

The factors driving the demand growth for specialist disability services are:

- There are increasing numbers of people with a disability due to population growth
- People who are born with, or acquire, a disability are living longer and healthier lives as a result of the achievements of the medical, health care and therapeutic communities
- The capacity of families/carers to provide support is decreasing due to carers ageing, smaller family sizes and increasing workforce participation[31]
- Community expectations regarding the type and amount of services received have changed; people with a disability, families and carers are seeking a range of choices to meet their support needs.

These demand drivers also result in growth in the demand for services for people with a disability in other government or service sectors.

An example is in the education sector where there has been a 76% increase in NSW Government expenditure for school students with a disability or special needs in the last seven years. Reasons include:

- Changed expectations about education for students with a disability
- Increased awareness and/or diagnosis of certain conditions that impact on education
- Increased incidence of certain conditions such as autism, mental health disorders and foetal alcohol syndrome disorders[32].

Population Growth

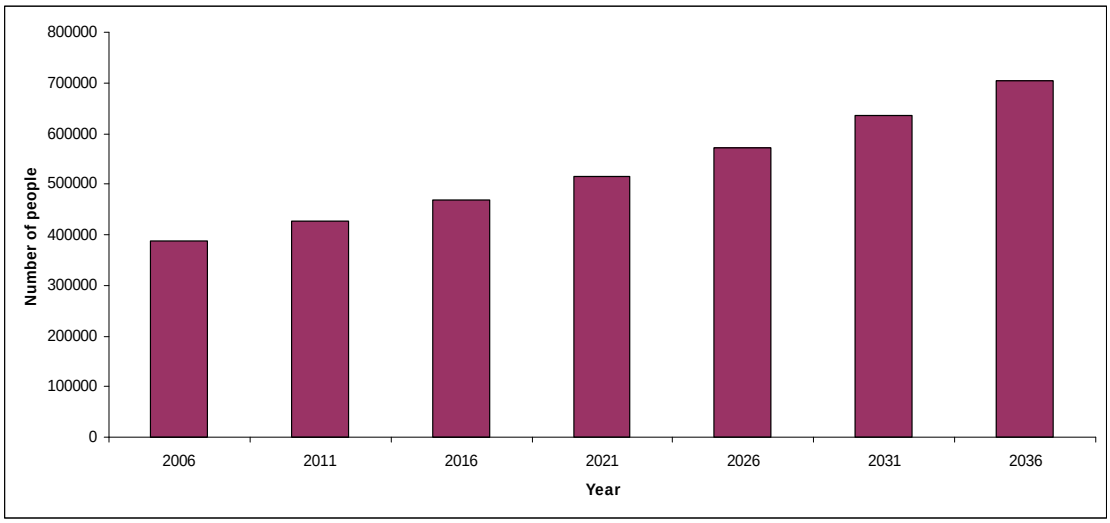
Overall, there is projected to be a 1.9% per annum average increase in people with severe/profound core activity limitations over the period 2011-2016. This percentage growth is in line with the pattern of general population growth.

It is anticipated that the number of people in NSW with severe/profound core activity limitations will increase from approximately 388,000 in 2006 to over 460,000 in 2016 to as much as 700,000 by 2036 (Figure 13).

[31] Disability Investment Group, *The Way Forward: A New Disability Policy Framework for Australia,* 2009

[32] NSW Parliament Legislative Council General Purpose Standing Committee no. 2; *The provision of education to students with a disability or special needs,* Report 34, July 2010

FIGURE 13: Projected prevalence of people in NSW with severe/profound core activity limitation 2006-2036



Source: ABS: *SDAC 2003: Summary of Findings – State Table for NSW*; NSW Department of Planning: *Population Projections – 2006 - 2036*

Informal Support

Informal support – through families, friends and carers - provides nearly seventy five percent of the assistance required by Australians due to disability or illness. Every year informal carers provide over 1.2 billion hours of support[33]. Sustaining the informal care system can be significant in effectively managing the disability services system budget.

Actuarial studies found that the percentage of total care and support estimated to have been met through informal care decreased from 2004-05 to 2008-09.

However, whilst less of the total proportion of care was provided by the informal sector, there was still an increase in the overall number of informal care hours provided. This trend, can be attributed to a combination of population growth and ageing, and reinforces the importance of strategies to support sustainability of the informal care sector.

There is strong evidence that the availability of informal care will continue to decline. Long-term trends in carer capacity modelled by NATSEM[34] signal a decrease in carer capacity over time, mainly due to the ageing of the carer population and other demographic factors such as the tendency towards smaller families and increased female workforce participation.

[33] Access Economics, *The Economic Value of Informal Care*, 2005

[34] Percival R & Kelly S, *Who's going to care? Informal care and an ageing population,* NATSEM, University of Canberra, 2004

Carers also have poorer health compared to the rest of community, significantly higher levels of depression and pain, and are twice as likely to experience difficulty in paying utility bills and providing ongoing care.[35]

The economic and social benefits gained by sustaining long-term care arrangements in the community are dependent upon the community's ability to support carers' wellbeing.

The projected decrease in informal care levels will have a gearing impact on the related rise in need for formal care. Actuarial analysis found that a reduction in levels of informal care would necessitate a significantly higher percentage increase in formal care services to achieve the same overall level of support. The analysis determined that a 1% decrease in informal care will result in up to a 4.5% aggregate increase in the demand for formal service provision.

Recent supply modelling indicates that the carer ratio is likely to fall by approximately 1.6% per annum from 2006 to 2036 – this would result in a 7.2% p.a. increase in the demand for formal service provision.

A further issue is that significant numbers of people with a disability who have an ageing parent carer have missed out on the benefits of appropriate prevention and early intervention supports therefore enter the service system requiring higher levels of support.

Non-traditional client groups

Historically access to specialist disability services has been targeted to people with an intellectual disability. This meant that people with other types of disability who need high levels of physical and/or cognitive support options were limited to supports available through the mainstream health systems and Residential Aged Care Facilities. As a consequence, these clients often ceased to participate in age appropriate activities of their choice, lost contact with friends and family and had a reduced quality of life. Others had fractured relationships with family and friends, or family and friends also developed health and stress problems such that they were no longer able to provide care as before.

Stronger Together included a focus on developing new approaches or expanding models of care that support people to live in their communities either alone, with family or friends, or in some cases, in group settings. This included strategic priorities to expand options for people with a disability who have traditionally had difficulty accessing services provided or funded by ADHC.

[35] Ranmuthugala, Binod, Brown & Percival*, "Impact of home based long term care on informal carers",* Australian Family Physician, Vol 38, No. 8, August 2009, pages 618-620.

Typically, these are people with adult-onset disabilities such as cognitive impairment arising from Acquired Brain Injury and/or severe Physical Disability arising from neurological degenerative conditions such as Motor Neurone Disease, Multiple Sclerosis, Muscular Dystrophy and Huntington's Disease.

In addition, as more people are now cared for in their own homes for longer periods and are returned home sooner following an acute hospital stay, disability support needs more often intersect with complex health and personal care. People who have quadriplegia and are ventilator dependent require a joint service response from NSW Health and ADHC.

The intersection and provision of appropriate models of support for people requiring ongoing or episodic health or clinical type supports, as well as assistance with accessing the community and tasks of daily living, remains difficult. These client groups and their families are often more vocal in seeking supports and articulating expectations that include improvements in health management and other support strategies that better meet the lifestyle choices, opportunities for employment or other meaningful engagement in community life.

Aids and Equipment

A further demand driver is access to appliances, aids and equipment which enable people with a disability to engage and participate within the community. Equipment is a key aspect of people's environment, and one which can significantly facilitate functioning. In 2003, a total of 1,886,200 people nationally (48% of people with a disability) used assistive equipment.

For people aged under 65 years with a disability, the most commonly used equipment was 'medical aids' (used by 611,000 people or 24% of people with a disability in this age group) and mobile or cordless phones (222,800 or 8.7%). Equipment of all kinds was likely to be used by people with profound activity limitations, especially equipment associated with the core activities—self-care, mobility and communication[36].

Recent reviews of the programs that provide assistive technology in NSW revealed the need for reforms to ensure that there was equitable and timely access to assistive technology.

EnableNSW was established by NSW Health to implement the supported recommendations to reform a fragmented system of multiple programs operating in different locations, into a single, streamlined service, where the provision of assistive technology, including prosthetic limbs and home respiratory services, is coordinated by one entity (i.e. EnableNSW).

[36] AIHW: *Disability and Disability Services in Australia* 2006

The end result of this consolidation will be a single point of entry for all the NSW Health disability support programs. While these reforms are not yet complete, the NSW Government has demonstrated its commitment to improve access by increasing the budget for the aids and equipment program (Program of Appliances for Disabled People) by an extra $9 million in the last two years bringing the total annual recurrent budget for this program to $35.3 million.

CASE STUDY[37]

The Specialised Equipment Essential for Discharge (SEED) Program is administered by EnableNSW. The program provides timely access to essential equipment needed to facilitate discharge from hospital for eligible people with a newly sustained spinal cord, or acquired brain injury.

Peter is a 45 year old man who sustained a C5 spinal cord injury following a fall from his pushbike. He was admitted to a specialist spinal injury unit for rehabilitation but was keen to get home as quickly as possible so that he could resume his roles of being a husband and a father to his nine year old daughter and twelve year old son.

In order to be able to go home, Peter needed a power wheelchair, pressure care cushion, hoist and sling, an adjustable bed with bed scanner, a pressure care mattress and a customised shower commode. The total cost of this equipment was $54,000.

Peter's equipment was approved and ordered through the SEED Program which meant that his discharge from hospital was not delayed due to the availability of equipment.

The issue of demand and drivers for change is not limited to NSW. The Australian Institute of Health and Welfare, in 2006, found that equipment services in Australia were provided by a mosaic of services, generally through the health or veterans systems or the non-government sector and that no national data on these various programs was being compiled[38]. More consistent access to aids and equipment is a reform priority under the National Disability Agreement.

[37] NOTE: All case studies are based on real people but use fictitious names.

[38] AIHW: *Disability and Disability Services in Australia,* 2006 – p35

6. NATIONAL CONTEXT

From a national perspective, the disability service system is characterised by complex and duplicated administration, accountability and reporting requirements and policy and governance systems. This is despite considerable and costly activities at the national and jurisdictional level aimed at delivering consistency of service outcomes across jurisdictions including numerous agreements or arrangements to address specific issues, such as cross border service delivery.

The current disability service system – with responsibilities spread across the nine Australian, State and Territory Governments - has resulted in divergent and inconsistent policies, eligibility criteria and inequity in access for people with a disability to the supports that they need.

The system is fragmented within and across jurisdictions, at both State and Territory and Australian Government levels resulting in a multilayered service system that people with a disability and their carers find difficult to navigate. An example of this fragmentation is the duplication and confusion that currently occurs in the provision of continence aids.

CONTINENCE AIDS IN NSW

People in NSW who require continence aids can currently access assistance through two separate schemes:

- The Australian Government's Continence Aids Payment Scheme (CAPS) - previously the Continence Aids Assistance Scheme
- The NSW Government's Program of Appliances for Disabled People (PADP)

Some of the issues faced by people requiring this service include:

- Separate application forms for these schemes – a person wanting to access both services has to fill in different application forms
- Different views between programs of whether incontinence is a health condition or a disability
- Different eligibility criteria
- Different methods of delivery assistance - under CAPS, an eligible person is paid a subsidy directly into their nominated financial institution and then needs to source products themselves. Under PADP, a person is provided with products (supply limits apply), delivered to their home and based on what products are recommended by an eligible prescriber.

The duplication under the current system results in unnecessary paperwork and confusion with the person with a disability not always getting the products they want when they need them.

A further example of the multilayered nature of the current service system can be seen in the case study below.

CASE STUDY[39]

Geoff is in his early thirties and has Down Syndrome. He lives with his ageing parents and currently accesses a range of services funded by both the Australian and NSW Governments.

Geoff works three days per week at an Australian Government funded supported employment service. On the other two week days he attends a community access service and one Saturday each month participates in activities arranged by the local recreation service. Both these services are funded through the NSW Government.

Geoff and his family receive respite services funded by the NSW Government. He is also involved with the local (Australian Government funded) disability advocacy service.

To receive these services, Geoff had to complete separate application processes for each of the Australian and the NSW Government services and undergo multiple assessments to determine his eligibility and support needs.

The multi layered nature of the disability service system means that much work on policies and procedures, and reporting and accountability systems is duplicated. Total expenditure on administration by all jurisdictions in 2008-09 was over $390 million or 7.4% of total expenditure on services for people with a disability[40].

Jurisdictions' best efforts and intentions in undertaking reform work will not completely overcome this fragmentation and lack of consistency or reduce the expenditure on administration. National reform requires the consensus of all jurisdictions on the changes to be implemented. This consensus is often hard to attain as the negotiating position of jurisdictions reflects individual service or administrative structures and political realities. Often the result is a compromise or agreement to a minimum national position.

Reform work is currently occurring through the National Disability Agreement. Reform activities also include the development of:

- The National Disability Strategy
- Other cross border agreements
- A Portability Protocol to facilitate the movement of people with a disability between jurisdictions.

[39] NOTE: All case studies are based on real people but use fictitious names.

[40] Productivity Commission: *Report on Government Services, 2010*

National Disability Agreement

The National Disability Agreement (NDA), which commenced on 1 January 2009, replaced the previous Commonwealth State/Territory Disability Agreement. It also encompassed several bilateral agreements previously held with the Australian Government, including the Younger People in Residential Aged Care Program. The NDA was developed as part of the significant reform work under the Intergovernmental Agreement on Federal Financial Relations (IGA)[41]. The IGA was negotiated to provide a robust foundation for collaboration on policy development and service delivery across governments.

A key objective of the NDA is to progress reforms which place people with a disability, their families and carers at the centre of services across the country. All aspects of the NDA contribute to, or measure progress towards:

> *"People with a disability and their carers have an enhanced quality of life and participate as valued members of the community."*

The NDA commits all governments to work towards new, mutually agreed objectives which have a focus on achieving the following outcomes:

- Improving economic participation and social inclusion
- Enabling choice, wellbeing and independence
- Improving support for carers and families.

The NDA established reform directions which enhance the social and economic participation for people with a disability and which support their families and carers. This includes a commitment to achieving this through reform initiatives in ten priority areas as well as other areas of service delivery and accountability. A full list of the reform priorities is included at Appendix B**.**

The process for delivery of this reform agenda has required considerable administrative and financial investment by all jurisdictions and the slow pace of reform achieved to date reflects the complexity of multiple disability service systems with different historical, policy and service perspectives. The number of reform priorities and the interdependencies between these priorities has added additional complexity with multi layered negotiations required to map and advance any form of consensus agreement for achievement of reform.

This was recently demonstrated in national work to progress harmonisation of the rules for accessible parking. Agreement was reached on the format of a new Australian Disability Parking Permit, but agreement was only reached on national minimum standards for concessions and national minimum eligibility criteria. The result is greater harmonisation of parking rules but not national consistency. People with a disability when travelling interstate will continue to need to check what parking concessions are operating at their destination.

[41] http://www.coag.gov.au/

National Disability Strategy

The NDA recognises that improved outcomes for people with a disability, their families and carers are also contingent upon effective coordination of efforts across all areas of government. The NDA commits jurisdictions to the development of a National Disability Strategy (NDS) to complement the reform work undertaken by the specialist disability service systems.

It is proposed that the NDS will provide an overarching national policy approach to achieving and assessing progress towards improved outcomes for people with a disability in mainstream areas such as employment, income, education, health, transport, justice and infrastructure. The NDS will provide direction at a national level and will deliver a whole-of-government, whole-of-life approach to outcomes for people with a disability. The Strategy is also an important mechanism to ensure that the principles underpinning the *United Nations Convention on the Rights of Persons with Disabilities* are incorporated into policies and programs that have implications for people with a disability, their families and carers.

It is anticipated that the NDS will be finalised in the first quarter of 2010-11 and will establish a 10 year plan for improving participation of people with a disability in all areas of life.

It is proposed that the NDS will include six policy areas:

- Inclusive and accessible communities: physical environment including public transport, parks, buildings and housing, digital information and communications technologies, civic life including social, sporting, recreational and cultural life
- Rights protection, justice and legislation: statutory protections such as anti-discrimination measures, complaints mechanisms, advocacy, the electoral and justice systems
- Economic security: jobs, business opportunities, financial independence, adequate income support for those not able to work, and housing
- Personal and community support: inclusion and participation in the community, person-centred care and support provided by specialist disability services and mainstream services, informal care and support
- Learning and skills: early childhood education and care, schools, further education, vocational education, transitions from education to employment, life-long learning
- Health and wellbeing: health services, health promotion and the interaction between health and disability systems, wellbeing and enjoyment of life.

The Australian, State and Territory governments have developed the Strategy in partnership and with assistance from the Australian Local Government Association. The intended purpose of the National Disability Strategy is to:

- Establish a high level policy framework to give coherence to, and guide government activity across mainstream and disability-specific areas of public policy
- Drive improved performance of mainstream services in delivering outcomes for people with a disability
- Give visibility to disability issues and ensure they are included in the development and implementation of all public policy that impacts on people with a disability
- Provide national leadership toward greater inclusion of people with a disability.

The emphasis on mainstream services and public policy continues the growing recognition that people with a disability should be able to access mainstream services in their community and that these services should cater for all people in their community. This connection with mainstream services is further explored in this submission as one of the principles which should underpin the national disability service system.

Cross-Border Agreements

Memorandum of Understanding (MOU) between Victoria and NSW

The aim of the MOU is to assist ADHC and the Victorian Department of Human Services to engage in a collaborative approach to the delivery of specialist disability services in cross-border regions of NSW and Victoria:

- To establish arrangements for the better coordination of service delivery of cross-border specialist disability services
- To enable eligible individuals living in cross-border community to access specialist disability services funded by the State other than their State of residence, where it is considered appropriate to do so
- To establish an ongoing forum in which cross-border issues can be discussed and resolved
- To facilitate a better understanding of each department's policies and services as it affects day to day regional business.

The Tri-State Agreement

The Western Australia, South Australia and the Northern Territory Governments in 2004 formed the Tri-State Disability Services Group to develop a framework agreement to ensure a coordinated approach to providing disability services to the Ngaanyatjarra, Pitjantjatjara and Yankunytjatjara lands covering 350,000km^2 across the three jurisdictions. The framework agreement has guided the operations of the three jurisdictions in delivering services to the people of the region over the past five years.

The Interstate Portability Protocol

In 2000, the Disability Services Ministers endorsed a national policy framework regarding the interstate transfer of people with a disability. This framework or Protocol establishes a mechanism to assist people with a disability transferring between jurisdictions to negotiate programs and services to achieve a comparable level of support. Work is currently underway to improve the implementation of the Protocol across jurisdictions.

7. THE CASE FOR A NATIONAL DISABILITY SERVICE SYSTEM

The NSW Government strongly supports the investigation of fair, equitable and sustainable options for a national approach to operating and financing services for people with a disability.

The Inquiry is an important milestone in the development of a consistent national approach to disability services. It is an opportunity to introduce a system that will provide the best possible outcomes for those members of the community who have a disability, and for their families and their carers. There is a need to move away from the current fragmented, inconsistent system. Access to the supports that a person needs to participate in their community should not be dependent on where the person lives.

The current disability service system is becoming unsustainable and, for many people with a disability, will not deliver the supports they need in the way that they want those supports delivered. Government provision of specialist disability services is currently funded by general revenue and there are a number of disadvantages to this approach, including a lack of transparency and accountability, limited incentives to address long term issues relating to cost and sustainability, and difficulty in addressing increasing demand.

Whilst the initial impetus for the Productivity Commission Inquiry may have been economic concerns (at both a service system and individual/family level) there is also a clear need for systemic change in the way that the service system is administered, accessed and delivered, as well as financed.

As is identified in the Disability Investment Group report[42], the current disability system is not working effectively. There is a need to stop the "blame game" and for governments to work together to deliver a national system that is sustainable, cost effective for all who need it, and that provides the services and supports that people with a disability and their carers want, in the way they want them delivered. The Inquiry comes on the back of a ground swell of support for changing how our society treats people with a disability and how disability services are financed and delivered.

The Disability Investment Group further notes that "Australia has a robust social security system which entitles all citizens to health services and income support based on individual needs and circumstances. However, while Australians with disability are entitled to these universal services, there is no equivalent entitlement to disability care and support services. The Australian system of formal support is failing many people with disabilities, their families and carers"[43].

[42] Disability Investment Group, *The Way Forward: A New Disability Policy Framework for Australia,* 2009

[43] Disability Investment Group, *The Way Forward: A New Disability Policy Framework for Australia,* 2009, p2

The NSW Government proposes the establishment of a national disability service system. The design of a new national disability service system presents an opportunity to reset and rebalance the contributing components into an integrated system and to remove artificial impediments created by differing layers of government control.

SUSTAINABLE OUTCOMES

A national disability service system has the potential to establish a long term sustainable system and deliver substantial outcomes to assist people with a disability. A national system would:

- Recognise the need for care and support for people with a disability
- Achieve equity between all people with an existing disability and those who acquire a disability in the future
- Recognise the future demands on the formal care system with the ageing of the population
- Engage in a partnership between funded support, informal support and community based activity and infrastructure
- Achieve system integration of the current disparate elements to eliminate gaps and duplication of services
- Provide clear accountability and responsibility while ensuring quality, minimising administration and red tape
- Eliminate cost shifting between levels of government.

The following sections outline the NSW proposal and discuss in more detail the components required to make up a national disability service system including financing, governance, design, and principles underpinning such a system.

8. FINANCING OF THE SYSTEM

A well designed social insurance scheme

The NSW Government recognises that over the medium to long term, existing funding sources cannot meet the cost of future demand for disability services. An additional revenue source needs to be explored to ensure a sustainable system into the future able to meet the needs of people with a disability.

The NSW Government supports consideration of funding through a disability insurance scheme based on a social insurance model. A social insurance model is based on a levy applied across the broader community to provide an adequate financial source to deliver a specific social welfare outcome.

The features of a disability insurance scheme based on a social insurance model would be:

- all members of the community would be covered
- the risk of disability would be shared amongst the community
- the scheme would be widely accepted by the community
- the support costs of people with a disability could be met over their lifetime
- benefits are delivered according to assessed need.

NSW supports a social insurance model as it offers a contemporary social policy solution to a financial constraint. A social insurance model is also able to deliver economic benefits. This model can reduce the overall cost of disability services as with greater certainty of appropriate support, the focus could be on early intervention and decisions that encourage employment, community participation and meaningful activity for people with a disability.

Examples of social insurance schemes from overseas include:

- New Zealand Accident Compensation Corporation (ACC) Scheme

  The ACC Scheme provides comprehensive, no-fault personal injury cover for all New Zealand residents and visitors to New Zealand. The Scheme came into operation in 1974. I t works closely with businesses and the community to prevent injury, ensure that individuals get treated for their injuries and help individuals get back to everyday living as soon as possible. These services are funded through a number of levies on people's earnings, business' payrolls, the cost of petrol and vehicle licensing fees. The NZ Government covers claims for injuries to people who are otherwise unfunded from levies.

- Deutsche Socialversicherung

  German Social Insurance is a statutory insurance system that provides financial protection against illness, unemployment, old age, industrial

accidents and the need for long term care[44]. The system is primarily financed through contributions paid by employees and employers. Long term care insurance is compulsory and is tied to statutory health insurance cover.

Those covered by long term care insurance are those who, due to physical, mental or psychological illness or disability, will require substantial assistance with carrying out normal day to day activities for at least six months. Long term care insurance provides either benefits-in-kind or cash benefits used to finance basic personal care and help with household tasks. Services can also include nursing, aids and technical equipment and subsidies for equipping the person's home to facilitate care.

A scheme funded via a Medicare type levy

There are a range of mechanisms for funding and structuring social insurance schemes. Funding can be from taxes or general revenue, from levies on employers and employees or from individuals or from a blend of these funding sources. The structure of social insurance models can also vary from models based on purely an 'insurance' model - where payments are based on an actuarial model and are made from income from investments through to others such as Medicare where payments are made from levies on income and from a significant top-up from general revenue to others such as the Family Tax Benefits, the Baby Bonus and the proposed Paid Parental Leave Scheme which are paid solely from general revenue.

In supporting a disability insurance scheme, the NSW Government recognises that a proven mechanism which has wide acceptance in Australia is a Medicare type levy on income.

The levy when complemented by existing compensation and disability funding would then be set at a level that provides sufficient income in an 'insurance' sense to ensure sustainable funding for supporting people with a disability in the long term.

One of the consequences of a levy based on income is that the levy would generate larger amounts of funding from the more populous States, such as New South Wales. The modelling of the insurance scheme will need to consider this and predict the relationship between potential income to be derived from each State and Territory and projected cost of service commitments to be returned to residents. Where disparities and inequities are identified further discussion with the States and Territories will be required in relation to the implications for this.

[44] http://www.deutsche-sozialversicherung.de/en/index.html accessed 18 August 2010.

Recommendation 1

The Productivity Commission consider the establishment of a national disability service system based on a social insurance model, financed with a Medicare-like levy together with redirection of existing State, Territory and Australian Government funding.

In developing the model, the Productivity Commission could consider other social insurance schemes within Australia and internationally.

Linkages with current services and compensation schemes

The proposed disability insurance scheme should attempt to "capture" all current sources of funding. This includes:

- Funding from injury insurance premiums. Injury insurance currently provides both third party protection against being sued and fixed amounts of first party cover for injury – usually income replacement for a set period, plus some coverage for additional expenses and tables of maims payments. Where insurance and compensation schemes cannot be included, the disability insurance scheme should seek to complement the principles of existing insurance and compensation schemes to prevent incentives for participation in one scheme over another.

  The disability insurance scheme, if it includes current compensation schemes and has a no fault framework, should have the following benefits:[45]

  - Better health outcomes through immediate access to support, resulting in faster return to work rates
  - A fairer allocation of resources compared with a scheme based on compensable lump sum payments
  - Reduced legal costs for compensation claims
  - Less disputes regarding claims, eligibility and access.

- Funding from existing State and Territory specialist disability services as well as funding from Commonwealth Disability Pension and Carer Allowance Schemes. The relationship between Income Support Payments, that is payment made due to inability to work and that relates to payment to assist with cost of living, and payment made in recognition of costs associated with disability would then be more clearly differentiated. This will also minimise the risk of:
  - the development of a two tier system with different levels of support between old and new schemes
  - cost shifting between levels of government or between systems.

[45] PriceWaterhouseCoopers, *Accident Compensation Corporation New Zealand Scheme Review*, March 2008

Recommendation 2

Any Disability Insurance Scheme should be inclusive of existing disability funding from Australian, State and Territory Governments and complement existing compensation schemes where these are not appropriate for inclusion into the national scheme.

9. GOVERNANCE

The objective for all Governments should be to manage the disability service system in a way that maximises outcomes for people with a disability at a cost that is affordable to the community. Investment in building a cohesive new national disability service system which improves participation, employment and meaningful activity for people with a disability will reduce the overall impact of disability both for the individual, their family, and the community.

Achieving this requires more than a financial solution. However the experience of the inconsistencies and inequities that are part of the current multilayered system suggests that a coordinated service system can only be achieved where administration of the system is vested in one level of government.

An insurance model requires that the one body control the pool of funds, the investment of funds and the overall management of services. Virtually all aspects of service delivery can be contracted out with the central agency setting standards and outcome measures.

GOVERNING AGENCY RESPONSIBILITIES

The governing authority should be responsible for the following matters:

- Setting the required funding level based on a whole of life liability valuation
- Setting the economic assumptions for inflation and investment return that underpin that valuation
- Setting the investment charter and overall management of the pool of funds in accordance with that charter
- Putting in place guidelines to assess eligibility to the scheme and to undertake needs assessment
- Setting service delivery standards and accreditation
- Establishing the appropriate protocols and incentives structure to ensure that vital services in other systems, e.g. health and education, fully support people with a disability
- Establishing appropriate data sets to inform ongoing funding and service delivery and to monitor the performance of the scheme against evaluation criteria
- Establishing a case management system to collect individual and episodic data to reconcile with actuarial valuation and re-set fundamentals if required
- Establishing clear mechanisms for complaints and resolution of disputes.

Options for administration of a national disability service system

Two options are possible for the one-tier of government administration of the disability service system:

Option One – Administration by the State and Territory Governments.

Under this option State and Territory Governments would take responsibility for administering the national disability service system. This option presents opportunities to leverage:

- Existing established administrative systems and infrastructure. Considerable State investment has occurred to develop administration and infrastructure capable of supporting an efficient and cost effective specialist disability service system.
- The experience of States and Territories in funding and managing non-government organisations (NGO) to operate services. In NSW approximately 60% of specialist disability services are provided by non-government organisations.
- The experience of States and Territories in direct service provision for people with a disability, which are often the providers that families turn to for services for people with the highest support needs, including medical requirements.
- Intersection with all support from other State based services, especially health and education. Outcomes for people with a disability are not delivered by specialist disability services alone, an integrated approach between service systems supports life outcomes for people with a disability as well as contributing to the sustainability of specialist disability responses.
- Local and regional knowledge and presence. Historically the service systems have developed differently in each State and Territory. This reflects the capacity for State based systems to respond to any distinct local or regional requirements including the availability of appropriate service providers. In NSW a regional administrative and direct service delivery structure has been operating effectively building on local are knowledge, contract management relationships and service planning systems.
- Reform initiatives already being progressed both at a national and State/Territory level. As evidenced in Section 4, the NSW Government's financial investment under *Stronger Together* is to both provide additional service capacity and create an opportunity to redirect and reshape the service system.

The risks of this option include:

- The continuation of current inconsistencies and inequalities in service access for people with a disability between jurisdictions
- Differences in service access by people with a disability in border areas

- Difficulty with portability of current services and/or funding for people with a disability who wish to move interstate
- The potential lack of a national perspective in dealing with emerging issues
- A separation between the levels of government with financing responsibility and administrative responsibility which could lead to cost shifting and disincentives
- The difficulty in linking statutory Australian Government responsibilities (income support, carers payments) within an integrated system.

Many of the above potential risks can be effectively mitigated through appropriate national agreements.

Option Two - The Australian Government assumes full responsibility for all aspects of system administration and delivery.

Under this option, State and Territory Governments would affect a full handover of the disability service system to the Australian Government. This would present opportunities for:

- Consistency and equality across Australia. People with a disability would be entitled to access the same level of service whether living in Bundaberg or Blacktown. Assessment of need would also be measured in the same way against the same criteria wherever people lived.
- Integration with other national systems, such as is to occur under the new National Health and Hospital Network reforms with a single level of responsibility for Aged Care. It may also allow better integration of specialist disability services with income support arrangements, allowing for an holistic approach to supporting people with a disability.
- Ease of portability of funding across jurisdictions without jeopardising current level of support.
- Introduction of cost control mechanisms through the establishment of national procurement such as aids and equipment, and single systems for quality assurance and accreditation.
- Elimination of multiple reporting layers and reporting obligations, with resultant red tape reduction and cost savings.
- Opportunities for promotion of national best practice and research.

A fundamental risk for administration by the Australian Government is that this results in remoteness from service users. This is especially an issue in human services; local knowledge and capability to respond locally is essential to getting good outcomes. A national system administered centrally will, by its nature, be less capable of building on local strengths.

Any separation in responsibility for administration of disability, health and education risks a loss of responsive mainstream supports in these vital areas.

The risks presented by this option also include the loss of the significant investment by NSW under *Stronger Together,* particularly in sector development and service reform including the prevention and early intervention focus.

State and Territory Governments are also direct providers of disability services, often for people with very high support needs. This support role and its existing professional expertise could be lost in the transition to a national system.

There is also a risk in the loss of local and regional knowledge which is currently invested in staff who work either directly with people with a disability in their community and with the NGO sector in planning, contracting and evaluating service options.

The NSW Government position

The NSW Government would prefer that funding generated under a national disability insurance scheme is allocated to State and Territory service systems for administration under a national framework.

This builds on the strength of the current systems while providing a framework to achieve appropriate national consistency. Most importantly it keeps accountability for disability outcomes within the level of government responsible for health, education and community services. It also keeps the focus on regional/local administration which is vital for good people outcomes.

However NSW recognises that the Australian Government may have a disposition to retain any social insurance levies in a national fund administered centrally. In these circumstances, the NSW Government would be prepared to consider supporting a national scheme that transferred responsibility for all specialist disability services to the Australian Government. However such a transfer would be conditional on:

- Full inclusion within the national scheme of the current Australian Government financial contributions to income support and disability employment services; that is a new disability insurance scheme should not become a complete replacement funding source for existing financial commitments.
- A fully integrated system that is not premised solely on the financial solution and that retains and continues significant service system reforms and achievements currently in place or being progressed within States and Territories, and nationally.
- Incorporation within the national disability service system of all proposals and recommendations in this paper to realise the full range of economic and social benefits for people with a disability and their families and carers.

Recommendation 3

Any new national disability service system should be administered by one level of government.

Recommendation 4

The Productivity Commission undertake further analysis to identify a governance structure for a national disability service system that maximises direct benefits for people with a disability, provides the framework for effective and efficient administration, and considers issues of current jurisdictional responsibilities.

10. SYSTEM DESIGN

Broad Based Coverage

Eligibility for care and support

The Terms of Reference for the Productivity Commission Inquiry specify that the Inquiry should cover disability present at birth or acquired through an accident or health condition, but not due to the natural process of ageing. The Terms of Reference also notes that any long term care scheme should be for those in significant need of support i.e. profound or severe disability.

However the NSW Government recommends that the Productivity Commission consider the benefits of inclusion of all people who have a disability as being eligible for support through a national disability service system with the level of support dependent on their level of assessed need. A national system with broad coverage would:

- Promote inclusiveness through the removal of bureaucratic and arbitrary rules for access to support
- Enable removal of current restrictive eligibility criteria for certain disability services and would reduce discrimination based on disability type. This is a particular issue for people with adult onset disability who often fall outside of traditional eligibility criteria
- Help bring provision of disability services in Australia in line with the UN Convention of the Rights of People with a Disability (signed and ratified by Australia in July 2007).

The NSW Government proposes a broad based approach to eligibility for a national disability service system rather than a narrow approach with restriction to diagnosis or disability type. Broad criteria for eligibility would eliminate requirements for complex and multiple assessments. This would reduce the first level of administrative complexity and cost for a national system.

Further, taking a broad rather than narrow approach to coverage would:

- Build acceptance of the national disability service system and the associated disability insurance scheme

  Australian taxpayers in contributing to a disability insurance scheme, in the same way as with Medicare, will expect that the resulting national disability service system should be able to support their needs or those of any family members or friends who have a disability.

- Include people with mental health issues and those with chronic illness, where their condition requires long term support and care with activities of daily living.

An approach to eligibility based on a needs assessment would consider these client groups within the scope of eligibility. The issue of what services and supports are then received as a consequence of eligibility would take into account the responsibility of other service systems, such as health, to meet core elements of service need. This would reduce the opportunity for cost shifting between service systems and levels of government and the need for the States and Territories to maintain residual service systems for people who fall outside the national system.

- Support the implementation of low cost, low level and early intervention support strategies.

  Ensuring access for all people with a disability would enable all eligible people with a disability to benefit from early intervention strategies and ongoing (if necessary) low level supports. This would, in most cases, stop (or delay) the need for the person to access more restrictive, higher cost services as they age.

- Support a robust and sustainable service system that can flexibly respond to changes in service demand.

  A broader scheme although potentially having a bigger 'up front' cost presents greater opportunities for managing demand and the cost drivers that are making the current systems unsustainable in the longer term. A broader scheme also provides the opportunity to address the issue of unmet demand and to provide support to all people with a disability in line with assessed need.

- Simplified Access. Broad coverage will remove confusion created by the current arrangement of different rules for different diagnostic groups. This clarity of eligibility and equitable response to community needs will meet community expectations for a national disability service system. The administrative cost savings achievable through simplified access and removal of layers of eligibility assessment has the potential to offset the cost of inclusion of more people, particularly if supports delivered reflect assessed need at an individual level rather than fixed service or program responses.

It should be noted that the need for support reflects a range of individual capabilities, attitudes, and circumstances. This need can be expressed as being the product of the severity of disability and the capacity of the person to manage the disability, including with family support. Therefore, a person may be eligible for the system but, due to their capacity to self care or due to strong family support, may not access any services in the immediate future.

On equity grounds, the new system should also apply, whatever eligibility criteria are chosen, to all who have previously met eligibility criteria and are

currently receiving a disability service or support, regardless of whether they have a pre-existing disability.
It is proposed that the Productivity Commission consider this broader eligibility when conducting economic modelling for any national disability service system. Finally, it is noted that age related disability is excluded from the Productivity Commission's Terms of Reference. However, a national disability service system would need to manage the intersection and transition issues between disability services and aged care in order to cater for the additional needs associated with ageing for a person with a disability.

The care model should recognise a continuum of care that would be required throughout a person's life and take account of available support. For most disabilities, ageing will increase the impact of the disability and reduce the capacity of the person to self manage or be supported by a family member.

Financial capacity or means testing

The issue of means testing for the purposes of eligibility is not the same as assessment of financial capacity for co-contribution to service purchasing.

Under a social insurance model, everyone contributes to the insurance scheme through their taxes or a levy and all who are eligible are then able to benefit from the scheme. The amount that a person contributes in a social insurance premium, through tax or a levy is usually already related to their income level. There should then be no means test on eligibility for benefits such as with Medicare or health insurance.

Under a social insurance model, benefits would be provided to meet an individual's assessed needs which would include functional needs but would also consider other available supports. This has the potential to impose some limits on services provided. This is in contrast to benefits such as income support where it is appropriate that a means test apply.

Additionally, the cost associated with the administration of means tests has the potential to consume a disproportionate share of the administration of the proposed system at both the eligibility and service provision stages.

An exception to the application of a means test or financial limit to service entry may apply for a transitional period where it may be necessary to stop a person accessing supports from multiple sources (double dipping). For example, if a person has received lump sum compensation that includes funds for future care, it would be reasonable to apply a means test. This principle already applies for people who have received compensation for loss of future earning capacity when applying for a disability support pension. It also applies in the treatment of compensation cases by Medicare.

Range of Services

A national disability system should support broad coverage of services available with the potential for support and services for all people graduated to the level of need.

The approach should be to create tailored packages that reflect personal choice and need and provide whatever supports are required to undertake daily living tasks - to access work, the community and other social activities. This approach requires a complete absence of restriction based on service types or activities.

Support provided under a national disability service system should have the capacity to facilitate access to all services needed by participants as a result of their disability – inclusive of health services, personal care, aids and equipment, housing, education and vocational training, employment support, and transport. Individual packages should be designed to meet individual needs with flexibility as to priorities.

In practice, for those with severe or profound disability, daily care will be the major service accessed and is likely to dominate scheme funding requirements. The experience of the NSW Lifetime Care and Support Scheme is that provisions for attendant care can make up 80% of an individual package.

CASE STUDY[46]

Sara is 16 and lives with her parents and two siblings in regional NSW. She has an intellectual disability, physical disabilities and complex medical needs.

The family home was extensively modified (at their expense) to accommodate Sara's needs, including a hoist and sling system. Sara's family also funded an electric wheelchair and specially modified vehicle to enable her to travel with them. Sara attends a special school and receives services from a range of health and allied health providers. The family receives some respite services.

Sara and her family are starting to consider the future support she will need upon leaving school and the family home. She is likely to seek support in securing a housing solution with assistance to live independently. She will want support to enable her to access her community and participate in social and recreation activities as well as ongoing support with her medical and therapy needs.

An individual package under a life time care and support solution should be flexible in how this assistance is tailored to her changing needs.

[46] NOTE: All case studies are based on real people but use fictitious names.

A national disability service system, including linkages to informal support networks and mainstream services, should be able to facilitate the full range of services that people with a disability may have used in the past and will need to access in the future.

An effective disability system that provides a broad range of support that contributes to improved independence, enhanced functioning and facilitates employment for a person with a disability, will deliver offsets in health, income security, and in the longer term aged care systems.

The NSW Government recognises that if a national disability service system covers services that are currently funded through State and Territory or Australian Government Budgets that there will need to be funding adjustments on a Budget neutral basis. This will require detailed negotiations between Governments.

Recommendation 5

All people with a disability currently receiving a service or support from a State or Territory or Australian Government funded disability service should be deemed eligible for the new national disability service system.

Recommendation 6

The Productivity Commission consider the possibility of broad coverage with regard to eligibility and scope of supports available.

A broad based approach does not include financial capacity assessment or means testing at the point of determining eligibility.

Modelling consider the costs and benefits of including all people with a disability who require long term care and support.

Recommendation 7

The Productivity Commission consider mechanisms to quantify and cost the potential offsets to other systems, such as health, through a broad approach to service provision under a new national disability service system.

Incentives to ensure cost containment

Overall the principle responsibility for government is to manage the system to deliver improved outcomes for participants at a cost that is affordable to the community. The development and introduction of a new, national, integrated disability service system presents an opportunity to address some operational or administrative systems issues that will be critical to ongoing sustainability and cost effectiveness of any new system. This includes an investment in improving participation in education, employment and meaningful activity, as well as building opportunities for private financial contributions and mutual responsibilities.

Co-payment and private financial contributions

With health, aged care, and education, a universal system is available for all Australians, however there is also a government subsidised private system that complements these services and creates capacity for private financial contributions. Opportunities for financial contribution in the current disability system are limited to service fees or co-payments, with some limited, innovative models enabling private contribution to the housing component of services.

The introduction of a disability insurance scheme must build on capacity for personal contribution and innovative solutions for future financial management. This includes the maintenance and expansion of Special Disability Trusts, and shared equity financing of housing solutions. Individuals, where they have capacity, should also be free to buy additional supports in the open market

There is also scope for co-payments in areas such as home and vehicle modification, recreational and leisure activities. The individual should also retain responsibility to meet all the usual health and living costs not associated with their disability.

The ability to make a co-payment or to purchase additional services is dependent on income. It is essential that the level of income support for those who are not in employment or who do not have another source of income is maintained through the Income Support system. An adequate income is needed to meet everyday health and living costs and to make co-payments, where appropriate.

System Integration

A new national disability service system must build integration between the current disparate components that impact on the lives of people with a disability. This is critical both from the perspective of effective outcomes for the individual and also for sustainability for the system going forward.

There is a risk that people will still slip between the cracks, or the blame game will continue between levels of government. The design of the new national disability service system needs to integrate and clarify the contributing roles of mainstream services, families, carers, the broader community, income support and employment services. The design also needs to consider the intersection over the life cycle with health and aged care service systems.

A national disability service system has the potential to eliminate duplication and gaps and result in:

- Consistent and improved quality of care through a single approach to quality assurance within a Standards framework.
- Removal of dual reporting and compliance costs for service providers.
- Reduction in red tape and back-of-office costs for governments.
- Improved buying power through a single national procurement process generating efficiencies.
- Shared/combined structural workforce management.
- Opportunities for promotion of national best practice and research.
- Clarity of roles and responsibilities of disability services and support services within mainstream services systems such as education or health.

Partnerships with the Non Government Sector

A national system should:

- Establish a funding and purchasing model that preserves current levels of informal care as well as promoting growth in the NGO sector.
- Reduce regulatory burden on the NGO Sector
- Deliver outcomes for people with a disability through one quality assurance system.
- Build on the existing Australian and State and Territory Government structures for funding, purchasing, monitoring and regulation of providers.
- Build on the social capital capacity able to be achieved by NGO partners.

Dealing with government regulations imposes direct costs on NGOs and distracts from day to day business operations. In particular, time-consuming, poorly-designed, ineffective or excessive red tape impacts on the efficiency of NGOs and ultimately results in extra costs. Delivering one funding, purchasing, and reporting and regulation system will not only provide consistent reporting, would mean that the NGO sector can focus its effort into delivering outcomes for people with a disability.

One quality assurance system will create opportunities to drive greater consistency in continuous improvement and refine and improve the delivery of outcomes for people with a disability. This will strengthen the NGO sector and build strong communities through a focus on continuous improvement and outcome focused service delivery.

As noted in the Productivity Commission's report, *Contribution of the Not for Profit Sector* (February 2010), the non-government sector is large and diverse and makes a significant contribution to the economy, Australian society and communities, and as a vehicle for government service delivery.

The non-government sector facilitates and contributes to building social capital, which is "the relationships, understanding and social conventions that form an important part of the mediating environment that shapes economic and social opportunities", and the extent of non-government activity is often viewed as an indicator of the health of society. A strong, robust and effective non-government sector is more able to contribute to and build the capacity of the community and 'social capital' for society and community benefit.

In a changing operating environment it will be important to maintain the current levels of community support through charitable and philanthropic arrangements. Charitable funds in future could assist with major expenses outside of the national scheme and provide funding for research into preventing or ameliorating the effects of disability.

Consumer Driven Market

Nearly all aspects of the operations of a national disability service system could be contracted or supplied by third parties to the system administrators.

An effective service market is dependent on the capacity for consumer choice and the extent to which choice is supported by the individual understanding their capacity to influence market change, particularly price and quality.

However this would require a managed transition as a market not only needs service providers operating under regulated conditions but needs informed and educated consumers who can exercise choice. Innovation can be developed through establishing a services market. This will happen as current service providers adapt programs to meet the changing needs of their clients and will be driven by self management and the exercise of choice.

One of the characteristics of the current system of disability services is that much of the community support is arranged around programs which the person must 'fit into". For other services the limited funding restricts the services which are available and therefore limits the ability to support the person to meet employment, educational and community participation aspirations.

A scheme which meets people's needs and builds their sphere of control and influence over what support is are provided can reduce a care burden and maximise health and social outcomes for the person with a disability. , and reduces overall family stress, allowing all family members to be happier and more productive.

Encouragement to participate in employment

An example of an effective strategy for cost containment is the area of employment. The great majority of people on disability support pensions would be able to undertake some employment if the system facilitated this.

Redesigning the system so that it provides opportunities and incentives for people with disabilities to undertake employment should be a critical component of the new scheme. The economic as well as the social benefits of having people with a disability able to contribute to community prosperity should be a key evaluation criterion.

A Benefit of System Redesign – Transition to Work

The NSW Government reform of post school programs under *Stronger Together* has demonstrated the improved outcomes that can be achieved by reforming existing service models.

Some 1,000 young people leave school each year and are unable to enter the workforce or further education because of skill limitations due to their disability. Over the past four years, two thirds of these young people are directed toward a Transition to Work (TTW) program, which is a time-limited (2 years) program of skill building to help them become work-ready. More than half of each annual TTW cohort has been successful in subsequently transitioning to employment (compared with less than 5% before 2006).

This change in focus has meant that 1,420 young people with a disability are now in employment and who might otherwise have needed ongoing specialist services. This specialist support would have cost up to $40 million per annum, escalating over time.

The success of the Transition to Work program in NSW has clearly demonstrated the significant individual outcomes and the improved efficiency that can be gained through the redesign of legacy specialist disability service models and a more appropriate balance of investment between specialist and community support.

Encouragement towards independence and self reliance

Sustainability of support and enhanced individual outcomes are also achieved when the service system shifts to focus on self care, self management and enablement. An 'enablement' approach has an emphasis on supported self care and self management and encourages people to be as independent as possible.

An enablement approach focuses on individual goals and outcomes, and provides an environment that supports the individual to challenge themselves and take risks which ultimately builds independence. Services work alongside people to work out how they can assist to overcome areas of difficulty in tasks of daily living. The focus is on working with people to help them learn or re-learn skills that they need to live independently.

Models of enablement have been successfully adopted across the UK and New Zealand in aged care and disability services. Results include:

- Lower rates of admission to residential aged care or accommodation services
- Reduced intensity of service responses
- Improved outcomes through more targeted and effective interactions with health, therapy and rehabilitation services
- Reduced per client service package cost
- Improved staff retention due to increased satisfaction with work outcomes.

Workforce Issues

A national system should:

- Invest in and build service infrastructure by supporting the development of workforce skills and the competence of management boards
- Build sector and workforce capacity to deliver appropriate service responses through innovative recruitment strategies and targeted training and skills development establishing the disability sector as an 'industry of choice'.

Community workers providing services to people with a disability are in demand from the aged care, other community care and human services sector, which creates the opportunity to drive higher standards of skills in the workforce. An ageing population and government policy to improve nursing and attendant care competencies in the aged care sector will increase the level of demand for skilled workers.

However a system that encourages a larger market will create interest amongst both current providers seeking to expand services and possible new entrants into the market, from other health services and aged care, which should ensure a competitive market for care in the immediate future.

Integration with the Aged Care Service System

The service system should recognise a continuum of care that would be required throughout a person's life and take account of available support. For most disabilities ageing will increase the impact of the disability and reduce the capacity of the person to self manage or be supported by an informal carer. A national system should provide:

- minimal disruption to clients and existing providers
- no net costs to the State, including over time
- minimal duplication of service provider reporting
- clear pathways for clients in navigating the new system
- seamless service provision, including interfaces between care systems.

Under the National Health and Hospital Agreement, it is anticipated that the Australian Government will establish integrated and coordinated care systems to improve client services in community aged care services. A significant part of the new aged care service system will be the delivery of community care services to older people in their home.

These services such as personal care, domestic assistance and community transport reflect the services that are needed by people with a disability and would be available under a national disability service system. For effective service delivery, particularly in rural areas, it will be essential that services are co-ordinated and partnership developed between disability and aged care service providers. There will also be opportunities for resource sharing.

The establishment of a national disability service system also provides the opportunity for the integration of the aged care and disability service systems in the longer term to produce a single community care service system. Such a community care service system would result in significant administrative savings while providing an effective and efficient service system that would meet the needs of both older people and people with a disability.

Recommendation 8

Cost modelling of a disability insurance scheme to include consideration of opportunities to maximise private contributions within a universal national disability service system.

Recommendation 9

In developing a national disability service system, the Productivity Commission consider incentives to ensure cost containment including building system integration, establishing a consumer driven services market, encouraging participation in employment and establishing a system that encourages independence and self reliance.

Recommendation 10

The Productivity Commission consider inclusion of strategies that build effective partnerships with the non-government service sector, enhance workforce capability and establish integration with aged care service systems.

11. PRINCIPLES UNDERLYING A NATIONAL DISABILITY SERVICE SYSTEM

The introduction of a national disability service system requires changes to the existing system in order to maximise and fully realise the potential social and economic benefits and individual outcomes that could be realised through a national disability service system.

"We have learned that individualised support and funding, in and of themselves, provide no guarantee that people's lives will be better. Their potential lies in their individual nature, combined with a focus on building community capacity, network building, and unencumbered planning[47]*.*

The NSW Government has demonstrated, through *Stronger Together,* the benefits of systems changes that refocus services on person centred approaches and early intervention.

A national disability service system should be based on the following core principles:

- Needs based assessment
- Person centred approaches
- Whole of life early intervention and prevention
- Sustaining the support of family and carers
- Mainstream services and community support
- Culturally appropriate services.

Needs based assessment

Eligibility for the national disability service system should be based on need. This can be by way of a needs assessment or by diagnostic proxies where a person has an injury, disease or condition that meets pre-set criteria. The use of diagnostic proxies will avoid multiple assessments for those people who would definitely be eligible for the system. Services and supports should then be provided by the system on the basis of assessed need.

This 'de-differentiated (all disability) approach'[48] has a number of benefits that contribute to the personal value of the services provided to the individual and the ultimate sustainability of the service system.

[47] Lord J and Hutchinson P, *Individualised Support and Funding: building blocks for capacity building and inclusion,* Disability and Society, 18(1), 2003, p85

[48] As quoted by Bigby 2007 pp 70, Sandvin.J. & Soder. M (1996). 'Welfare State reconstruction'. In J Tossebro, A. Gustavsson & G Dryendahl, *Intellectual Disabilities in the Nordic Welfare States* .Hoyskole Forlaget, Norway

The way in which individual service levels are determined must focus on the identification of what a person can and cannot do, at a certain point in time, their ability to improve over time and what they need to assist them and the potential benefit of assistance to their participation in everyday life. The facets of a person's life such as location, access to services, family circumstances and any disadvantages need to form part of the needs assessment rather than eligibility assessment.

The underlying principle of the assessment of individual needs should be that the person's needs are determined against real life demands[49] and that people with lesser needs receive the support that they need but are not unnecessarily drawn into the disability service system.

Person centred approaches

All Governments are working towards a service system where services are person centred and provide timely access to supports based on assessed need. Person centred approaches place as much control as possible with the person with a disability and their family. The person has control and choice over their life – which services and supports to access; how services are delivered (where, by whom, at what times); and changing services or providers if they desire.

Person centred approaches maximise participation in community life and access to generic mainstream services, rather than being only focused on what the specialist disability services can provide. The outcome is that when individuals and their families are better connected to their community, they can make more informed choices, access support more suited to their needs and live the life they desire.

International and Australian experience suggests individualised funding or packaged support is an effective mechanism for achieving a person centred approach and delivery of enhanced quality of life, self management of services and support, increased independence, choice in rehabilitation and care and overall satisfaction.

Individualised funding often result in efficiencies when the right level of resources are put in the control of the person with a disability or their family. Individualised funding has been found to ensure that where limited resources are available, these are used effectively to support individual outcomes[50].

[49] Eager and Green et al: ' Functional Assessment to Predict Capacity for Work in Population of School leavers with Disabilities' *International Journal of Disability, Development and Education,* Vol. 53, No. 3 pp 331-349, 2006

[50] Duffy, S, 2005, *Individual Budgets: Transforming the Allocation of Resources for Care*, Journal of Integrated Care, 13(1) and Duffy, S, 2007, *The Economics of Self-Directed Support,* Journal of Integrated Care, 15(5) cited in Bennett & Bijoux, *Strategic Social Policy Research & Evaluation*, 2009

A concrete example of the positive outcome of packaged support and early intervention is the rate of return on investment seen in the Lifetime Care and Support Scheme where a person who receives early rehabilitation and support and is able to return to work, will consume on average only 70% of their assigned package.

CASE STUDY[51]

Andrew from rural NSW was injured in a car accident, sustaining an injury to his thoracic spine leading to complete paraplegia. The Lifetime Care and Support Scheme (LTCS) was notified about Andrew by the acute care hospital and a LTCS application was accepted two weeks after injury.

In the acute care and hospital rehabilitation phase, the LTCS coordinator met with the family and provided information about the Scheme. Travel and accommodation support for Andrew's immediate family was arranged so they could support Andrew while in hospital in Sydney.

During rehabilitation, Andrew's need to return home and return to work was clearly integral to all aspects of his rehabilitation. The LTCS coordinator met with Andrew and the treating team to understand the range of supports Andrew would require and what he would likely achieve during rehabilitation.

The LTCS coordinator also met with the family to commence the home modifications process in preparation for Andrew's return home. LTCS also funded equipment including: customised wheelchair and seating, commode, continence equipment and established a pharmacy and GP account in preparation for discharge home. Andrew's personal care needs were assessed and arranged with an accredited care provider in his area.

Now at home, Andrew continues to plan his rehabilitation with assistance from a case manager commissioned by the LTCS. Included in the plan are a home exercise program with regular review by a local therapist who receives supervision from a Sydney based expert spinal physiotherapist. Also, a return to work plan at the local hire company is in place.

Andrew feels he is now engaged in planning for his future needs and managing the day to day aspects of his disability. He is living at home but has a long term goal to have his own place and to have a family one day, all of which is achievable as result of early planned intervention.

Whole of life early intervention and prevention

A national disability service system should have an early intervention and prevention focus. Research highlights the importance of early intervention and prevention in preventing problems escalating, for the person with a disability and families. The outcome for individuals can be seen in a reduction in the impact of disability and improved transitions through life stages.

[51] Note for the purpose of this report names used in case studies are fictitious.

Early intervention and prevention improves the future outcomes for people with a disability by:

- Responding swiftly to their health or other support needs
- Minimising the impacts of their disability
- Minimising the escalation of problems
- Maximising opportunities for people with a disability, their families and carers to achieve the greatest benefit
- Reducing the stress on families and carers by giving them the support when they need it most.

Early intervention and prevention delivers social benefits to people with a disability, their families and communities through: increased school performance; higher employment and skill levels; decreased welfare expenditure; lower criminality rates in families; reduced child abuse and neglect notifications and some decrease in health service (emergency room) attendance rates[52].

CASE STUDY[53]

In November 2009, EnableNSW received a request for a power wheelchair for Kylie, a four year old girl with cerebral palsy who lives in rural NSW and who was due to start school in January 2010.

EnableNSW has established the Children's Equipment Pool (CEP) as a trial project as one strategy to reduce waiting times for equipment. Following consultation, items such as power wheelchairs, manual wheelchairs, specialised strollers and bathing equipment were purchased and placed in the Children's Equipment pool so that they were available for immediate delivery.

Kylie's needs meant that she met the guidelines for provision of a power wheelchair and EnableNSW immediately arranged for a power chair from the CEP to be delivered to her for trial.

The trial was successful and the chair was permanently provided to Kylie so that she could spend the holidays becoming proficient in using it.

Timely provision of a power chair meant that Kylie could start school with the independence to choose where she wanted to move and who she wanted to play with, rather than being reliant on a teacher's aide to push her in a stroller.

[52] http://www.niftey.cyh.com/webpages/whoarewe/whyniftey.htm Cited in p. 3, Fish, E. (2002): *Stronger Families Learning Exchange Bulletin, "The benefits of early intervention";* No. 2 Spring/Summer 2002; Stronger Families Learning Exchange. Also refer to: Aked, J., Spratt, S., Lawlor, N. & Steur, N., (2009) 'Backing the Future: why investing in children is good for us all', *Action for Children*, September, United Kingdom, p8.

[53] Note for the purpose of this report names used in case studies are fictitious.

Cost benefits for government also result from reducing the need for remedial services (such as welfare assistance; certain special education services; juvenile justice; health services; crisis driven care); avoiding high cost service solutions; better education outcomes; and increased workforce participation (for people with a disability and their parents).

Employment benefits for the individual can include enhanced ability to meet the costs of disability and superannuation. While greater employment participation by people with a disability has the potential to reduce Disability Support Pension and Carers Allowance payments and increase revenue from income tax payments.

Sustaining the support of family and carers

The majority of people with a disability live, work, and interact as part of their local community largely through the supportive networks provided by their families and friends. I n 2006, over 540,000 people in NSW were providing informal support to family members or others with a disability, a long term illness or related problems[54].

The introduction of a national disability service system should not be seen as a substitute for or result in the diminishing of these supportive networks – which clearly focus on the needs and wishes of the person a disability. The design of the system should be to encourage and include strategies that further foster, develop and maintain the capacity of families, carers and local communities. Those relationships, capability and integration in a community are best strengthened continuously, not just in times of crisis or stress. The system design also needs to be flexible as individuals within communities will build their resilience and respond to challenges in different ways.

A national disability service system funded by a disability insurance scheme has the potential to give people with a disability the assurance and certainty of support they desire throughout their life stages. This certainty can form a fundamental base in planning for the future for the person with a disability, family and carers.

The system however needs to ensure not only support for the person with a disability but also adequate support services for their families and carers, where appropriate. Supporting families and carers has the potential to lessen the impact of any decline in the level of informal care and, thus, lessen the move of people with a disability to more intensive, and restrictive, formal services.

There is also evidence that people with intellectual disabilities benefit from engaging in recreational activities with their peers[55].

[54] ABS: *Census of Population and Housing* 2006

[55] Beresford, B. and Clarke, S., Improving the wellbeing of disabled children and young people through improving access to positive and inclusive activities, *Disability Research Review, 2009*

There is a need to enhance social networking opportunities for people with a disability that encourage them to form friendships with others with similar interests, particularly after work/school hours and at weekends. This not only provides a support effect for the carer but enhances the independence and social networks of the person with a disability.

Mainstream services and community support

A national disability service system should also champion the inclusion of people with a disability in mainstream supports and activities. People with a disability across the spectrum of need have the same rights as others in the community to the range of mainstream government and community services and supports. A national disability service system cannot reduce the responsibility of mainstream services and systems to include and respond to people with a disability.

A continued commitment by all levels of government to the implementation of the policy priorities and associated areas for future action under a National Disability Strategy must be maintained to ensure mainstream services and support complement any future national disability service system.

People with a disability should continue to have access to mainstream primary health care including therapy services so that they are not artificially relegated to support from a potentially duplicate and often higher cost 'specialist' service response. A new national disability service system has the potential to address issues at the interface between the health and disability service systems, particularly supporting long term rehabilitation, slow to recover programs and effective transition from acute health services for those with chronic or complex conditions.

Careful consideration also needs to be given to specialist disability support within mainstream services to ensure that support is not adversely impacted through the establishment of a national disability service system. For example, students with a disability and with therapy and/or complex health support need in NSW government schools rely on support provided through specialist disability services and health systems. Clarity about the roles and responsibilities of these specialist services that support access to mainstream services, such as education, would be needed in any national approach to disability services.

Barriers experienced by people with a disability may be physical, such as inaccessible buildings and streetscapes; infrastructural, such as a lack of appropriate transportation; procedural, such as accepting applications only in writing; or social, such as a lack of information in accessible formats and attitudes of people. A national disability service system cannot address these issues on its own. A continued commitment by all levels of government and communities will still be required to ensure that people with a disability are included in their communities and can function at increased levels of independence, without reliance on other people or specialist services.

Culturally appropriate services

Consistent with the principle of a person centred approach, a national disability services system also needs to be responsive to issues that impact on appropriate service and support options for:

- Aboriginal people.
- People from a culturally and linguistically diverse (CALD) background.

Aboriginal People

NSW has the largest number of indigenous people in Australia with 137,000 identifying as Aboriginal or Torres Strait Islander people.

Aboriginal people are twice as likely (1.5 to 3.0 times depending on age) to have severe or profound core activity limitation[56]. Chronic diseases and associated risk factors are responsible for about two-thirds of the life expectancy gap between Indigenous and non-Indigenous Australians. These health factors, if untreated, can cause life changing disabilities such blindness, mobility and speech impairment and intellectual disability. Research shows however that Aboriginal people use health, welfare and community services less than other Australians, relative to need[57].

The challenge of a national disability services system will be to ensure that Aboriginal people with a disability have every opportunity to reach their potential, at the same time supporting and sustaining the unique community responses that are a strong feature of Aboriginal culture. Services and supports will need to be delivered in ways which foster independence rather than reliance on formal care and lifetime support. Service delivery models will also need to respect cultural values, meet community expectations and build the confidence of Aboriginal families to access disability services.

People from Culturally and Linguistically Diverse (CALD) Backgrounds

Almost 17% of the NSW population was born overseas and is from a culturally and linguistically diverse background. This ranges from older established ethnic groups to new refugee arrivals.

For services to be effective they need to be delivered in a way that recognises the impact of culture, language, religion, age, gender and migration and settlement experience on individuals' health and well-being.

[56] ABS: *The Health and Welfare of Australia's Aboriginal and Torres Strait Islander Peoples*, 2008

[57] Aboriginal Disability Network of New South Wales, *Telling it Like it Is: A Report on Community Consultations with Aboriginal People with a disability and their Associates throughout NSW,* 2004 – 2005, sourced 3 August 2010 from http://www.pwd.org.au/adnnsw/news/telling_it_like_it_is.doc p. 29.

Responding to the challenges and opportunities of cultural diversity needs to be a core part of the national disability service system, presenting an opportunity to improve practices that are person and family centred.

Service data indicates a low uptake of services by people in this population group, especially in the younger age groups. People born in non-English speaking countries are three times less likely to use a government funded disability service than a person born in an English speaking country[58].
A national disability service system needs to provide accessible, inclusive and responsive services to meet the diverse needs of its client target group including people from CALD backgrounds. Working with diversity necessitates the implementation of flexible, innovative and responsive approaches to service provision. It also involves working within different contextual frameworks and the ability to work cross culturally from a culturally competent skill base.

Recommendation 11

A national disability service system be based on the principles of:

- **Needs Based Assessment**
- **Person centred approaches**
- **Whole of life early intervention and prevention**
- **Sustaining the support of family and carers**
- **Mainstream services and community support**
- **Culturally appropriate services**

Recommendation 12

The Productivity Commission explore a comprehensive variety of needs based assessment tools to identify an appropriate mechanism for effective assessment and determination of what level, and how, supports will be provided.

Recommendation 13

The Productivity Commission, in consultation with Aboriginal people, determine how a national disability service system can best meet the individual needs of Aboriginal people with a disability, at the same time as supporting unique Aboriginal community responses.

[58] Australian Government Productivity Commission 2008

12. CONCLUSION

A national disability service system has the potential to provide great value, both economically and socially, for all Australians living with a disability.

Economic Benefits

NSW proposes that any economic benefits achievable from a consistent national disability service system may include:

- An **efficient** system that can produce administrative cost savings as a result of economies of scale by operating a single system and reducing duplication in administration and policy development of the specialist disability system and various compensation schemes.
- A system that is based on an insurance scheme will be appropriately resourced and **sustainable** and, therefore, able to reflect contemporary disability practice that is person centred and provides an early intervention and prevention approach. That is, the system will have the ability to provide immediate support, when the person needs it, which can facilitate the benefits of early intervention and prevention approach and decrease the need for intensive longer term support later in a person's life.
- A system that can **respond immediately** to a person's need will result in better health outcomes that will have economic value to individuals (through improved earning potential) and for society (through reduced long term health expenditure and unemployment benefits).
- Building an **effective** system – using early intervention strategies, targeting a person's individual needs, targeting transition points in their life, linking people to their community and mainstream services and systems (including employment networks) – would lead to less reliance on pension income and increased tax revenue (applies to both people with a disability and their carers).
- A **comprehensive** system that provides an appropriate level of support including the aids and equipment necessary to participate in the community and access to housing, health services, transport and employment opportunities, can alleviate the financial burden of disability.
- Focusing on moving people who are on disability pensions into **employment**. This will assist people with a disability to manage their own lives and maximise their independence. Improved participation in employment by people with a disability will also provide a way forward to improved participation by carers in employment[59].

[59] Disability Investment Group, *The Way Forward: A New Disability Policy Framework for Australia,* 2009

- Employing people with a disability leads to **increased productivity** levels, reduced absenteeism, increased morale, more positive organisational culture and reduced workers' compensation. With the current ageing population and shortage of skills, there is a potential to utilise the entire workforce including people with a disability and their carers who represent a largely overlooked market segment[60].

Social Benefits

It is important that the case for change is not driven purely by economic considerations. Such a fundamental shift must also deliver significantly improved outcomes for the individual as well as broad social benefits.

NSW proposes that the social benefits achievable from a consistent national disability system include:

- Greater **equity** in allocating resources and access to support services and reduced inequality between population groups. A single national disability service system will reduce duplication of assessment processes and multiple eligibility criteria. A system that establishes broad coverage will positively impact lower socio economic groups and other disadvantaged groups as they will have greater access to the support required.
- Fostering **needs based** approaches enabling people to attain and maintain maximum independence. Building an effective system that delivers the services and support that people with a disability want would result in better outcomes and offers **choice, control and quality** of life for people with a disability and their families and carers.
- A comprehensive system, with timely access to appropriate support (including aids and equipment), would assist a person to increase skills and independence and provide greater opportunity for their **inclusion and participation** in their local communities, the development of social networks and sense of well being.
- Support that focuses on **increasing independence**, and uses person centred and early intervention and prevention approaches, facilitates sustainable community engagement and reduces the individual's reliance on supports in the longer term. It can alleviate the financial burden of disability.

Recommendation 14

The Productivity Commission conduct economic and financial modelling that considers the potential broad economic and social benefits in the assessment of the feasibility of a national disability insurance scheme and a national disability service system.

[60] Disability Investment Group, *The Way Forward: A New Disability Policy Framework for Australia,* 2009

APPENDIX A: Location of people with a disability in NSW

The following maps, drawn from the ABS Census 2006, show the distribution and proportion of people with a need for assistance in NSW. People with a need for assistance refers to those who needed assistance in one or more of the three core activities: mobility, self care and communication because of a long-term health condition, a disability or old age[61]. Need for assistance is conceptually similar to people with a profound or severe limitation in core activities defined in the Survey of Disability, Ageing and Carers.

Maps 1 and 2 show the distribution of people with a need for assistance in NSW - Map 1 for the full population and Map 2 for people aged less than 65 years only. The proportion is calculated by using the total number of people reporting a need for assistance in an ADHC Local Planning Area (LPA)[62] divided by the total number of people with a need for assistance in NSW.

Map 1 demonstrates that the highest percentages of people with a need for assistance live in the Sydney metropolitan area (with the exception of the Nepean), the Hunter and Illawarra areas and the north coast of NSW.

The western and southern areas of the state (encompassing the vast majority of the area of NSW) have a lower percentage of the disability population.

The picture is largely the same when only the population less than 65 years is considered. Decreased percentages are recorded for the Southern Highland and Northern Sydney areas. An increased proportion was recorded on the Mid North Coast.

Maps 3 and 4 show the proportion of the population in an ADHC LPA with a need for assistance – Map 3 for the full population and Map 4 for people aged less than 65 years only. The proportion is calculated by using the total number of people reporting a need for assistance divided by the total population.

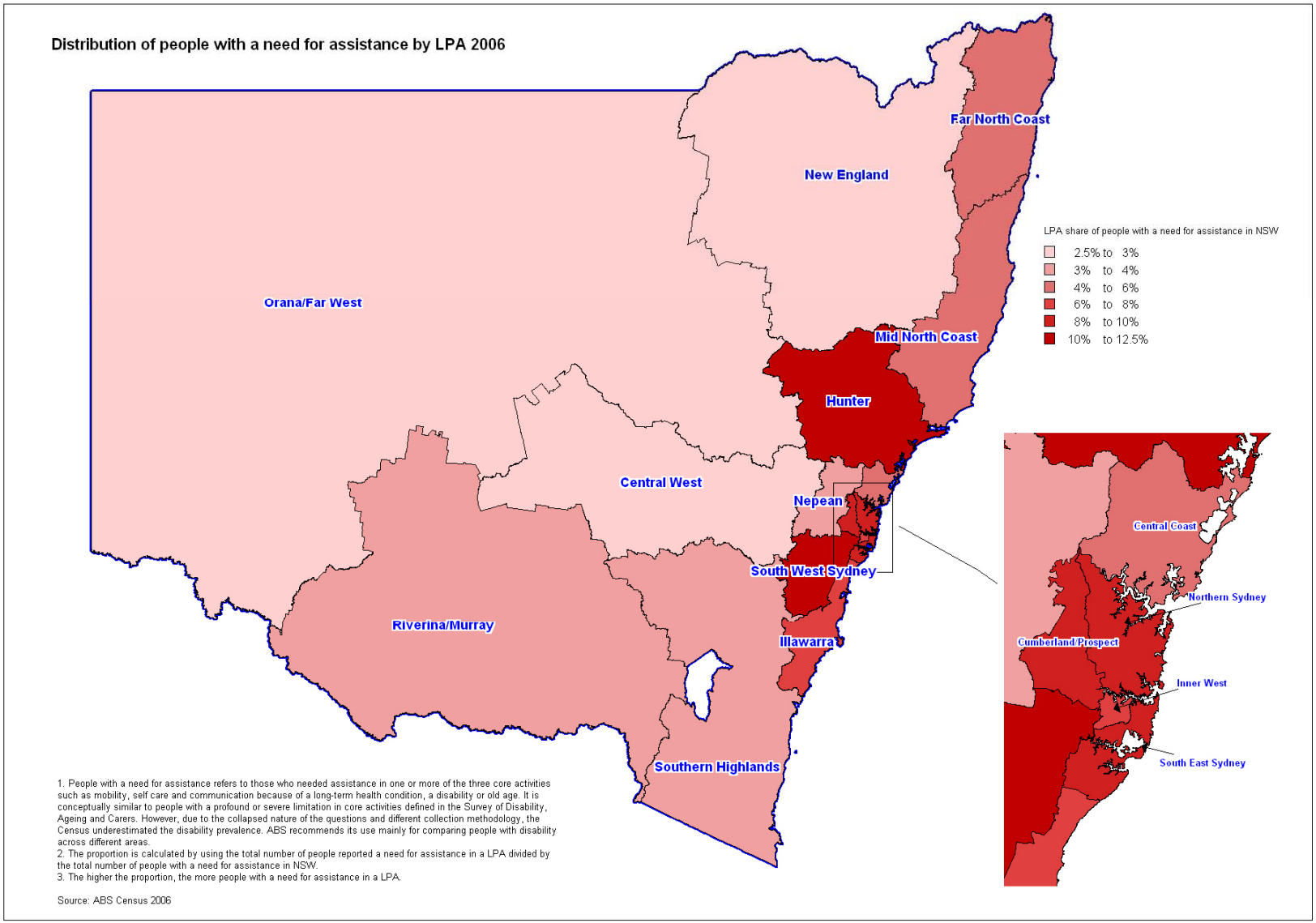
Map 3 demonstrates that the north coast has the highest proportion of its population with a need for assistance in NSW. The areas with the lowest proportion of their population having a need for assistance are in the Sydney metropolitan area (Northern Sydney; Cumberland Prospect; Nepean; South East Sydney and Inner West) – South West Sydney is the notable exception.

Narrowing the population to only those aged less than 65 years (Map 4) shows largely the same picture as Map 3. Increased proportions are notable in the Hunter, Illawarra and Inner West areas. No areas recorded a lower proportion when using the narrower age range.

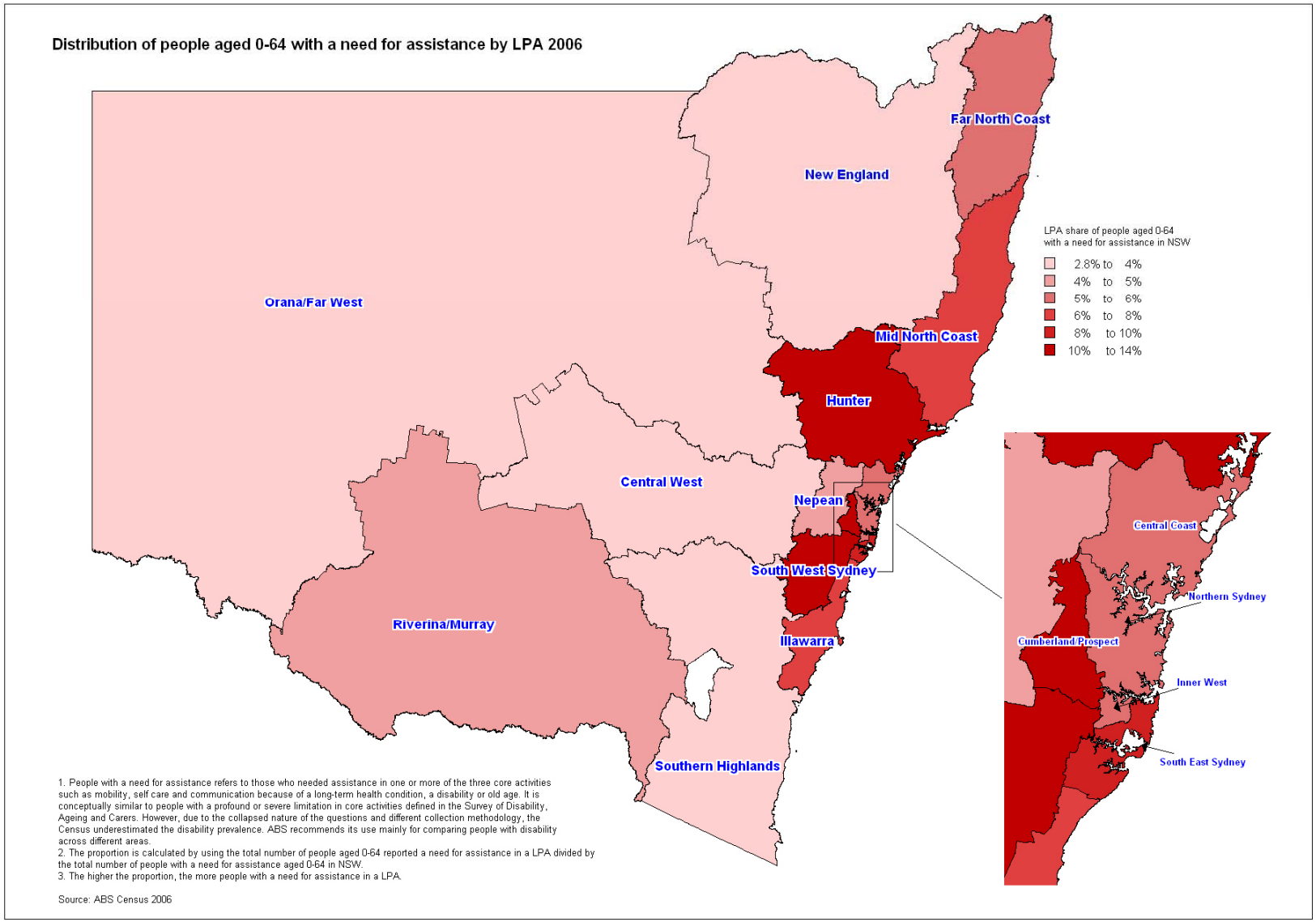
[61] However, due to the collapsed nature of the questions and different collection methodology, the Census underestimated the disability prevalence. The profound/severe disability rate from SDAC is 5.5%, compared to 4.5% of need for assistance rate in Census 2006. ABS recommends its use mainly for comparing people with a disability across different areas.

[62] ADHC Local Planning Area: For planning and service delivery functions ADHC divides NSW into six planning regions. Each region is further divided into Local Planning Areas (LPA). A full list of ADHC regions and LPA is at Appendix D.

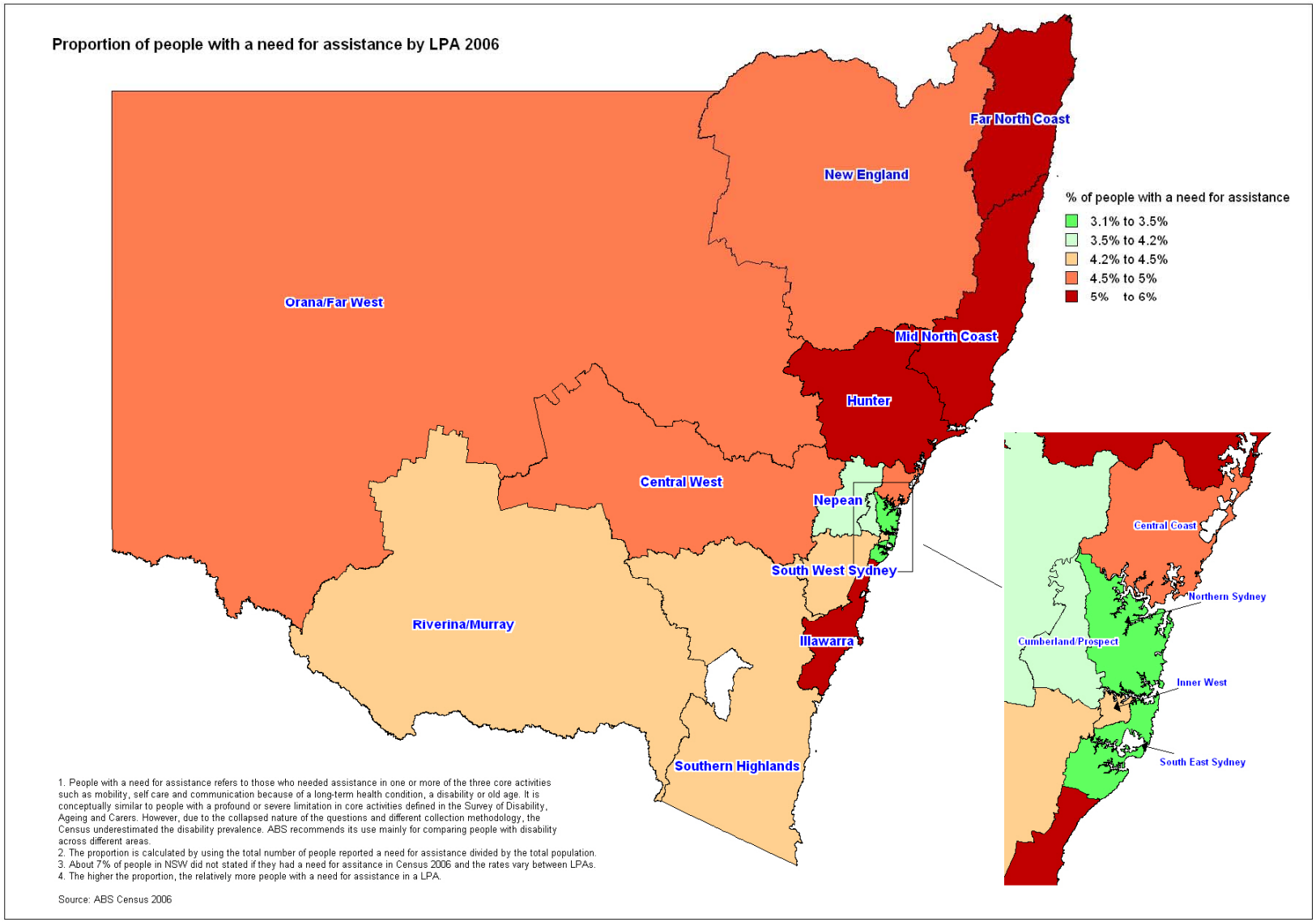
MAP 1


Distribution of people with a need for assistance by LPA 2006
Far North Coast
New England
Orana/Far West
Mid North Coast
Hunter
Central West
Nepean
South West Sydney
Riverina/Murray
Illawarra
Southern Highlands
LPA share of people with a need for assistance in NSW
2.5% to 3%
3% to 4%
4% to 6%
6% to 8%
8% to 10%
10% to 12.5%
Central Coast
Northern Sydney
Cumberland/Prospect
Inner West
South East Sydney
1. People with a need for assistance refers to those who needed assistance in one or more of the three core activities such as mobility, self care and communication because of a long-term health condition, a disability or old age. It is conceptually similar to people with a profound or severe limitation in core activities defined in the Survey of Disability, Ageing and Carers. However, due to the collapsed nature of the questions and different collection methodology, the Census underestimated the disability prevalence. ABS recommends its use mainly for comparing people with disability across different areas.
2. The proportion is calculated by using the total number of people reported a need for assistance in a LPA divided by the total number of people with a need for assistance in NSW.
3. The higher the proportion, the more people with a need for assistance in a LPA.
Source: ABS Census 2006

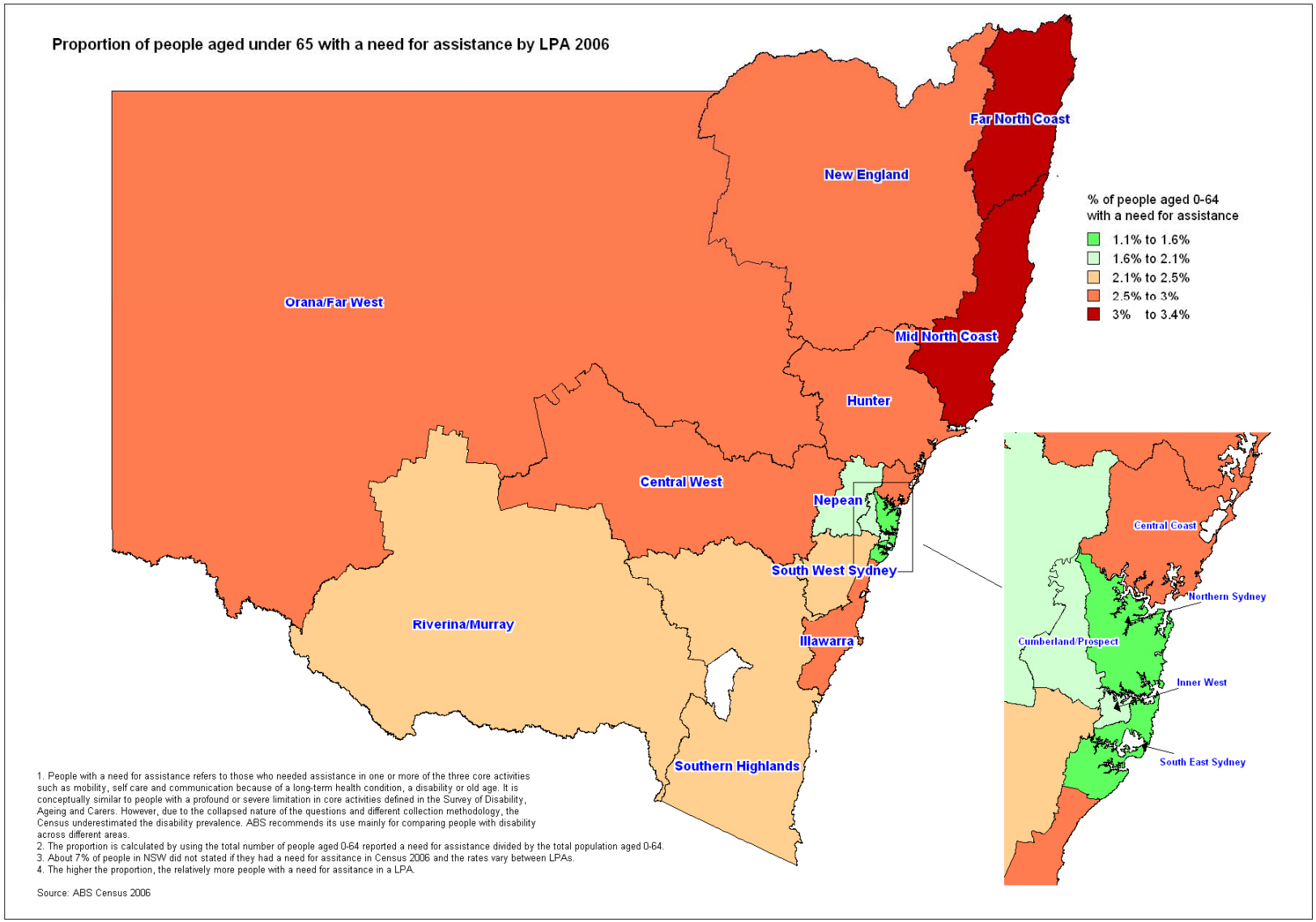
MAP 2


Distribution of people aged 0-64 with a need for assistance by LPA 2006
Far North Coast
New England
Orana/Far West
Mid North Coast
Hunter
Central West
Nepean
South West Sydney
Riverina/Murray
Illawarra
Southern Highlands
LPA share of people aged 0-64
with a need for assistance in NSW
2.8% to 4%
4% to 5%
5% to 6%
6% to 8%
8% to 10%
10% to 14%
Central Coast
Northern Sydney
Cumberland/Prospect
Inner West
South East Sydney
1. People with a need for assistance refers to those who needed assistance in one or more of the three core activities such as mobility, self care and communication because of a long-term health condition, a disability or old age. It is conceptually similar to people with a profound or severe limitation in core activities defined in the Survey of Disability, Ageing and Carers. However, due to the collapsed nature of the questions and different collection methodology, the Census underestimated the disability prevalence. ABS recommends its use mainly for comparing people with disability across different areas.
2. The proportion is calculated by using the total number of people aged 0-64 reported a need for assistance in a LPA divided by the total number of people with a need for assistance aged 0-64 in NSW.
3. The higher the proportion, the more people with a need for assistance in a LPA.
Source: ABS Census 2006

MAP 3


Proportion of people with a need for assistance by LPA 2006
Far North Coast
New England
Orana/Far West
Mid North Coast
Hunter
Central West
Nepean
South West Sydney
Riverina/Murray
Illawarra
Southern Highlands
% of people with a need for assistance
3.1% to 3.5%
3.5% to 4.2%
4.2% to 4.5%
4.5% to 5%
5% to 6%
Central Coast
Northern Sydney
Cumberland/Prospect
Inner West
South East Sydney
1. People with a need for assistance refers to those who needed assistance in one or more of the three core activities such as mobility, self care and communication because of a long-term health condition, a disability or old age. It is conceptually similar to people with a profound or severe limitation in core activities defined in the Survey of Disability, Ageing and Carers. However, due to the collapsed nature of the questions and different collection methodology, the Census underestimated the disability prevalence. ABS recommends its use mainly for comparing people with disability across different areas.
2. The proportion is calculated by using the total number of people reported a need for assistance divided by the total population.
3. About 7% of people in NSW did not stated if they had a need for assitance in Census 2006 and the rates vary between LPAs.
4. The higher the proportion, the relatively more people with a need for assistance in a LPA.
Source: ABS Census 2006

MAP 4


Proportion of people aged under 65 with a need for assistance by LPA 2006
Far North Coast
New England
Orana/Far West
Mid North Coast
Hunter
Central West
Nepean
South West Sydney
Riverina/Murray
Illawarra
Southern Highlands
% of people aged 0-64
with a need for assistance
1.1% to 1.6%
1.6% to 2.1%
2.1% to 2.5%
2.5% to 3%
3% to 3.4%
Central Coast
Northern Sydney
Cumberland/Prospect
Inner West
South East Sydney
1. People with a need for assistance refers to those who needed assistance in one or more of the three core activities such as mobility, self care and communication because of a long-term health condition, a disability or old age. It is conceptually similar to people with a profound or severe limitation in core activities defined in the Survey of Disability, Ageing and Carers. However, due to the collapsed nature of the questions and different collection methodology, the Census underestimated the disability prevalence. ABS recommends its use mainly for comparing people with disability across different areas.
2. The proportion is calculated by using the total number of people aged 0-64 reported a need for assistance divided by the total population aged 0-64.
3. About 7% of people in NSW did not stated if they had a need for assitance in Census 2006 and the rates vary between LPAs.
4. The higher the proportion, the relatively more people with a need for assitance in a LPA.
Source: ABS Census 2006

APPENDIX B: National Disability Agreement Priorities

The Parties (to the National Disability Agreement) have agreed to concentrate initial national efforts in several identified priority areas to underpin the policy directions and achieve reforms in the disability service system. They are:

a) *Better Measurement of Need:* A national model to estimate demand will be developed by mid 2010; data collected through the Survey of Disability, Ageing and Carers (SDAC) will be improved providing a stronger basis for demand estimates; improvements in the quality of data reported under the National Minimum Data Set and jurisdiction-level unmet demand data.

b) *Population Benchmarking for Disability Services:* A National Population Benchmarking Framework will be developed and initial population benchmarking of disability services, based on information available, will be achieved by mid 2010 and improve the evidence base to assist in policy, service and planning decisions.

c) *Making Older Carers a Priority:* The National Disability Priorities Framework will assist Governments to target services to more vulnerable population groups based on relative need (including older carers and Indigenous people with a disability).

d) *Quality Improvement Systems based on Disability Standards:* A National Disability Quality Framework with a National Quality Assurance system for disability services will be developed to introduce a national approach to quality assurance and the continuous improvement of disability services by mid 2010.

e) *Service Planning and Strategies to Simplify Access:* The National Framework for Service Planning and Access will be developed, focussing on providing a person centred approach to service delivery and to simplify access to specialist disability services.

f) *Early Intervention and Prevention, Lifelong Planning and Increasing Independence and Social Participation Strategies:* Early Intervention and Prevention Framework will be developed to increase Governments' ability to be effective with early intervention and prevention strategies and ensure that clients receive the most appropriate and timely support by mid 2011.

g) *Increased Workforce Capacity:* A national workforce strategy will be developed to address qualifications, training and cross sector career mapping issues and establishing the disability sector as an 'industry of choice' by the end of 2010.

h) *Increased Access for Indigenous Australians:* National Indigenous Access Framework will ensure that the needs of Indigenous Australians with disability are addressed through appropriate service delivery arrangements.

i) *Access to Aids and Equipment:* More consistent access to aids and equipment by end of 2012.

j) *Improved Access to Disability Care:* Systems that improve access to disability care and ensure people are referred to the most appropriate disability services and supports, including consideration of single access points and national consistent assessment processes in line with nationally agreed principles by end of 2011.

APPENDIX C: Disability Service Types

DISABILITY SERVICE TYPES

Service group	Service type
Accommodation support	• Large residential/institution (> 20 people) — 24 hour care • Small residential/institution (7–20 people) — 24 hour care • Hostels — generally not 24 hour care • Group homes (<7 people) • Attendant care/personal care • In-home accommodation support • Alternative family placement • Other accommodation support
Community support	• Therapy services for individuals • Early childhood intervention • Behaviour/specialist intervention • Counselling (individual/family/group) • Regional resource and support teams • Case management, local coordination and development • Other community support
Community access	• Learning and life skills development • Recreation/holiday programs • Other community access
Respite	• Own home respite • Centre based respite • Host family respite/peer support respite • Flexible/combination respite • Other respite
Employment	• Open employment • Supported employment • Open and supported employment
Advocacy, information and print disability	• Advocacy • Information/referral • Combined information/advocacy • Mutual support/self help groups • Print disability
Other	• Research and Evaluation • Training and Development • Peak Bodies • Other

Source: ADHC 2006.

APPENDIX D: ADHC Regions and Local Planning Areas

ADHC Region	ADHC Local Planning Areas
Metropolitan North	• Northern Sydney • Cumberland Prospect • Nepean
Metropolitan South	• Inner West • South East Sydney • South West Sydney
Hunter	• Hunter • Central Coast
Southern	• Illawarra • Southern Highlands
Northern	• Far North Coast • Mid North Coast • New England
Western	• Central West • Orana Far West • Riverina Murray

APPENDIX E: NSW Health Initiatives

The following describes some of the NSW Health initiatives already underway that are consistent with many of the aims of a national disability service system.

Promoting effective early intervention

NSW Health has a number of initiatives which recognise the importance of early detection and early intervention. These include:

- The Statewide Infant Screening for Hearing (SWISH) Program which was introduced in 2002 in recognition that early detection of, and treatment for, hearing loss is important for speech and language development and may minimise the need for ongoing special education. The program aims to identify infants born with significant hearing loss and introduce them to appropriate services as soon as possible after birth.

- Strategies such as the use of the Child Personal Health Record (Blue Book) and My Health Record.

- The Statewide Eyesight Preschooler Screening (StEPS) Program. This offers all 4-year old children free vision screening to ensure the early identification of childhood vision problems, during the critical visual development period, so that treatment outcomes can be optimised, and to avoid preventable vision impairment or blindness later in life. This program will cost $14.2 million over 4 years, with over 100,000 children screened and approximately 8,000 referred for further visual testing.

- Through its Universal Early Childhood Health Services and Universal Health Home Visiting, NSW Health also provides screening, assessment, identification and referral for child developmental issues including disability.

- Programs to encourage healthy lifestyle choices (such as childhood obesity programs like Munch and Move). In 2009/10, the NSW Government committed $13 million to anti-obesity initiatives. The proportion of overweight or obese adults has increased steadily from 38% in 1989-90 to 53% in 2004-05. The increase was most marked among obese adults, with the proportion of the adult population in this category doubling between 1989-90 and 2004-05 (from 9% to 18%). Over the same period, the proportion of overweight adults increased from 29% to 35%.[63]

Severe Chronic Disease Management Program

NSW Health is currently rolling out this program across NSW which builds on successful out of hospital health care initiatives in NSW such as the Post Acute Community Acute Care, community subacute care including Chronic Care Rehabilitation and the Health One NSW model.

[63] Australian Bureau of Statistics http://www.abs.gov.au/ausstats/abs@.nsf/mf/4719.0/

The Severe Chronic Disease Management Program will connect the care provided by these different health services with the care and support provided by General Practice and the Community Care sector for patients with severe chronic disease across NSW. The program targets people with the chronic diseases that result in the most frequent presentations to hospitals and respond best to improved care coordination and health coaching – Diabetes, Congestive Heart Failure, Coronary Artery Disease, Chronic Obstructive Pulmonary Disease and Hypertension.

Patients with severe chronic disease are being identified based on their age, diagnosis and frequency of unplanned admissions to hospital using hospital data. Older people (>65 years) and Aboriginal people (>45 years) are eligible if they have had 3 unplanned admissions to hospital in the last 12 months with one of targeted diseases as either their principal diagnosis or an additional diagnosis.

At enrolment, a comprehensive assessment is completed. A shared care plan is developed with the client, the Health Service and General Practice, and Community Care services where appropriate. The shared care plan is informed by the outcome of often multiple Specialist assessments and the availability of suitable community health and care services.

The Severe Chronic Disease Management service coordinates the implementation of the patient's shared care plan including access to health services and helps the patient or their carer navigate the community care system. Some of the health services may be provided by Specialists teams, usually on an episodic basis. These teams provide a progress report to GP when they transfer care at completion of a particular intervention. The GP is responsible for the patient's care in the community.

Patients with less severe chronic disease, the motivation to change their behaviour and the capacity to learn will be offered health coaching to enable them to better self manage their health.

Working in partnership with General Practice, Regional Implementation Plans have been approved and funded by NSW Health. Each region has annual patient enrolment targets and performance indicators have been incorporated into Area Health Service Chief Executive's Performance Agreements.

To date, 8,606 patients have been identified as eligible for the program based on hospital data for the period 1 July 2008 - March 2010. 5.2% of these patients identify as Aboriginal. The prevalence of severe chronic disease in Aboriginal people is twice that of non-Aboriginal people. The NSW Health Chronic Care for Aboriginal People program will work with Area Health Services to address the particular needs of this group.

An operational model for regional Severe Chronic Disease Management services was reviewed at a workshop with AHS and representatives from GP NSW, GP Council and the NSW Agency for Clinical Innovation in March 2010. With funding from NSW Health, GP NSW is developing a guide for working with General Practice to support Area Health Services to build strong relationships with General Practice to enable them to successfully implement the program.

The SAX Institute has been commissioned to develop tender specifications for the evaluation of the Program. A Minimum Data Set is being developed to monitor program implementation and enable program evaluation.

NSW Health aims to have a minimum of 43,000 patients enrolled in the program by 2014.

Initiatives to strengthen the sustainability of family and carer capacity

In recognition of the essential role that carers play in supporting people with a disability, the NSW Carers (Recognition) Bill 2010 was passed on 17 May 2010. Its objectives are:

- To enact a NSW Carers Charter to recognise the contribution to society of persons who care for other persons who have a disability, mental illness or chronic illness or are frail with an aim to enable carers to achieve their maximum potential as members of the community.
- To require NSW government agencies to take action to reflect the principles of the Charter when providing services that affect carers.
- To establish a Ministerial Advisory Council for Carers.
- It also requires NSW public sector agencies to have an awareness and understanding of the NSW Carers Charter.
- Human service agencies (such as NSW Health) have additional obligations including taking action to reflect the principles and reporting annually on compliance.

The NSW Carers Action Plan 2007-2012 outlines the NSW Government's five year commitment to supporting carers in their caring role.

This includes strategies such as

- Development of better resources to educate service providers and clinicians about the needs and profile of young carers. Funded under priority two of the carers action plan (Hidden carers are identified and supported).
- Under the same priority ADHC was also funded to lead the development of a Statewide Young Carers plan.
- The Office of Industrial Relations have developed online resources to provide support to older working carers under Priority five of the carers action plan (carers are supported to combine work and caring).
- Funds have also just been provided to three CALD and two Aboriginal carer support services to provide support to carers in these target groups. This process was also funded under priority two of the carer's action plan.

Areas for further attention include:

- Recognition of the needs of young carers (in NSW defined as carers up to the age of 25 years) especially at life transition points. Young carers often struggle with transitions from school to work.
- Flexible working conditions for carers of young children with a disability to assist their access to the labour market while recognising the additional commitments required in parenting children with disability (such as attending medical and therapy appointments).
- Improved access to mainstream childcare services and holiday programs for children with disability as well as expansion of disability-specific respite options to assist parents in their caring role. This should be an opportunity to look to alternate ways of providing support to bring carers to the mainstream. Carer support services do not necessarily need to be attached to disability agencies. They should be opportunistic in nature and available in the places that carers frequent with their children - schools, childcare, shopping centres, swimming centres, medical centres and places of employment.

The NSW Family and Carer Mental Health Program

This program provides a comprehensive range of supports and services for families and carers of people with a mental illness through strengthening existing partnerships between families and carers, NGOs and Area Mental Health Services.

NSW Health funds four Non Government Organisations (NGO) to provide Mental Health Family and Carer Support Services across NSW. There is one NGO service provider in each Area Health Service. It is the role of these NGO to provide:

- Education and training packages which teach families and carers about mental illness and its management and help to build coping skills and resilience.
- Individual support and advocacy services for families and carers of people with a mental illness.
- Infrastructure support for peer support groups.

Service Models

The South Eastern Sydney Illawarra Area Health Service (SESIAHS) has developed best practice service models that are improving the care and support to people with developmental disabilities by linking acute health services with other services.

Examples include:

- The SESIAHS Developmental Disability Network (known as The Kogarah Model) which aims to promote the development of comprehensive multidisciplinary teams integrated with primary, community health and acute hospital services as well as ADHC, DET and non-government

agencies for children, young people and adults and their families/carers in their local communities.

- Transition Team Model which supports young people with complex needs in their transitions between health, disability and educational services. This integrated model of care provides opportunities for new innovative services such as Transition Clinics in specials schools.
- Programs to assist people with a long term disability who require mechanical ventilation to live in the community.

NSW Health programs such as the Adult and Children's Home Ventilation Programs mean that children and adults who are ventilator dependant and medically stable can be cared for in the community in recognition that extended hospital stays can cause distress and have a significant psychological effect on the person and their families.

These programs have a budget of $7million in 2010-2011 and will assist 15 adults and 15 children who need home ventilation.

The Children's Home Ventilation program allows children with a profound disability the opportunity to develop in a normal environment, achieve their developmental milestones and to go to school. NSW Health has worked closely with the Department of Education and Training to facilitate the school attendance of children who are ventilator dependant.

Hearing Aids and Cochlear implants for children and adults

Children who are born with a hearing impairment are diagnosed through the SWISH- Statewide Infant Screening of Hearing Program. Once diagnosed, children will be referred to Australian Hearing where they might be fitted with hearing aids. The Department of Health and Ageing currently funds hearing aids for children up to the age of 21 years.

The cost of providing devices which enable people with hearing loss to communicate is significant. Approximately $370 million a year is spent on hearing aids, including more than $240 million by the Commonwealth government through the Office of Hearing Services Program, and over $10 million a year is spent on cochlear implants

Cochlear Implant Program

A Cochlear implant is a surgically implanted electronic device that provides direct electrical stimulation to the auditory nerve. Unlike hearing aids, which make sounds louder, cochlear implants do the work of damaged parts of the inner ear (cochlea) to send sound signals to the brain.

Currently NSW provides funding for the insertion of a limited number (101) of cochlear implants each year, 54 of which are for children and babies. As a result of this funding, children and babies who have been assessed as requiring an implant

are scheduled for surgery. For children in NSW there is no waiting period for cochlear implants.

Hearing loss is a disability which requires consideration in the development of a national disability service system.

According to the Access Economics report into the economic impact and cost of hearing impairment in Australia, the predicted number of Australians with a hearing loss will steadily increase until the year 2050 when it is estimated that more than one in four of the population will have some type of hearing loss. 26.7% of people aged between 15 and 50 will have a hearing impairment (mild, moderate or severe in their worse ear) in 2050, compared with 17.4% for the same age group in 2005[64]. This increased prevalence is due to the ageing of the population, since hearing loss increases with age.

Hearing impairment creates direct health care costs, loss of productivity and loss of income tax revenue. A study by Access Economics in 2006 estimated the real cost of hearing impairment to the community as $11.75 billion in 2005, by calculating direct health costs as well as productivity losses, education and support services, communication aids and devices, carers, losses associated with government transfer payments and loss of wellbeing (burden of disease).

Loss of productivity accounts for more than half (57%) of all the financial costs ($6.7 billion). For instance, in 2005, approximately 158,876 people were not employed due to hearing loss, with half of those with hearing loss being of working age[65]. While devices and support can assist people with hearing impairment to maintain employment, these services are often difficult to access.

The cost of providing devices which enable people with hearing loss to communicate is also significant. Approximately $370 million a year is spent on hearing aids, including more than $240 million by the Commonwealth government through the Office of Hearing Services Program, and over $10 million a year is spent on cochlear implants.

Given the predicted increase in hearing loss incidence, the real financial cost of hearing loss is set to grow. The earlier a hearing loss is identified and intervention is commenced the better health outcomes, educational attainment, community and workforce participation can be achieved. Where special needs are supported in this environment and ongoing clinical and technological services are available, future costs can decrease.

The recent Community Affairs References Committee Senate Inquiry into Hearing Loss[66] highlighted the cost to Australia of lost productivity through hearing loss. This is the largest real cost of hearing loss. The committee agreed that early intervention and rehabilitation of people with a hearing loss will pay society back

[64] I bid: Access Economics (2006:7)
[65] Access Economics *Listen Hear! The economic impact and cost of hearing impairment in Australia*, February 2006, p5
[66] Commonwealth Government (2010). *Hear Us: Inquiry into Hearing Health in Australia*. http://www.aph.gov.au/senate/committee/clac_ctte/hearing_health/report/index.htm

in the long term with higher workforce participation and the associated spin-off economic benefits

Children with hearing impairment are increasingly able to access mainstream education due to the implementation of SWISH, the provision of devices and early intervention services.

The projected prevalence of hearing loss supports hearing loss early detection and intervention programs, as well as strategies to prevent noise induced hearing loss through hearing health promotion and education.

Programs like SWISH have increased demand for early intervention services and strengthened the outcomes achieved by these services. Early identification and intervention programs need to be followed up by accessible continuing services in educational and occupational contexts and throughout adulthood.

APPENDIX F: Mental Health Statistics in NSW

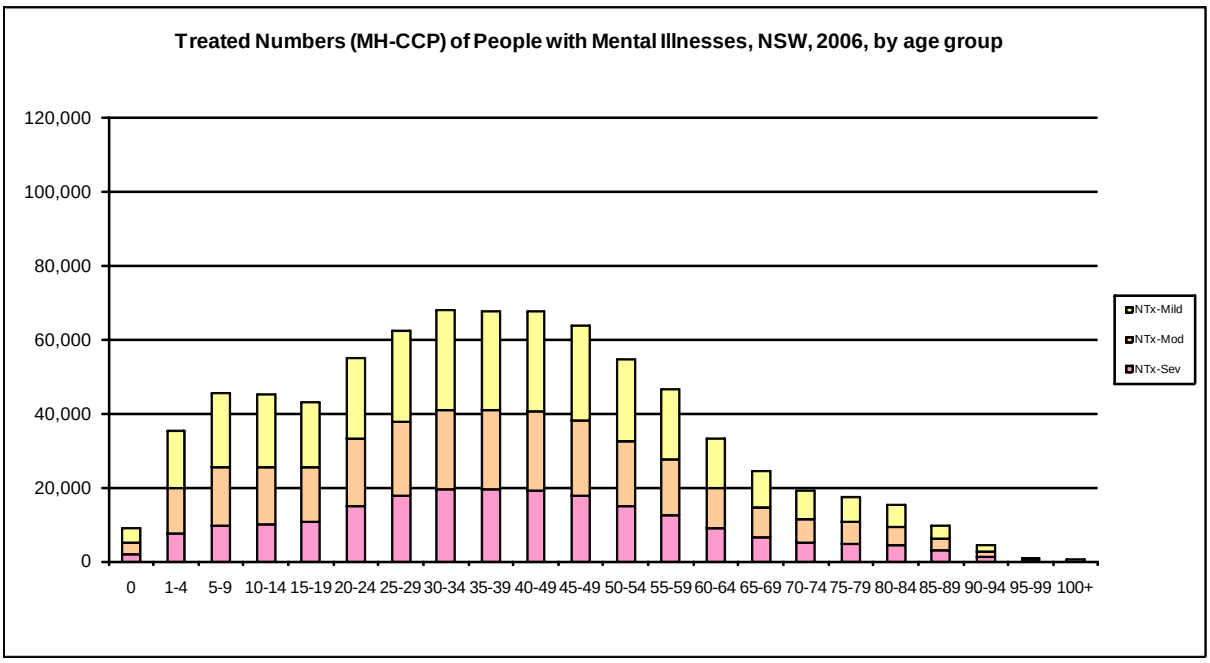
NSW Health developed a population-based planning model for specialist public mental health services in 1999-2000, known as the Mental Health Clinical Care and Prevention (MH-CCP) model. The model and its user guide are available on the Department's web site at URL: http://www.health.nsw.gov.au/resources/mhdao/MH_CCP_User_Guide_pdf.asp .

Currently NSW Health is in the final stages of revising the model. MH-CCP 2010 is a major revision, and contains a treatment of some of the disability support issues raised in the query. The information provided here is not final.

Demographic data for children and adults with mental illness in NSW

MH-CCP 2010 has used the Australian Burden of Disease (AusBoD) data published in 2007 to estimate the numbers of people with (a) diagnosable mental illnesses and (b) with a demand for services across the age range, by three levels of severity of distress and impairment of functioning. The labels mild, moderate and severe have specific definitions and determine the level and type of treatment required. The most prevalent illnesses (anxiety, depression) exist mainly at the mild and moderate levels where disability support is not required, and where clinical care is mainly provided by GPs under Medicare.

At the mild diagnostic level, the majority of people do not define themselves as ill, and do not want any services at all, not even "information", and to some extent this is true of those at the moderate level also, based on the Surveys of Mental Health and Wellbeing in 1997 and 2007. For the purposes of MH-CCP 2010, we have modelled the demand as 50% of mild 80% of moderate and 100% of severe illness. These are, if anything, slightly higher than actual demand. Overall, this leads to about 10% of the population being "treated" in the model, more or less equally divided across the three levels of severity, as indicated in the figure below.



The model is based on the standard planning year of 2006 for which census data are available.

The following three panels show the estimated numbers of people with different primary diagnoses, by age group and severity, for the standard NSW population of 2006. Note that "Treated" refers to the treatment provided in response to estimated demand in the model, across all providers. Actual treatment rates are unknown in the absence of a common healthcare identifier across all services and providers.

MH-CCP AGES 0-17 (Treated Numbers, NSW, 2006)

Dx=PRIMARY Diagnosis (MI)	Dx (N)	Tx-MI(N)	Tx-MILD(N)	Tx-MOD(N)	Tx-SEV(N)
J02 Schizophrenia	229	229	-	-	229
J04 Bipolar Disorder	205	205	-	-	205
J03 Anxiety/Depression	34,952	22,968	9,986	7,989	4,993
J05 Personality Disorder, isolated	1,442	883	466	373	43
J06 Anorexia Nervosa	652	606	-	182	424
J06 Bulimia Nervosa	837	779	-	234	544
J07a ADHD	38,672	25,413	11,049	8,839	5,525
SMHWB(C&A) - Balance	155,757	102,355	44,502	35,602	22,251
Subtotal (Dx of Primary MI)	232,748	153,439	66,004	53,220	34,215
Dx=PRIMARY Diagnosis (non-MI)	Dx (N)	Tx-MI(N)	Tx-MILD(N)	Tx-MOD(N)	Tx-SEV(N)
J07b Autism - *Excess over K09*	4,092	871	379	303	189
J07b Asperger's Syndrome + PDD (nos)	1,333	-	-	-	-
K01 Dementia - BPSD	2	1	0	0	0
K09 Intellectual Disability-MI	32,705	8,626	3,750	3,000	1,875
J01a Alcohol-MI	5,815	535	233	186	116
J01b Heroin-MI	282	76	33	26	17
J01c Benzodiazepines-MI	73	13	6	5	3
J01d Cannabis-MI	2,653	244	106	85	53
J01e Stimulants-MI	696	64	28	22	14
Subtotal (Dx with MI Concurrent)	47,650	10,430	4,535	3,628	2,268
TOTAL TREATED MI for MH-CCP		**163,869**	**70,539**	**56,848**	**36,482**

MH-CCP AGES 18-64 (Treated Numbers, NSW, 2006)

Dx=PRIMARY Diagnosis (MI)	Dx (N)	Tx-MI(N)	Tx-MILD(N)	Tx-MOD(N)	Tx-SEV(N)
J02 Schizophrenia	25,862	25,862	-	-	25,862
J04 Bipolar Disorder	27,850	27,850	-	-	27,850
J03 Anxiety/Depression	507,123	333,252	144,892	115,914	72,446
J05 Personality Disorder, isolated	121,782	74,531	39,376	31,501	3,653
J06 Anorexia Nervosa	3,279	3,049	-	918	2,131
J06 Bulimia Nervosa	3,180	2,957	-	890	2,067
J07a ADHD	4,521	2,971	1,292	1,033	646
SMHWB(C&A) - Balance	-	-	-	-	-
Subtotal (Dx of Primary MI)	693,596	470,472	185,560	150,256	134,656
Dx=PRIMARY Diagnosis (non-MI)	Dx (N)	Tx-MI(N)	Tx-MILD(N)	Tx-MOD(N)	Tx-SEV(N)
J07b Autism - *Excess over K09*	13,459	2,295	998	798	499
J07b Asperger's Syndrome + PDD (nos)	5,257	-	-	-	-
K01 Dementia - BPSD	2,870	1,221	431	401	390
K09 Intellectual Disability-MI	91,905	19,339	8,408	6,727	4,204
J01a Alcohol-MI	272,602	25,079	10,904	8,723	5,452
J01b Heroin-MI	15,166	4,086	1,777	1,421	888
J01c Benzodiazepines-MI	16,160	2,973	1,293	1,034	646
J01d Cannabis-MI	75,665	6,961	3,027	2,421	1,513
J01e Stimulants-MI	21,936	2,018	877	702	439
Subtotal (Dx with MI Concurrent)	515,020	63,974	27,714	22,228	14,032
TOTAL TREATED MI for MH-CCP		**534,446**	**213,274**	**172,484**	**148,687**

MH-CCP AGES 65+ (Treated Numbers, NSW, 2006)					
Dx=PRIMARY Diagnosis (MI)	Dx (N)	Tx-MI(N)	Tx-MILD(N)	Tx-MOD(N)	Tx-SEV(N)
J02 Schizophrenia	3,979	3,979	-	-	3,979
J04 Bipolar Disorder	2,308	2,308	-	-	2,308
J03 Anxiety/Depression	63,885	41,982	18,253	14,602	9,126
J05 Personality Disorder, isolated	19,766	12,097	6,391	5,113	593
J06 Anorexia Nervosa	7	6	-	2	4
J06 Bulimia Nervosa	-	-	-	-	-
J07a ADHD	-	-	-	-	-
SMHWB(C&A) - Balance	-	-	-	-	-
Subtotal (Dx of Primary MI)	89,946	60,372	24,644	19,717	16,011
Dx=PRIMARY Diagnosis (non-MI)	Dx (N)	Tx-MI(N)	Tx-MILD(N)	Tx-MOD(N)	Tx-SEV(N)
J07b Autism - *Excess over K09*	2,143	353	153	123	77
J07b Asperger's Syndrome + PDD (nos)	1,046	-	-	-	-
K01 Dementia - BPSD	61,940	26,329	9,291	8,651	8,387
K09 Intellectual Disability-MI	17,004	3,460	1,504	1,203	752
J01a Alcohol-MI	12,965	1,193	519	415	259
J01b Heroin-MI	541	146	63	51	32
J01c Benzodiazepines-MI	699	129	56	45	28
J01d Cannabis-MI	465	43	19	15	9
J01e Stimulants-MI	74	7	3	2	1
Subtotal (Dx with MI Concurrent)	96,878	31,658	11,608	10,504	9,546
TOTAL TREATED MI for MH-CCP		92,031	36,252	30,222	25,557

Level of need for people with a secondary diagnosis of mental illness (i.e. co-morbid with intellectual disability, acquired brain injury or physical disability)

The detail (above) regarding mental illnesses associated with intellectual disability is based on the Australian work of Einfeld and Tonge. NSW Health has supplemented the AusBoD estimates of age-sex-specific prevalence of Intellectual Disability (diagnostic group K09 in the tables above) with an estimate of the additional prevalence of mental illnesses not already included in the primary diagnostic data. The same source has been used to estimate an additional contribution from the AusBoD group J07b (Autism).

Estimate of demand in NSW for a disability and long term care and support scheme for people with a mental illness

To estimate overall demand the summary table below is more useful than the diagnosis specific tables.

MH-CCP 2.008 "Treated Prevalence"							
Prevalence	Promote	Prevent	MILD	MODERATE	SEVERE	CC	TOTAL
Age 0-17	84.6%	5.2%	4.4%	3.5%	2.3%	10.2%	100%
Age 18-64	81.5%	6.0%	5.0%	4.0%	3.5%	12.5%	100%
Age 65+	85.2%	4.8%	3.9%	3.3%	2.8%	10.0%	100%
All Ages	82.8%	5.6%	4.7%	3.8%	3.1%	11.6%	100%
Pop 2006	Promote	Prevent	MILD	MODERATE	SEVERE	CC	TOTAL
Age 0-17	1,446,431	84,537	70,539	56,848	36,482	163,869	1,610,300
Age 18-64	3,750,554	256,563	213,274	172,484	148,687	534,446	4,285,000
Age 65+	828,669	43,853	36,252	30,222	25,557	92,031	920,700
All Ages	6,025,655	384,954	320,065	259,554	210,726	790,345	6,816,000

This indicates that 210,726 people in NSW (3.1% of the population) experienced severe illnesses requiring the treatments specified in the model in 2006. An approximate estimate for 2008-09 may be obtained by pro-rating the June 2006 population of 6,816,000 to the projected population of December 2008 (that is, the 2008-09 mid-year estimate), namely 7,011,864. (However, the productivity Commission would probably wish to use ABS population projections rather than the specific projections for NSW Health by the NSW Department of Planning.)

This implies that the numbers with severe illnesses in NSW in 2008-09 would have been:

Age 0-17	37,032
Age 18-64	152,521
Age 65+	27,253

Even amongst those with severe illness, only some need disability support, and estimating either the demand for or the supply of specific services is problematic. This is partly because community mental health staff – mainly registered nurses - provides both clinical and psychosocial services, and it is arguable that clinical skills are needed to provide rehabilitation-focussed and recovery-focussed disability support to people with severe mental illnesses. There are also service coordination issues if these functions are delivered by different providers.

For example, the UK700 study of intensive case management versus standard case management for people with severe mental illnesses found that community mental health staff provided the same quantity of clinical services in both groups, but under intensive case management the volume of “psychosocial” services increased dramatically. Most of these were to do with activities of daily living, but generally had a ‘rehabilitation and skills training’ component, so that they were not simply psychiatric disability support services.

These issues were canvassed as part of the development of the Personal Helpers and Mentors (PHaMs) program within the COAG mental health initiative in 2006. For planning purposes it was estimated that 0.4% of the adult (18-64) population would require PHaMS support, as originally planned. This figure of 0.4% is also used in planning in Victoria, and has been adopted in the NSW MH-CCP 2010 model. The original paper prepared for COAG by Whiteford and Buckingham would presumably be available to the Productivity Commission from DoHA. No corresponding estimates were produced for those aged 0-17 and those aged 65+.

Disability Support for Children and Adolescents Aged 0-17

In general, the severe mental illnesses that lead to functional impairment over time would not be expected to generate a substantial need for disability services in the 0-17 age group, as distinct from clinical services and support to families and carers. However, 16-17 year olds are eligible for the Commonwealth Personal Helpers and Mentors program, and in remote communities (mainly for Aboriginal people) there is no lower age limit on PHaMs eligibility, but data on the number of recipients in this age range would need to be sought from FaHCSIA.

Within this age group, the tables above indicate that there would be about 2000 children and adolescents with Intellectual Disability or Autism and severe mental illnesses. However, in those cases it seems likely that the role of mental health would be limited to clinical services.

Disability Support for Adults Aged 65+

For people aged 65 and over, a substantial proportion of those with severe psychiatric illness, 0.975% of the population aged 65+, were found to be accommodated in residential aged care facilities (RACFs) in the first and last survey by the Commonwealth in 1996. Unfortunately there is no more recent data on this topic, but it is still probably true that RACFs are a major source of disability support for older people whose eligibility may be determined by a combination of physical illness and difficulties in activities of daily living arising from severe mental illness.

There is no specific provision for older people in the Commonwealth Personal Helpers and Mentor's Program[67] and no published data on the proportion of PHaMs clients in the age group, even in the FaHCSIA submission to the recent inquiry into planning options for people ageing with disability.[68] However, it is probably rather small, and in any case the productivity Commission could pursue the issue with the mental health branch of FaHCSIA.

Apart from primary psychiatric illnesses, in this age group there is a substantial contribution to the demand for treatment from people with Behavioural and Psychological Symptoms of Dementia (BPSD) – see tables above. Many of the people in this group will already be accommodated in RACFs or in receipt of community aged care packages because of their primary dementia, so that the main role of mental health is in the provision of clinical services rather than disability support.

Within that total, it is estimated that about 45% of this age group – typically at the younger end of the range – have similar clinical needs to those aged 18-64 and can have them met by general adult services. Nevertheless, their eligibility for aged care support services means that the model of 'psychosocial" or "disability support" provision is different.

For all of these reasons the estimates provided here are focussed on the adult 18-64 age group. However, it should be noted that the NSW Community Mental Health Strategy states the intention to develop some of the "Adult" models of support for both younger and older consumers.

[67] Community Affairs Legislation Committee, 02/06/2009, Families, Housing, Community Services and Indigenous Affairs Portfolio, p. CA149. http://parlinfo.aph.gov.au/parlInfo/download/committees/estimate/12048/toc_pdf/6823-2.pdf

[68] http://www.aph.gov.au/Senate/committee/clac_ctte/planning_options_people_ageing_with_disability/submissions/sub20.pdf

Disability Support for Adults 18-64

One objective indicator of disability support needs for this age group is the number of people receiving Disability Support Pension for psychiatric or psychological causes (DSP-P). NSW Health has recently obtained and analysed the relevant data from Centrelink as part of the work to develop a resource distribution formula.

Overall, there were around 63,000 persons aged 16-64 receiving DSP-P support in NSW at 30 June 2008. Rates increased with age, from around 0.5% of men aged 20-24 years to 2.7% of men aged 60-64 years, and from 0.4% of women aged 20-24 years to 2.1% of women aged 60-64. [Note: it is probable that at the youngest age range income support is provided in other ways such as Newstart pending assessment of eligibility for DSP-P.]

During the period for which the data was obtained, eligibility for income support via the DSP-P would mainly have been based on the "30 hour rule" rather than the "15 hour rule" – that is, on the presence of severe mental illness that would prevent a person working for 30 hours a week, or being reskilled for such work within two years, even in a workplace where "reasonable adjustment" had been made. The change to a criterion of 15 hours per week would not have had much impact on these numbers at the time. The DSP-P numbers (63,000) at 30 June 2008 are about 41% of the estimated numbers of people with severe mental illnesses in this age group in 2008-09 (152,521), or 1.4% of the whole population aged 18-64.

The target for PHaMS by 2012-13 is 10,000 people and an evaluation was due to be available "in December of [2009]" [69] but it does not seem to have been published. Assuming that NSW has received a population share of these PHaMS services, PHaMS would have served about 3,000 people in NSW in 2008-09, or about 0.07% of the adult population aged 18-64.

However, although PHaMS services were originally planned to be targeted at the group with severe illness and complex support needs, there are widely expressed concerns that implementation of PHaMS has broadened and to some extent modified the target population. This can be found in the Senate report on the topic.[70] The Productivity Commission would be able to track the debate on this issue via FaHCSIA, and seek access to the evaluation report.

Thus at present, pending the results of the PHaMS evaluation, we estimate that none of the basic psychiatric disability support needs are being met by PHaMS, and NSW mental health planning aims to achieve coverage of 0.4% of this age group.

[69] Community Affairs Legislation Committee; 02/06/2009; Families, Housing, Community Services and Indigenous Affairs Portfolio, p. CA140.
http://parlinfo.aph.gov.au/parlInfo/download/committees/estimate/12048/toc_pdf/6823-2.pdf

[70] http://www.aph.gov.au/Senate/committee/clac_ctte/mental_health/report/c05.pdf

Level of support by existing Health services

Not all of the disability support levels in the 2010 model are in place, and there are also "legacy" services offering a range of services that are not modelled. In the NSW Health *Framework for Housing and Accommodation Support* (2002: State Health Publication No CMH 020212) (see diagram on last page of this document) there are six levels and types of consumer characteristics corresponding to levels and types of support needed, described as:

A: Very high or high disability, safety risk to self or others ➔ (Inpatient Non-Acute Care).
B: Very high disability, no safety risk ➔ (24-hour extended non-acute care)
C: Need for rehabilitation ➔ (Residential rehabilitation).
D: High disability ➔ (Accommodation support provided daily, clinical treatment and rehabilitation provided as planned).
E: Moderate disability ➔ (Accommodation support provided weekly, clinical treatment and rehabilitation provided as planned).
F: low or no disability ➔ (Accommodation support provided as required, clinical treatment and rehabilitation provided as planned).

Since the *Framework* was developed, the Housing and Support Initiative in NSW has evolved to provide a range of support across the groups labelled C through F above. To compare the levels of HASI support, we have converted the average funding levels into annual hours of care at the Victorian contract rate, with the results below:

- V-HASI (Very High HASI) = 843 hours/ year (16 hrs/wk).
- H-HASI (High HASI) = 648 hours/year (12.5 hrs/wk).
- M-HASI (Medium HASI) = 421 hours/year (8 hrs/wk).
- L-HASI (Low HASI) = 124 hours/year (2.4 hrs/wk).

Based on estimates from Area Health Services of demand for these existing HASI services, we estimate that the current supply services is about 50% of demand, as noted in our original brief.

At the most intensive level (Level A above), the demand is estimated directly from the number of people spending 365 days a year in hospital (Very Long Stay patients) because the nature of their disability and risk is such that 100% of this demand must be met, and the cost is such that it is not provided unless needed. These VLS places are only provided in specialist psychiatric hospitals. We estimate that with intensive rehabilitation over a considerable period about 40% of the current group of these patients may be transferable to a slightly lower level of support, but this remains to be established.

At the next most intensive level, the 24 hour supported community residential accommodation described at Level B in the *Framework;* we have combined the existing pre-HASI support of this type in NSW with a new level of HASI, currently the subject of consultation, called X-HASI (extended HASI).

Lastly, since NSW Health currently funds a range of pre-HASI support services at levels that fall between the new HASI levels, we have converted existing pre-HASI services into their HASI equivalents for the purposes of modelling and gap analysis.

Overall, the model accounts for the most intensely supported 0.072% of those in need (72 per 100,000). To put this in perspective, the lowest level of HASI in NSW (L-HASI) more or less corresponds to what is called Intensive Home-Based Outreach Support (IHBOS) in Victoria (IHBOS is 3 hrs/ week versus 2.4 hrs/wk in L-HASI), and the next step in the Victorian framework is Community Care Units that correspond to V-HASI or X-HASI. Other jurisdictions have similar gaps in their range of service provision, though many are moving to provide a similar range to the HASI spectrum in NSW.

The gap in the NSW range of disability support services is a level of support below L-HASI, corresponding to levels E and F of the NSW *Framework*. In modelling to meet this, we have adopted the Victorian standard HBOS level (1.5 hours/ wk) to bring the total supported population up to 0.4%. This would require 328 HBOS places/ 100,000 people aged 18-64. Taking all modelled services together, NSW is currently meeting about half the cost of this form of support overall.

Since the main gap is in the lowest level of support (HBOS) it is probable that at present this level of support is being (partially) provided by clinical staff on an ad hoc basis, since a moderate amount of the activity time recorded by ambulatory care clinical staff is codes as “psychosocial”.

Additional information regarding service usage

Acute Inpatient: Each year there are around 40,000 admissions to mental health units. Of these around 1.1% (approx 500) have a primary diagnosis of an organic mental condition (including dementia), and around 2.3% (approx 1000) have a primary or secondary diagnosis of a developmental disability. (NB. These are admissions, not individuals).

Non-acute Inpatient: There are currently approximately 350 persons with longer term admissions (>500 days) for mental health care in NSW. Past work has suggested that around a third of these persons could be discharged from hospital if community supports (including appropriate accommodation) were available.

Ambulatory Care: NSW Health provides approximately 2 million contacts to around 120,000 individuals each year. No data is available on diagnosis/co-morbidity.

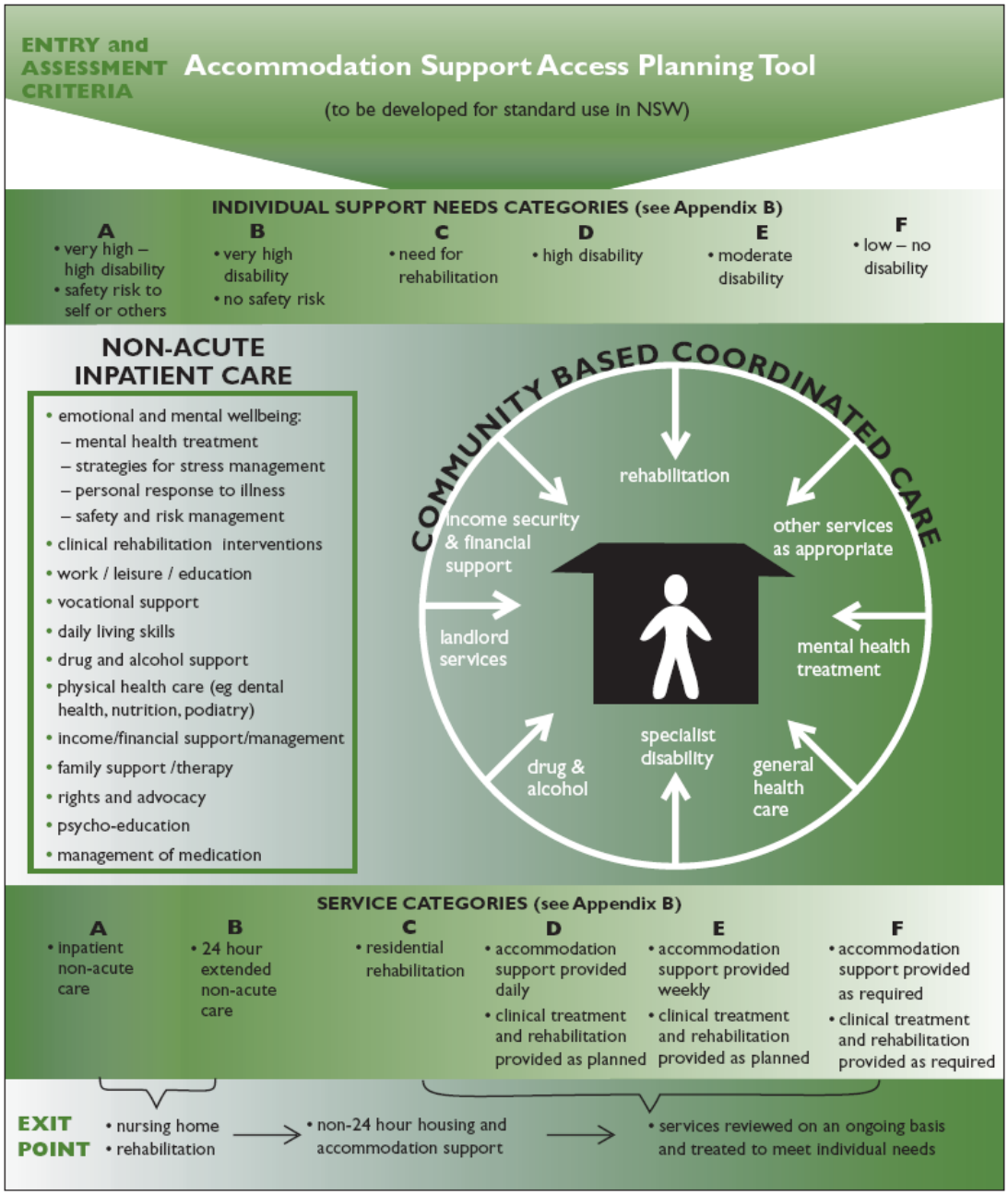
One marker of need for chronic care might be the level of ambulatory contacts received. These are highly skewed, and as in all health services a minority of persons consume a majority of contacts.

Over a one year period:

- Around 11,000 individuals have at least weekly contact (21% of clients, 58% of contacts).
- A further 1200 have daily or more than daily contact (1% of clients, 22% of contacts). Many in these groups will have complex illnesses with psychiatric, substance, physical health and/or developmental co-morbidities.

There would clearly be some overlap between these populations.

Housing and Accommodation Support Framework for people with mental health problems



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