

**INQUIRY INTO SERVICES PROVIDED OR FUNDED BY  
THE DEPARTMENT OF AGEING, DISABILITY AND  
HOME CARE**

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Ageing, Disability & Home Care Submission  
Inquiry into services provided or funded by  
Ageing, Disability and Home Care

August 2010



**Human Services**  
Ageing, Disability & Home Care

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## **CHAPTER 1: Introduction**

### **The NSW Department of Human Services**

In July 2009, the NSW Government announced the creation of 13 principal Departments to ensure the Government can deliver more integrated services, a stronger client focus and realise more efficient delivery of services, particularly in corporate and shared service functions.

The Department of Human Services (DHS) was formed as a result of the amalgamation of the former Departments of Community Services, Housing NSW, the NSW Aboriginal Housing Office, Ageing Disability and Home Care, Juvenile Justice, Aboriginal Affairs NSW, and NSW Businesslink to:

- Deliver better outcomes for clients.
- Improve services through better alignment, integration and coordination.
- Increase capacity to respond to the demand for services.
- Improve organisational structures and practices to ensure the efficient operation of the new Department.

### **Our Purpose**

Within DHS, Ageing, Disability & Home Care (ADHC) is one of the largest human services organisations in NSW. In 2010/11, ADHC has a total budget of \$2.5 billion, employs more than 13,000 staff (80 per cent of whom work in direct client services), and provides or funds services that support more than 260,000 people.<sup>1</sup>

ADHC exists, at a broad level, to promote inclusiveness in our society. Our clients face extra hurdles in community participation beyond what is faced by the broader population.

We seek to make a difference by recognising the value that people contribute to

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<sup>1</sup> This count includes clients receiving services from both the Disability and HACC programs, but excludes those clients benefiting from ADHC: Ageing Grants, Seniors Card and Events programs.



society no matter their age or their disability, by providing services and supports that build skills, independence and stability. We do this by providing support to families and carers. In many cases they are the cornerstone on which frail older people and people with a disability are able to live fully and participate within the community.

Our key client groups are older people, people with a disability, their families and carers, who require services and support in areas such as:

- early intervention, skill development, therapy, and community participation.
- respite and support for carers.
- advocacy and information.
- personal assistance, and intensive in-home support.
- supported accommodation in the community and in specialist facilities.

We also oversee a number of services that target the ‘well aged’ population in general, such as the Seniors Information Service, the administration of the NSW Seniors Card scheme, Seniors Week events and the Premier’s Seniors Concerts.

We measure our success against two key results areas:

Result Area	Definition
<b>1. Community Support</b>	Ensures that the ability of people with a disability to live in their own home is maximised through services that strengthen families and carer relationships and maximises the independence and skills of people with a disability. In the medium and longer term, these investments are designed to make optimal use of informal care networks, reduce escalation of need, and prevent unnecessary crises that may result in the relinquishing of care.
<b>2. Specialist Support</b>	Provides services to ensure that people with ongoing intensive support needs are living in suitable accommodation and participating in the community.

The Agency’s Service Results Logic is at *Appendix 1*.

## **Our values**

Our values guide our actions with each other, clients, service providers and other agencies, and form the basis of all business relationships, decisions and actions. The Agency's five core values are:

- client focus – client need is the rationale for our activities.
- equity – equitable and accessible services within available resources.
- integrity – honesty, openness and accountability in dealing with others.
- performance – striving for excellence and continuous improvement.
- valuing people – recognising our people.

## **Legislation**

The *UN Convention for 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 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 relates to 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.
- *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 is administered jointly with the Minister for Community Services and established the Disability Council to monitor government policy implementation.

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. These include: anti-discrimination legislation, disability services legislation, guardianship, administration and mental health legislation.

## **Our organisation**

The Agency is responsible for delivering a wide and diverse range of community support and specialist care services directly or through the Home Care Service of NSW statutory authority. It also funds around 900 local government and non government organisations to provide similar services across NSW.

The Agency's services (operated and funded) are administered via its six regions – Metro North, Metro South, Hunter, Northern, Southern and Western. *Appendix 3* includes Regional Maps and comparative population and service data. Its regional structure enables us to foster closer ties with local

communities and more effectively manage intake and vacancy services. Each Region has four business streams that manage the services we deliver to clients:

- Accommodation and Respite manages the group homes and respite centres that the Agency operates.
- Community Access matches our services to clients based on their needs. Community Access also manages programs that support people with a disability to participate more actively in community life through therapy, early intervention, skill development and other activities.
- The Home Care Service of NSW (Home Care) helps older people and people with a disability to continue to live independently in their own home by providing domestic assistance, personal care and respite for carers in their own home.
- Service Development and Planning manages our relationships and contracts with the service providers who are funded to deliver services on our behalf.

The Agency's central office, located in Sydney, develops statewide policies and programs for the business streams. The central office also provides corporate support to the rest of the organisation.

The Office for Ageing (OFA) advises the NSW Government about ageing policy and administers the Positive Ageing Grants Program. The OFA provides advice to the Minister, Director-General, Executive, business units and regions on strategic issues relating to the ageing population, in particular the whole-of-government strategies to address ageing issues.

## **Our Governance**

The Agency's corporate governance framework supports executive decision making and the management of our strategic goals and operational objectives. ADHC is a large complex organisation whose operations are devolved across the state. Decision making and implementation oversight reflects a cross

section of the views and responsibilities within the Agency through:

- an *Executive* to oversee committees, set directions and maintain an overview of Agency performance.
- An *Operational Performance Committee* to review operational performance against specific indicators that relate to regional and business stream performance.
- *Standing Committees* based around key infrastructure.
- an *Ageing 2030* Implementation Committee to oversee implementation of ADHC-led initiatives.

The Chief Executive is responsible to the Minister for Ageing and Disability Services and to the Director-General of the Department of Human Services for overseeing our governance activities.

### **The Audit Committee**

The role of the Audit Committee is to assist the Chief Executive to perform his duties in relation to the Agency's systems of internal control, risk management, internal and external audit functions and compliance to legislation. The Committee supports ADHC's corporate governance framework by providing an independent assessment of the risks facing the organisation and the appropriateness of its controls and mitigation strategies.

The primary objective of the Audit Committee is to assist the Chief Executive to fulfil his obligations and oversight responsibilities in regards to:

- quality of client care.
- identification and management of key business, financial, information systems and regulatory risks.
- compliance with relevant laws, regulations, government policies, accounting standards and codes.
- ensuring the adequacy of the internal control framework.

- maintaining the integrity of interim and annual financial reporting and disclosures.

The activities and functions of the Audit Committee are governed by its Charter that sets out the framework and the manner in which it operates and executes its responsibilities. Under the Charter, the Audit Committee functions as an independent oversight and review mechanism. It has an independent Chairperson and an independent member.

Findings and recommendations arising from the deliberations of the Audit Committee are reported to the Chief Executive and to the Corporate Management Board. Audit Committee members are required under the Charter to declare any potential conflicts of interest that may arise and remove themselves from proceedings in relation to these matters.

The Audit Committee is empowered to conduct or authorise investigations into any matters within the Audit Committee's scope of responsibilities and have access to ADHC management and information relevant to fulfilling its responsibilities.

In 2009 the Audit Committee Charter was amended in line with the "Better Practice Principles for Public Sector Audit Committees" provided by the Australian National Audit Office. The amendments reflect an increase in focus on the risk management and compliance frameworks and associated control environments. The composition of the Committee and its reporting relationships with the Executive and other corporate governance committees was also revised.

## THE DISABILITY CONTEXT IN NSW AND AUSTRALIA

### Population data

The Australian Bureau of Statistics (ABS) estimates that one in five people in NSW has a disability. The vast majority of these have a mild or moderate disability and go about their everyday lives with little or no additional support.

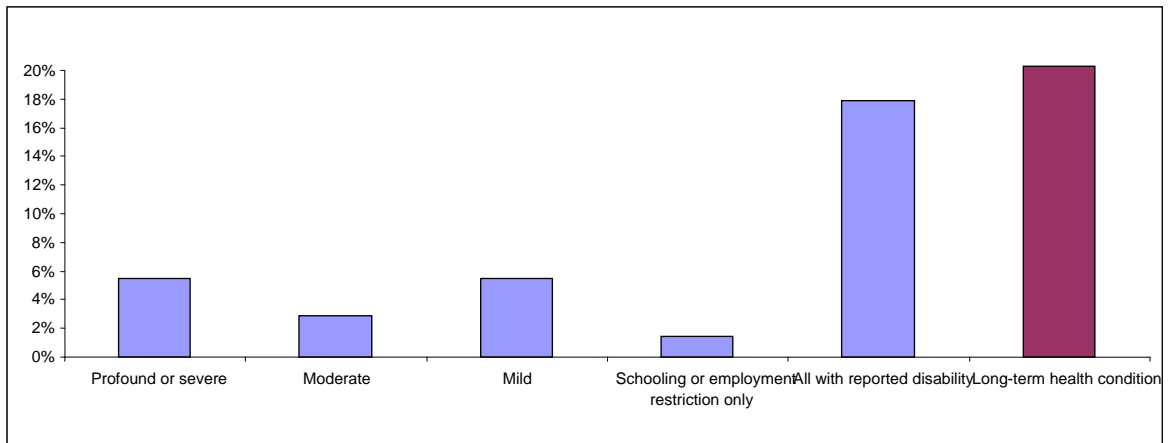
Approximately 450,000 people have a severe or profound disability which impacts on their ability to communicate, to care for themselves or to move about the community.<sup>2</sup> This number is evenly split between people under 65 years and people 65 years and above. While most live independently or with family, some require the assistance of Government to participate in education, work and community living.

<b>Core-activity limitations<sup>3</sup></b>	Core activities are communication, mobility and self care. Four levels of core-activity limitation are determined based on whether a person needs help, has difficulty, or uses aids or equipment with any of the core activities. The four levels of limitation are:
Profound	The person is unable to do, or always needs help with, a core-activity task
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.

<sup>2</sup> This paper uses Australian Bureau of Statistics data and definitions. 'Profound' is defined as unable to perform a core activity or always needing assistance with a core activity. 'Severe' is sometimes needing assistance with a core activity. Core activities are self care (such as bathing, eating and using the toilet), mobility and communication. All types of disability (eg intellectual, physical, autism) are included.

<sup>3</sup> ABS: *Survey of Disability, Ageing and Carers (SDAC) 2003*.

**FIG. 1 - Proportion of people with a disability by disability level or long term health condition**



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

NSW data on types of disability, location, education, labour force participation and income security are at *Appendix 4*.

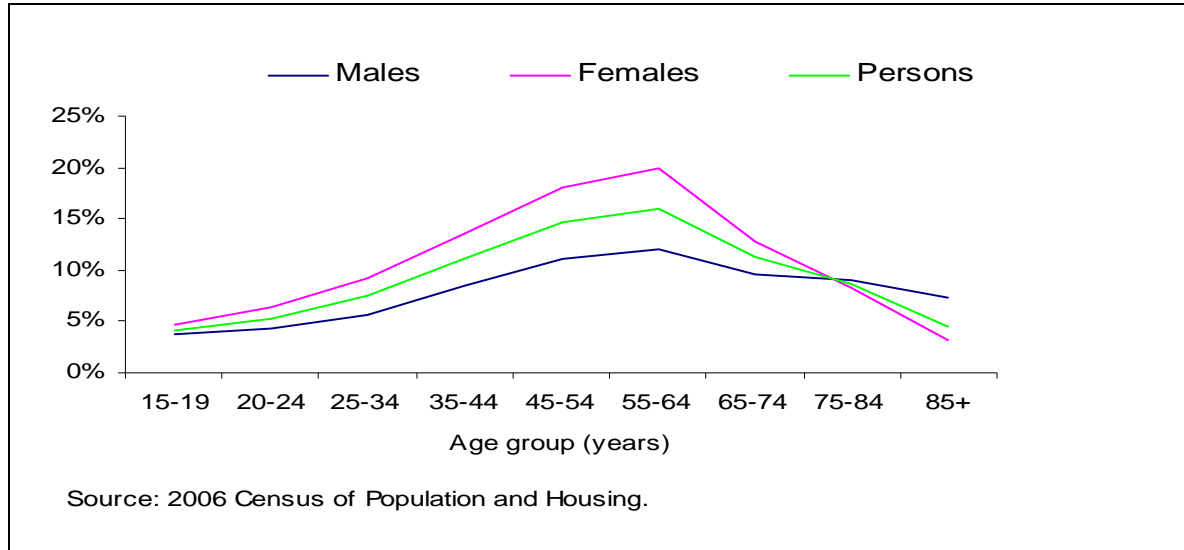
In 2006, over 540,000 people in NSW were providing informal support to family members or others with a disability, a long term illness or related problems. Nearly half of the people who provided assistance in NSW were aged 50 years and over and 62 per cent were female<sup>4</sup>.

The Census data revealed a strong relationship between providing assistance and age in NSW. As people age, they are more likely to provide unpaid assistance until they reach 65. After 65, the likelihood of providing assistance decreases. For both men and women, people in the age group 55-64 had the highest rate of providing assistance (12% for men and 20% for women). See Figure 2.

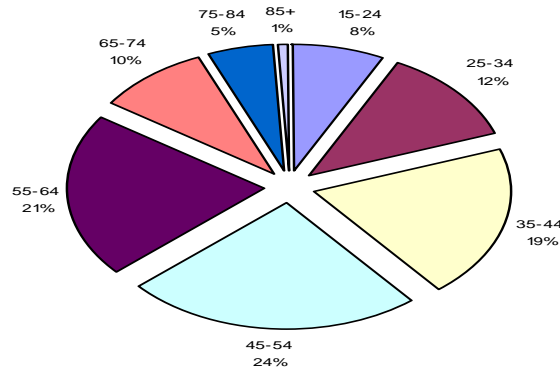
<sup>4</sup> ABS: *Census of Population and Housing*. This data only refers to people who were 15 years and older.



**FIG. 2 - Proportion of people in each age group who provided assistance, NSW**



**FIG. 3 – Age distribution of people who provided assistance, NSW**



Source: 2006 Census of Population and Housing.

While people aged between 45 and 64 years comprised 31% of the population aged 15 years and over, they accounted for nearly half of those who provided assistance (Fig. 3).

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.

## **The Specialist Disability Services System**

Assistance for people with a disability currently sits within a complex arrangement of specialist disability support, mainstream services, as well as the natural support mechanisms available through carers, families and broader community interactions. This complexity is further compounded by the arrangement of responsibilities between different levels of government. The Australian Government takes responsibility for employment and income support, while the States and Territories assume responsibility for specialist disability services. An outline of the services provided to people with a disability by State, Territory and Australian Governments is at *Appendix 5*.

The objective of the specialist disability services system in NSW is to enable people with disabilities to participate fully in the community. Each person with a disability has individual needs and life aspirations that need to be respected and supported.

People with a disability are supported through a range of specialist disability services including:

- Community Access – intensive family support, early intervention, therapy, behaviour support, case management.
- Learning and Life Skill Development – Transition to Work and Community Participation.
- Respite – flexible respite and centre based respite.
- Community Living / Accommodation support – in-home support, group homes and large residences.

Services are delivered by government and through local government, community not-for-profit organisations and private for-profit organisations. The current profile of the disability sector indicates that ADHC funds 460 disability organisations to provide services to people with disability. Figure 4 gives an overview of clients assisted and funding allocated by program type.

**FIG. 4 - Summary of client counts and funding allocations by specialist disability program – NSW - 2008-09**

Program	ADHC Operated		ADHC funded		TOTAL	
	Clients	\$M	Clients	\$M	Clients	\$M
<b>Short term community supports</b>						
Support for families and children			7,100	45	7,100	45
Transition to Work			1,400	19	1,400	19
Therapy and other interventions and case work	12,000	75	9,700	25	21,700	100
Advocacy				10		10
<b>Ongoing community supports</b>						
Intensive personal care			670	42	670	42
Respite	1,810	38	6,300	78	8,110	116
Community Participation (inc. PSO)			4,300	102	4,300	102
Day Programs	540	20	6,300	58	6,840	78
<b>Specialist supports</b>						
Community Living	1,600	250	5,260	316	6,860	566
-Boarding house relocation						
-Leaving Care						
-Criminal Justice Program						
Large Residences	1,160	177	590	37	1,750	214
Emergency Response			230	28	230	28

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

Note: The client counts are unique by program only. The costs are direct service costs.

There is an increasing recognition that the life of a person with a disability and their families and carers needs to be considered in a broader context than specialist disability services. The essence of “a good life” for a person with a disability is the same as for a person without a disability. “A good life” is about family, friends, communities and opportunities. It is about having meaningful relationships, having purpose, having good times, making a contribution, participating in fun activities and in meaningful activities.

The national disability policy arena (National Disability Agreement; National Disability Strategy) is driving a whole of government and whole of life approach that promotes social inclusion and universal access to mainstream services for everyone in the community. Specialist disability supports are not positioned as a solution or as an “add on”, but as one component of a broader system.

Repositioning the role of specialist disability services in NSW as facilitating a good life for people with a disability, their carers and families requires us to step outside the prism of traditional specialist disability supports. It means supporting families to build a good life from the ground up, emphasising strengths not deficits and building strong informal support networks. It also means improving

access to mainstream services, finding solutions within local communities, and, where necessary, making the pathway to specialist supports simple, clear and without stigma.

### **The HACC Program**

ADHC currently administers the Home and Community Care (HACC) Program, a joint Australian and NSW Government initiative under which NSW contributes approximately 40 per cent to program funding with the remaining 60 percent provided by the Australian Government.

The program provides funding for services which support people who are frail aged, younger people with disability and their carers, who live at home and whose capacity for independent living is at risk or who are at risk of premature or inappropriate admission into residential care.

HACC services are delivered by over 600 service providers including NSW government agencies such as NSW Health and the Home Care Service of NSW, local governments and non-government organisations.

The HACC service system is a community focused system and relies significantly on the contribution of volunteers in services such as Meal on Wheels, social support and community transport. Ageing, Disability and Home Care (ADHC) administers the HACC Program on behalf of NSW in conjunction with NSW Health and Transport NSW.

**Fig. 5 – HACC Program Funding 2008/09**

	<b>2008/09 Funding \$ million</b>	<b>2009/10 Funding \$ million</b>	<b>2010/11 Funding \$ million</b>
Australian Government	\$326.96	\$351.27	\$374.25
NSW Government	\$219.34	\$235.62	\$251.06
Total	\$546.3	\$586.89	\$625.31
Unmatched NSW Award Increase Funding	\$4.06	\$4.06	\$4.06
<b>Total Budgeted Expenditure</b>	<b>\$550.36</b>	<b>\$590.95</b>	<b>\$629.37</b>

At the Council of Australian Governments (COAG) meeting on 19 and 20 April 2010, NSW agreed to a package of national health reforms which includes establishing the Commonwealth as the level of government with full responsibility for aged care.

Under the National Health and Hospitals Network Agreement (NHHNA) there will be a split of responsibilities for aged care and disability services at age 65, or at age 50 for Indigenous Australians, with the Commonwealth to assume full responsibility for aged care services from 1 July 2012. This includes services provided in NSW under the HACC Program.

Specifically, the Commonwealth will assume responsibility for:

- funding and program management of basic community care services currently provided under the HACC program for people 65 years and over and 50 years and over for Indigenous Australians.
- funding specialist disability services provided under the NHHNA for people aged 65 years and over and 50 years and over for Indigenous Australians.

States/Territories will assume responsibility for:

- funding and regulating basic community care services currently delivered under the HACC Program for people under the age of 65 and under 50 for Indigenous Australians, which will be incorporated under the National Disability Agreement
- funding packaged community and residential aged care services delivered by the Commonwealth for people under the age of 65 and under 50 for Indigenous Australians.

The NHHNA commits to a budget neutral funding transfer for changes in the roles and responsibilities for HACC and related programs.

Figure 6 gives a breakdown of HACC clients and expenditure for the 2008/09 Financial Year (the most recent year for which full year figures are available). This shows that 49,259 clients (21% of HACC clients) are under 65 years of age. The expenditure on this group was \$190 million or 34% of the program's funding.

**Fig. 6 – HACC clients and expenditure 2008/09 illustrating the age split**

Age Group	Clients		Expenditure	
	No.	%	\$M	%
under 65	49,259	21%	190,177	34%
65 +	184,381	79%	356,123	66%
<b>Total</b>	<b>233,640</b>	<b>100%</b>	<b>546,300</b>	<b>100%</b>

NSW is working with the Australian Government to ensure that transition arrangements ensure:

- 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.

It is presumed that for the purposes of most of this submission - taking note of Clause 1(d) of the Terms of Reference which focus on compliance with the Disability Services Act - the HACC program is out of scope due to its primary focus on frail older people, and the agreement with the Australian Government to transition arrangements. Further information on the HACC program and the NHHNA decision is at *Appendix 14*.

## **Strategic Directions in NSW**

A number of initiatives, together with new funding, have made the past few years a period of significant change and expansion in disability services in NSW. We have benefited from significant increases in disability funding through the *Stronger Together: A new direction for disability services in NSW 2006–2016* strategy as well as the Australian Government's Disability Assistance Package.

2010/11 is the fifth year in the initial five-year phase of *Stronger Together*, through which an additional \$1.3 billion<sup>5</sup> in funding is being made available to provide many thousands more service places across a range of areas including early intervention and family support, accommodation, respite, day programs and post school programs, therapy and case management.

The implementation of this major investment in specialist disability services since 2006 has centred on expanding services in areas of obvious need while building the foundations for sector wide reform.

*Stronger Together* has enabled us to commence the move away from services that assume one size fits all, to person-centred approaches. It is also enabling us to create a stronger and more integrated disability sector through enhanced collaboration. It is important that the increasing investment in services in NSW should deliver value for money as well as improved client outcomes. ADHC's long-term strategy to improve value for money in the sector involves working in partnership with non-government organisations to reform funding arrangements.

The Agency is also investing more resources in the area of research, evaluation and data collection. This is to ensure that we have the best possible evidence base to help us make decisions on how we spend resources to ensure optimal outcomes for our clients and their families. These efforts help us to understand what works and why, and where gaps in services and support exist.

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<sup>5</sup> \$1.3 billion is in the dollar terms of the year of announcement (i.e. 2006/07). 2010/11 dollar term is approximately \$1.5 billion.

The implementation of *Stronger Together* is discussed further in Chapter Two and in *Appendices 6 and 7*.

## **NSW State Plan**

In the *NSW State Plan*, the Government signals its commitment to expand the engagement of people with a disability in work, education and community life. Ageing, Disability and Home Care (ADHC) has responsibility for meeting two *NSW State Plan 2010* goals:

- Closing the gap in the unemployment rate between people with a disability and the overall community by 50% by 2016. This is equivalent to around 6,000 jobs; and
- Increase the out of home participation rate of people with a severe or profound disability to at least 85%. This is equivalent to an additional 8,900 people participating in the community.

Achieving these goals sits within the framework of *Stronger Together*, which provides real funding increases of \$270 million in its first five years to expand and improve programs that specifically target improving opportunities for community participation and transition to work.

Approximately half of the *NSW State Plan* target for the employment of people with a disability will be met through young people successfully completing our intensive skills based training programs, *Transition to Work* (TTW). More than half of the school leavers who participate in TTW successfully transition to employment or further education (compared with less than 5% before 2006). Had these improved results not been achieved, 1,420 fewer young people with a profound or severe disability would be in employment and there would have been an ongoing need for community participation supports.

The balance of the employment target will be met with a mix of other strategies that include promoting disability employment with the NSW public sector,



improving employment outcomes for people with disabilities from school and TAFE, using NSW Government procurement to create additional employment opportunities for people with a disability and, where possible, encouraging disability employment by the private sector.

In December 2009, the NSW Government exempted public sector agencies from regulations requiring open tenders when purchasing goods and services from registered businesses that employ mostly people with a disability. ADHC has provided funding to National Disability Services to promote the scheme and provide information about services provided by registered disability employers to public sector agencies.

ADHC is currently collaborating with the Department of Premier and Cabinet to develop a NSW Public Sector Employment Strategy and increase employment opportunities for people with a disability.

*Stronger Together* phase one gave school leavers unable to enter the workforce access to an ongoing program (*Community Participation*) designed to support their development and enhance their ability to continue to live independently in their own communities. The program also gives carers a respite effect and the opportunity to participate in the workforce. Over 2,000 young people have entered the program since 2006 and another 500 will enter in 2011. An independent client satisfaction survey conducted in 2009 found that 95% of clients and their families were positive about their services.

The Companion Card NSW was launched in March 2009 to enable people with a significant and permanent disability, who require attendant care for the rest of their lives, to participate in community activities and events. The Card enables free admission to attendant carers supporting people with a disability. There are 6,380 Companion Card holders in NSW and 1,880 businesses affiliated with NSW Companion Card.

***Better Together: a new direction to make NSW Government services work better for people with a disability and their families 2007-2011***

*Better Together* is the NSW Government's whole of government strategy that builds on commitments made in the *NSW State Plan* to promote fairness and opportunity for all people, including those with a disability, to participate in community life. Priority areas for action include:

*Accessible infrastructure* – 120 CityRail stations across the CityRail network are now independently wheelchair accessible, with further stations to be upgraded in the future. A total of 350 accessible buses entered service in 2008/09 – 295 in the Sydney Metropolitan Area and 55 in the Outer Metropolitan Area.

*Early intervention* – under this initiative, funding of \$10 million over five years has been allocated to increase the availability of quality early childhood intervention services for children with a disability aged under seven years and their families and to develop innovative early childhood intervention service models and practices for children with a disability and their families.

*Therapy access* – To make it easier for people to access therapy support in the community, agencies have identified the principles that support an effective therapy service system. This will improve therapy access. In addition, ADHC and the NGO sector are developing an evidence base by piloting outreach therapy service for aboriginal children and examining assistive technology for pre-school children. By the end 2010/11, the overall increase in the number of therapy places through *Stronger Together* will be over 3,700 places at a cost of \$51 million.

*Autism* – Strengthening services and support for people with autism spectrum disorders and their families by focusing on strengthening early detection, diagnosis and assessment services leading to clear intervention and support plans for individuals and their families. The investment in autism specific

services builds on and complements the NSW Government's investment in supports and services for all children and young people with a disability, including those with autism. Between 2007 and 2010, we will have invested over \$17 million to support children and young people with autism and their families through services, projects and activities specifically relating to autism. This amount will increase to \$22 million in 2010/2011, with the introduction of the Autism Early Years Demonstration Service, providing 20 child care places for children with autism, and outreach support for up to 50 children with autism in child care settings in Western Sydney. ADHC has also provided fixed term funding for three years for the provision of a Regional Assessment Service.

*Access to community support and specialist accommodation* – improving access, whether that be assistance to return home after hospitalisation, rehabilitation or nursing home care, or specialist supported accommodation for those that cannot return home. ADHC continues to work through partnerships to provide programs such as Young People in Residential Aged Care, Leaving Care, Disability Housing Support Initiative, Shared Equity, People with an Acquired Brain Injury, and Attendant Care.

*Carers* – supporting and recognising the 750,000 carers in NSW so that they are respected and valued, as well as improving services for carers and the people they care for. This commitment aligns with the *NSW Carers Action Plan*. Under *Stronger Together* the number and types of respite services available have been increased, providing greater flexibility and responsiveness to carer needs.

*Aboriginal Communities* – This focus complements *Two Ways Together*. Specialised training courses in otitis media for teachers, allied health workers, parents of Aboriginal children and communities continue to be provided.

*Research* – collaboration and communication between agencies in the area of disability research has been strengthened.

Implementation of the National Disability Strategy in NSW (see below) will further progress and expand work in this area.

### **The National Perspective**

From a national perspective the disability service system is characterised by complex and duplicated administration, accountability and reporting systems and policy and governance systems. This is despite the considerable and costly activities at the national and jurisdictional level aimed at delivering consistency of service outcomes across jurisdictions, and numerous agreements or arrangements to address specific issues such as cross border service delivery. This work includes the reform work commenced under the Commonwealth State Disability Agreement (CSDA) and continued through the National Disability Agreement, the development of the National Disability Strategy, as well as other cross border agreements and a Portability Protocol to facilitate the movement of people with a disability between jurisdictions.

Under the initial CSDA and subsequent agreements, responsibility for the provision of specialist disability services was separated, with the Australian Government responsible for employment services, and States and Territories responsible for all other specialist disability services. Shared responsibility remained for advocacy, print disability and information services. Total government expenditure on these services in 2008-09 was \$5.2 billion with State and Territory governments funding the majority of this expenditure (71.1 per cent, or \$3.7 billion)<sup>6</sup>.

Despite facing some common challenges - such as the legacy of disability services being perceived as the sole or main source of support for people with a disability, their families and carers - the shape of reform in each jurisdiction varies. Current reforms being progressed at various levels across many jurisdictions include:

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<sup>6</sup> Productivity Commission: *Report on Government Services 2010*

- Focussing service delivery on the person with a disability, and measuring effectiveness and the achievement of outcomes;
- Meeting the increasing complexity of client needs;
- Addressing disability service system constraints, including considering alternative sources of funding for disability supports;
- Building capacity of the workforce and the service sector; and
- Improving the quality of services.

### **The 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 has been developed as part of the significant reform work under the new Intergovernmental Agreement on Federal Financial Relations (IGA). The IGA has been 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. 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.

All governments agreed to reform directions which enhances the social and economic participation for people with disability, and supports their families and carers. The NDA includes commitment to achieving this through driving reform initiatives in ten priority areas and other areas of service delivery and accountability. A full list of the reform priorities is included at *Appendix 8*.

The process for delivery of this reform agenda has required considerable administrative and financial investment by all jurisdictions and the slow pace of reform achievement reflects the complexity of 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. NSW leads national work in two areas: improving the measurement of current and future need, and increasing the focus on early intervention and prevention.

For NSW, the new Agreement offers approximately \$1.74 billion in total funding over five years, including \$118 million in new funding. This brings the Australian Government's share of the contribution towards funding for the NSW specialist disability service system to approximately 19% for 2010/11, compared with the NSW Government's contribution of 81%.

All reforms specified in the Agreement complement and build on the significant developments already being progressed under the NSW Government's strategic plan for disability services, *Stronger Together: A new direction for disability services in NSW 2006–2016*.

The Agreement also clarifies roles and responsibilities, and includes new public accountability requirements. Of most significance is the inclusion within scope of the Agreement of income support for people with a disability and their carers. Given the centrality of income support in the lives of many people with a disability and their carers, this development provides the prospect of more considered policy development over time.

Additionally, the Agreement includes a commitment to working towards implementing the following Australian Government commitments, noting that further discussions are required about Australian Government resources to meet financial requirements:

**Ageing, Disability & Home Care (ADHC) Submission to the Parliamentary Inquiry**

- The establishment of a National Disability Strategy.
- Harmonisation of rules for accessible parking.
- The establishment of a National Companion Card Scheme.
- Ensuring Younger Veterans have access to specialist disability services.
- Modernise Print Disability Services.
- Community Aged Care Package election commitment – provision of top up disability supports for people living in group homes who are clearly demonstrating increased needs due to ageing.
- Consider improvements in the administration of advocacy.

## **National Disability Strategy**

The NDA recognises that improved outcomes for people with a disability, their families and carers, are contingent on effective coordination of efforts across all areas of government, not just the specialist disability system. The National Disability Strategy (NDS) is intended to be a key means for driving this coordination. It is anticipated that the strategy will be considered at the next COAG meeting.

The NDS will provide an overarching national policy approach to achieving and assessing progress for people with a disability in mainstream areas such as employment, income, education, health, transport, justice and infrastructure. The Strategy is also an important mechanism to ensure that the principles underpinning the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) are incorporated into policies and programs that have implications for people with a disability, their families and carers.

If approved by COAG, the first year of the Strategy will include the development of an implementation plan. The commitment and engagement of all NSW agencies will be sought over the next twelve months as the detail of implementation is worked through. The existing work of relevant agencies in improving access for people with a disability to services and facilities is recognised and it is anticipated that this existing work will be incorporated into the proposed NSW implementation plan. Implementation will occur within existing agency budgets. People with a disability, their families and carers, peak bodies and other stakeholders in the disability sector will be consulted in the development of the implementation plan.

## **Productivity Commission Inquiry into a National Disability Long Term Care and Support Scheme**

The NDS also seeks to maintain the profile of disability as a significant economic and social policy issue at a national level. It is a key vehicle for continuing the impetus of support for the Productivity Commission Inquiry into a National Disability Long Term Care and Support Scheme currently underway



and the opportunity this provides to address future resourcing of the disability sector.

The Productivity Commission Inquiry recognises that one of the great achievements of the medical, health care and therapeutic communities – as well as generations of professional and family carers – is that people who are born with, or who acquire, a disability are living longer and healthier lives than ever. Yet the government and broader community faces the reality that to sustain those remarkable achievements, there needs to be new, innovative and sustainable ways of funding the services and care that people with long-term support need both now, and into the future.

The Commission will examine a range of options for long-term care and support, including consideration of whether a no-fault insurance approach to disability is appropriate in Australia. It will also examine if a scheme would fit with Australia's health, aged care, income support and injury insurance systems.

## CHAPTER TWO: Supply and Demand of Disability Services in NSW

### Supply of Disability Services in NSW

In 2010/11 NSW will spend \$1.9 billion on the disability specialist services system.<sup>7</sup> An estimated 50,000 people with a disability and their families will receive supports from the NSW disability specialist services system.<sup>8</sup> See Fig. 7 below.

**FIG. 7 - Estimate of Budget and client counts by specialist disability program – NSW - 2010/11**

Program	ADHC Operated		ADHC funded		TOTAL	
	Clients	\$M	Clients	\$M	Clients	\$M
<b>Short term community supports</b>						
Support for families and children			7,300	40	7,300	40
Transition to Work			1,800	25	1,800	25
Therapy and other interventions and case work	13,000	80	15,000	27	28,000	107
Advocacy				10		10
<b>Ongoing community supports</b>						
Intensive personal care			700	57	700	57
Respite	1,900	35	8,000	93	9,900	128
Community Participation (inc. PSO)			5,000	130	5,000	130
Day Programs	300	12	8,000	72	8,300	84
<b>Specialist supports</b>						
Community Living	1,600	230	5,750	450	7,350	680
-Boarding house relocation						
-Leaving Care						
-Criminal Justice Program						
Large Residences	1,100	175	570	35	1,670	210
Emergency Response			150	15	150	15

Source: ADHC 2010/11 Budget Allocation; Preliminary MDS Data

Note: The client counts are unique by program only. The costs are direct service costs.

This compares with expenditure of \$590 million in 1998/99. Adjusted for inflation, this represents a real increase in disability funding of 120% for the period.

### ***Stronger Together: a new direction for disability services in NSW 2006-2016.***

In 2006 the NSW Government announced *Stronger Together: a new direction for disability services in NSW 2006-2016*. This 10 year commitment aimed to provide greater assistance and long-term practical solutions for people with a disability and their families. It detailed the government's commitment to making access to services

<sup>7</sup> This does not include funding for the HACC or Ageing Programs.

<sup>8</sup> This is an estimate of unique clients; clients often receive more than one service, hence the number of clients in Figure 7 is greater than the unique count.

fairer and more transparent, helping more people to remain in their own homes, linking services to need, creating more options for people living in specialist support services, and ensuring the long term sustainability of the service system.

The NSW Government committed over \$1.3 billion in new funding for the first five years of *Stronger Together* to 30 June 2011. See Figure 8. This reflected the need for an alternative approach and action in a number of areas:

- the demand for services is increasing each year. There was a need to provide more services and also to find ways to provide services more efficiently.
- services needed to be designed around the needs and circumstances of individuals and families, instead of a 'one size fits all' approach.
- the service system needed to be 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 needed to recognise peoples' 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.

**FIG. 8 – *Stronger Together* funding 2006/07 – 2010/11\***

<i>Stronger Together</i> funding	2006-07	2007-08	2008-09	2009-10	2010-11	TOTAL
	\$M	\$M	\$M	\$M	\$M	\$M
<b>TOTAL</b>	<b>155</b>	<b>193</b>	<b>282</b>	<b>332</b>	<b>378</b>	<b>1,339</b>

\* The announced cost was \$1.3 billion for the five years to 30 June 2011. That is \$1.6 billion in current dollars (taking account of indexation and additional capital provided in 2008 for decisions deferred when the original five year funding was approved).

Real progress has been made in the first four years of *Stronger Together* implementation. We know that the vast majority of care for people with a severe or profound disability comes from informal supports. We also know that early support for people with a disability and their families produces optimal social and economic outcomes. Accordingly, investments are being directed to reconfigure the disability services system in a way that focuses on early childhood intervention, and increases

community supports to enable families to remain together, carers to continue to care, and people with a disability to reach their full potential to participate in the community. Where people are not able to remain living with their families and carers, cost effective and sustainable models of support are delivering good results to the most vulnerable people in our target groups.

By 2009/10 an additional \$961 million had been invested in the disability sector under *Stronger Together*.<sup>9</sup> An outline of service expansions as at the end of 2009/10 is provided in Fig. 9. More detailed information is available in *Appendices 6 and 7*.

**FIG. 9 – *Stronger Together* Service Expansion data as at 30/6/10\***

<b>Specialist Disability Services Expansion: New Places as a result of <i>Stronger Together</i> implementation</b>		
	<b>New places allocated in the first 4 years (by 30/6/10)</b>	<b>Target in the first 5 years</b>
Therapy	3,157	2,880
Case Management	3,960	3,990
Behaviour Support	280	280
Family and Children's Services	5,455	3,040
Family Assistance Fund	6,412	0
Respite	3,289	1,330
Older Parent Carers	1,029	0
Day Programs	815	780
Post-school Programs	3,924	4,000
Specialist Supported Accommodation	677	990
Other Specialist Support	310	340
Leaving Care	224	450
Leaving Corrections	143	200
Innovative Targeted Support (accommodation support) for Aboriginal and CALD Clients	30	0
Disability Housing and Support Initiative	50	40
Intensive in-home support (ACP)	320	320
Younger People in Residential Aged Care	501	300
<b>Totals</b>	<b>29,899</b>	<b>17,950</b>

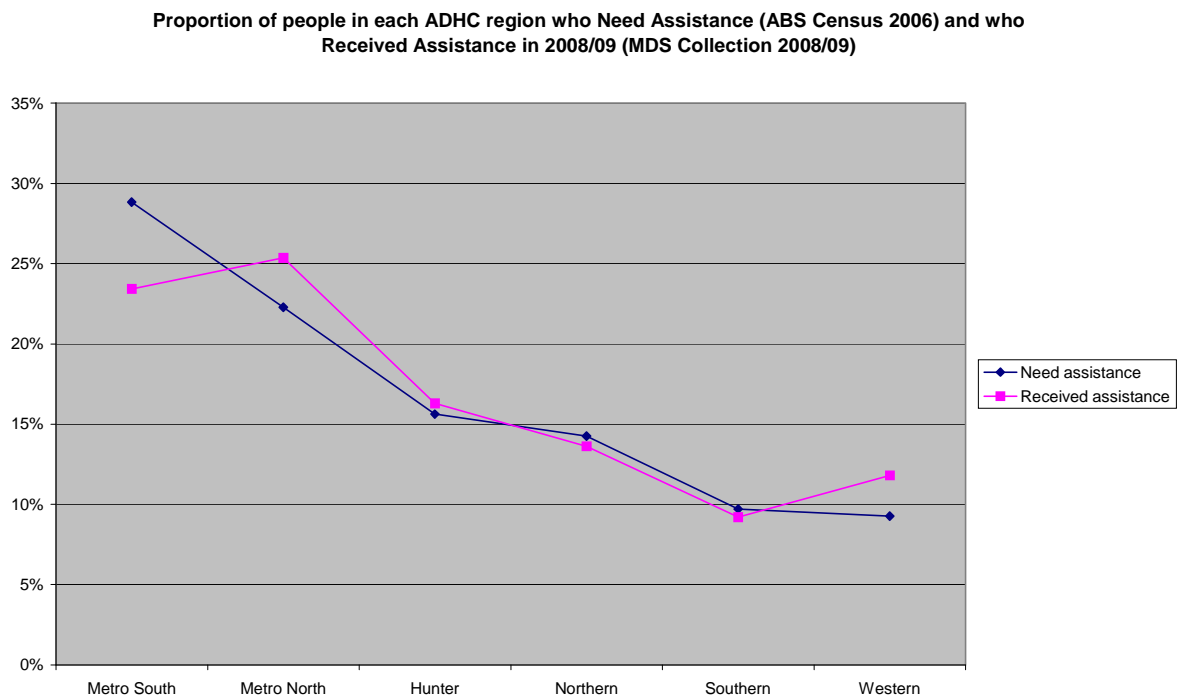
\* Preliminary data (unpublished)

<sup>9</sup> \$961 million is the announced investment (in 2006/07 dollars) for the first four years.

## Equity of Access

ADHC employs equity of access indicators to monitor whether people with a disability have equitable access to service irrespective of where they live in the State, or their Aboriginal and CALD status. Inequities in the regional supply of services relative to disability population prevalence were identified for each service type in the rollout of *Stronger Together* phase one funding and funding allocated accordingly. Fig. 10 below compares the current proportional allocation of specialist disability services by ADHC region to the proportion of people needing support to give an idea of equity across regions. It suggests that clients in the Metro South are relatively disadvantaged in receiving assistance compared with clients in Metro North.

**FIG. 10 -**



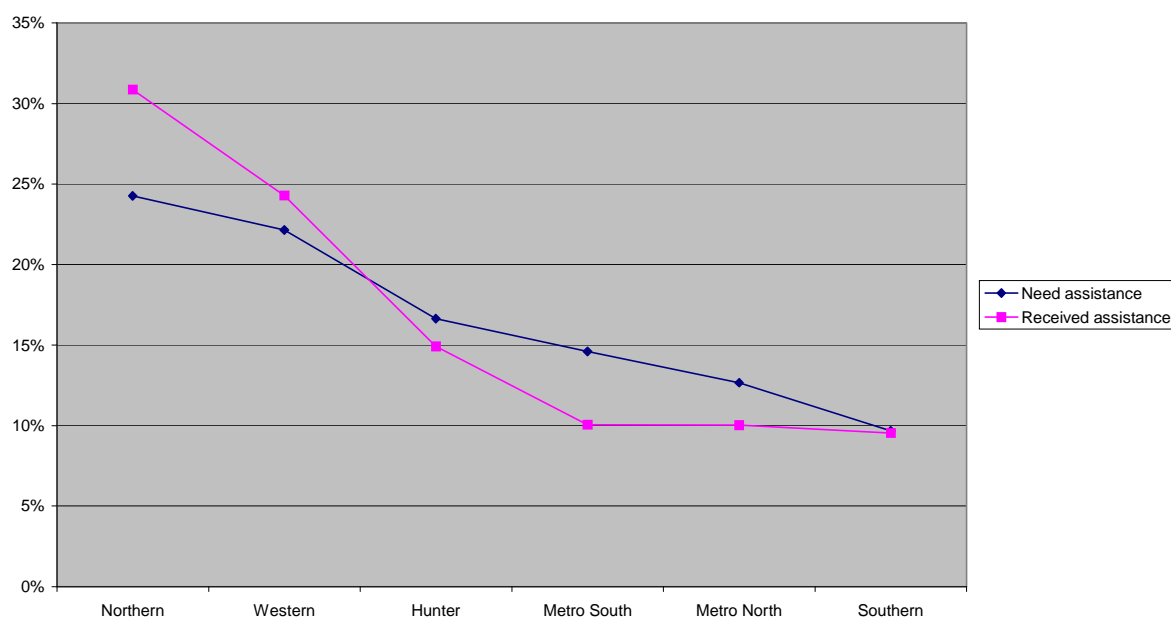
ADHC also monitors and measures its service delivery activity in relation to equity of access to services by Aboriginal people and people with a culturally and linguistically diverse (CALD) backgrounds on an ongoing basis. Evidence suggests a strong correlation between the proportion of services being received by Aboriginal people in a region and the number of Aboriginal people in that region. Similarly, the Metro South Region has the highest concentration of people from a CALD background and

also has the highest representation of CALD clients compared to other Regions. See Figures 11 and 12.

Notwithstanding these correlations, ADHC believes that it needs to do more to improve access to services by Aboriginal clients and clients from a CALD background and to improve the cultural appropriateness of services. Initiatives underway are outlined in Chapter three.

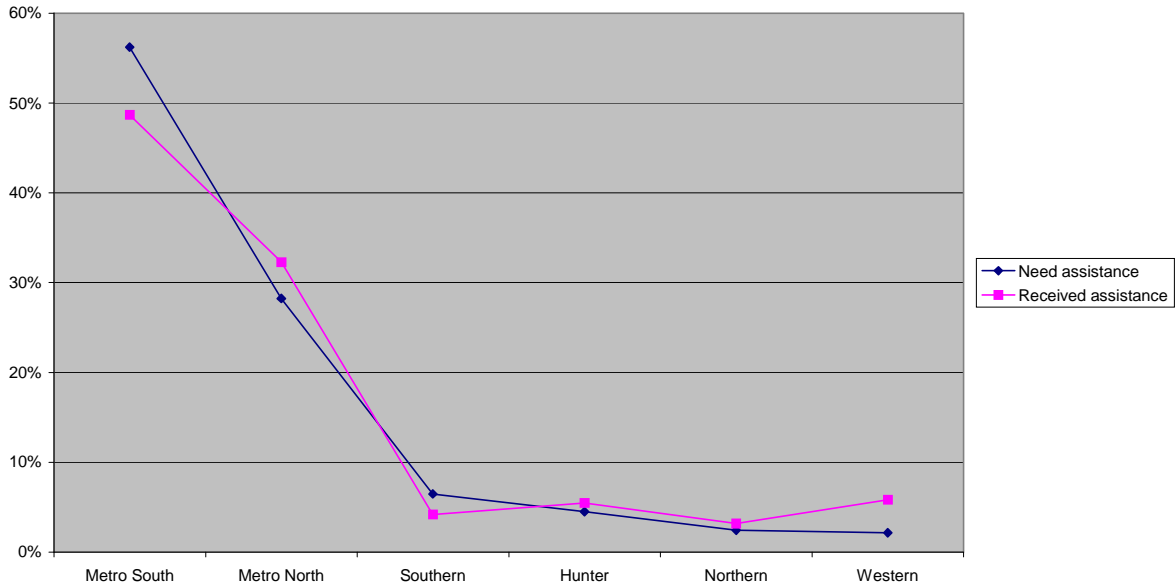
**Fig. 11**

**Proportion of Indigenous people in each ADHC region of NSW who Need Assistance (ABS Census 2006) and the Proportion who Received Assistance in 2008/09 (MDS Collection 2008/09)**



**Fig. 12**

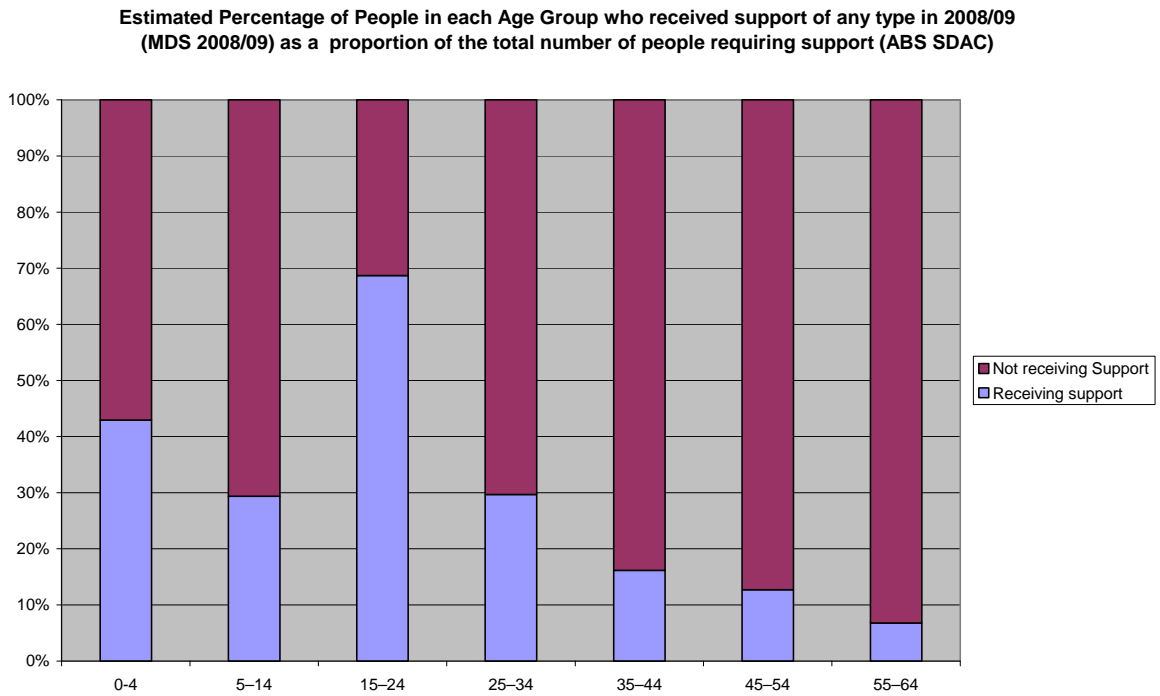
**Proportion of people from CALD background in each ADHC region of NSW who Need Assistance (ABS Census 2006) and the Proportion who Received Assistance in 2008/09 (MDS Collection 2008/09)**



### **The relationship between age cohorts and service delivery**

The same approach to equity of service delivery is not taken with respect to age. The age distribution of people with a disability does not correlate with the age distribution of service delivery because *Stronger Together* places greater emphasis on early intervention and prevention and community support for school leavers. Figure 13 below illustrates this point by showing that children and young people with a profound or severe disability are much more likely to receive support of any type than people in the older cohorts.

**Fig. 13 -**



However, care needs to be taken in reading Figures 13 to 16. The “need for assistance” data which is available through the ABS does not identify what type of assistance people require, nor does it identify whether the assistance sought is assistance from the specialist services system. Moreover, different age groups do have different support needs.

Fig. 14 below illustrates ADHC's focus on people leaving school through post school programs. In the 15-24 age group, approximately 35% of people with a severe and profound disability are being assisted with community access programs compared to less than 5% of people aged between 55-64 years.



**Fig. 14**

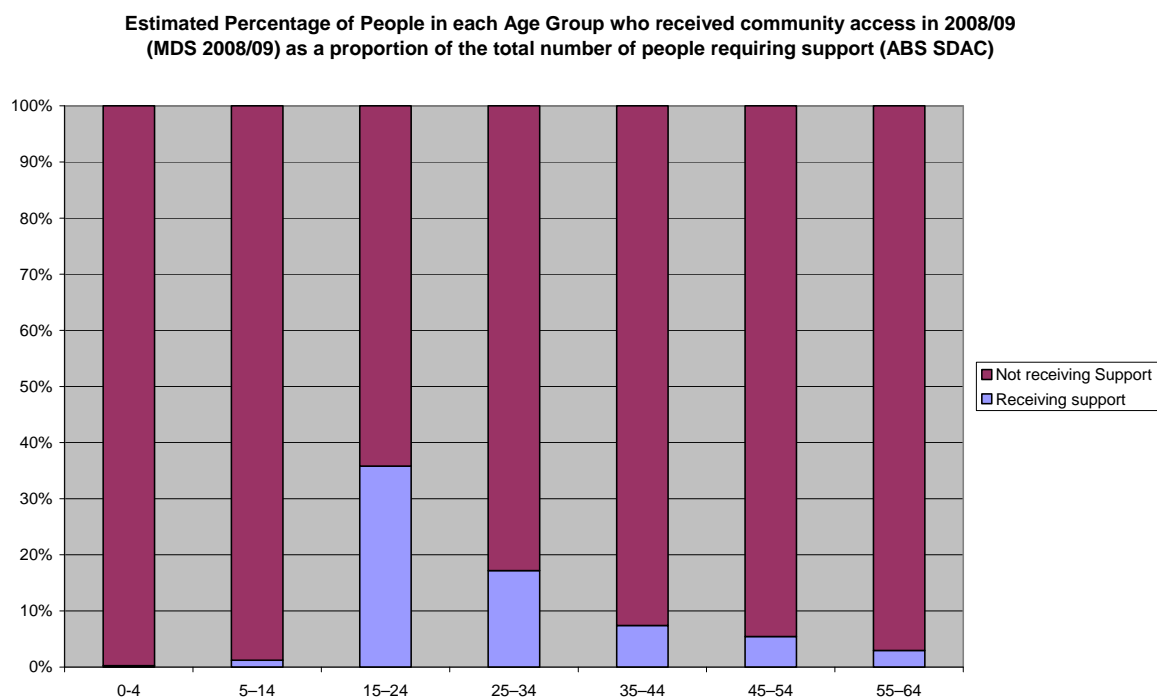
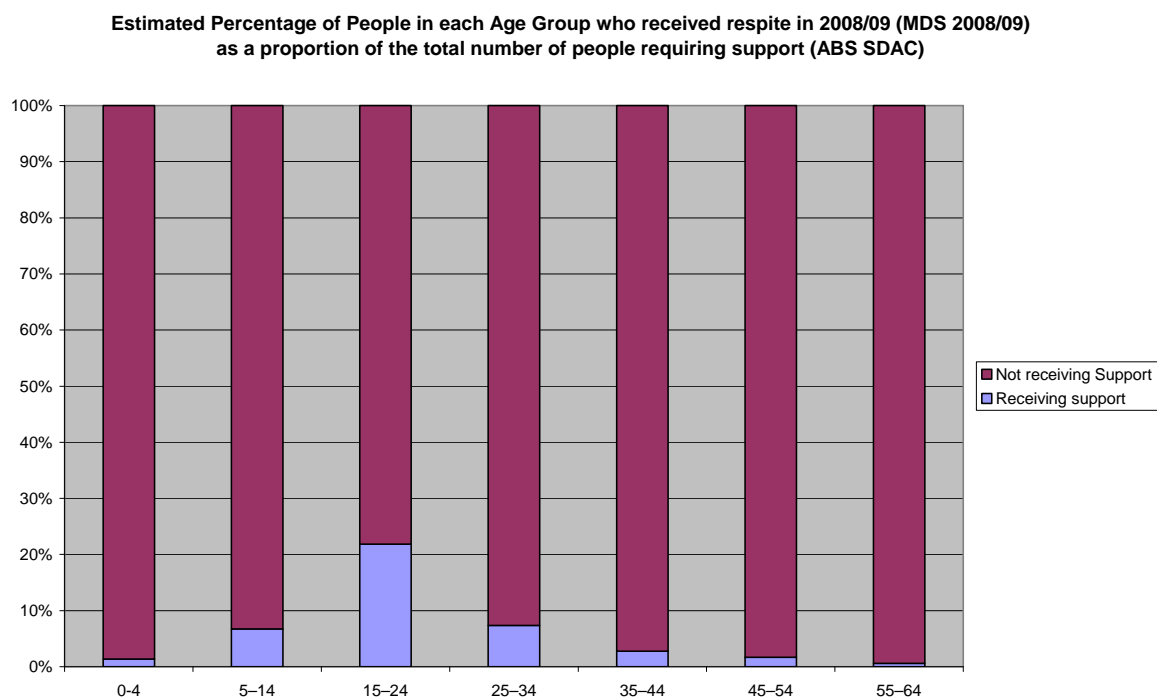


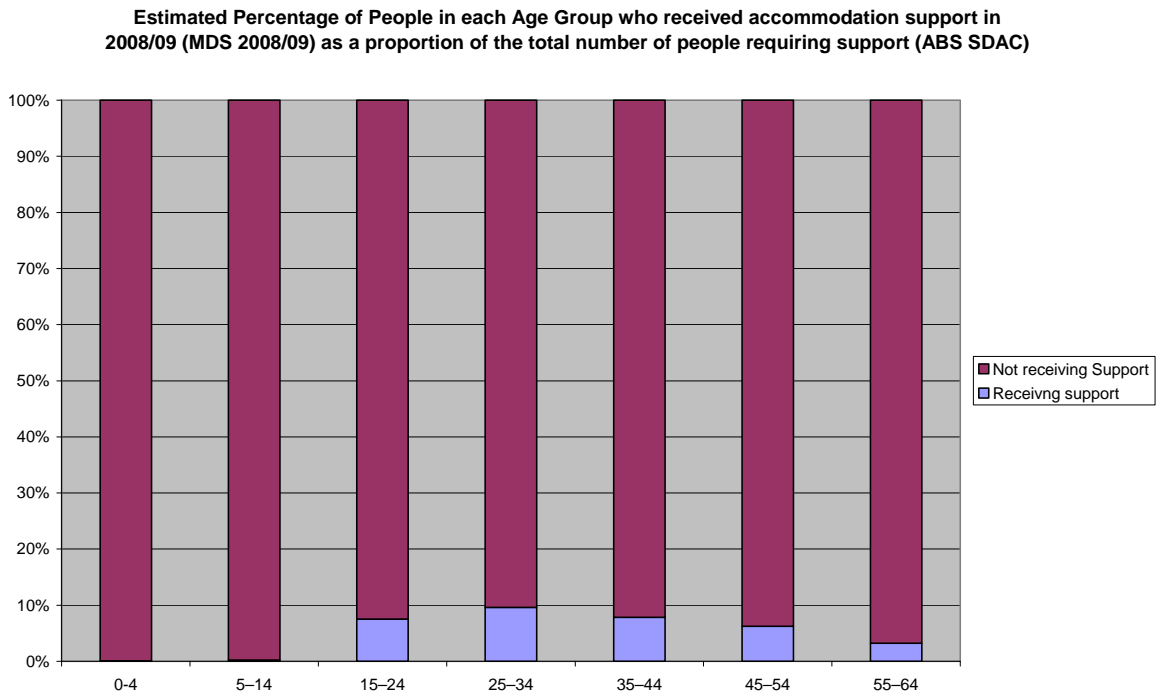
Figure 15 below illustrates that children, young people and their families and carers are most likely to be benefiting from respite services.

**Fig. 15**



The age groups most likely to be receiving accommodation support are in the 25 to 54 year categories, as illustrated in Fig. 16.

**Fig. 16 -**



### ***Stronger Together* service delivery expansions**

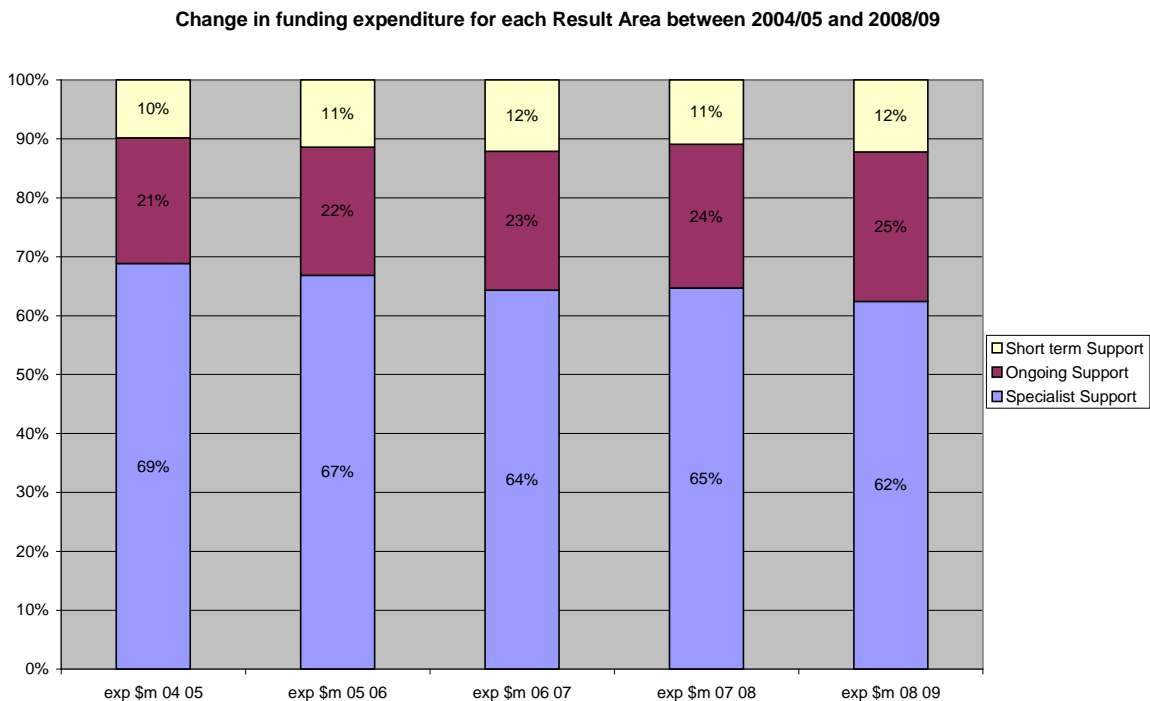
By changing our approach to service delivery, NSW has been able to almost double the number of people and families receiving disability supports. So far, over the course of *Stronger Together*:

- Over 20,000 people have been helped through early childhood intervention and family support, therapy day programs, respite, attendant care.
- Over 1,000 people have been placed in new supported accommodation places with new models being introduced.
- Four large residential centres have closed or are closing.
- New gate keeper controls have been introduced to put more rigour over entry to supported accommodation services.
- More flexible approaches to service planning have been implemented to ensure families receive the most appropriate supports at the right time.

- Stronger relationships in the sector have created a rich environment for collaboration and reform.

*Stronger Together* has grown capacity across all service types and has helped us to operate services more efficiently. The first three years of funding has seen the overall mix of disability services change, with a greater proportion of people moving into ongoing and short term community supports (see Figure 17). Whilst specialist accommodation services are an important part of the service system, increased community supports are essential to enable the broad needs for people with a disability and their families and carers to be met.

**Fig. 17 -**



**Specialist Support**

People who received support under the following programs:

- Community Living (ADHC and NGO);
- Large Residences (ADHC and NGO);and
- Emergency Response.

**Ongoing Support**

People who received support (usually ongoing) under the following programs:

- attendant care;
- respite (ADHC and NGO);
- community participation (including PSO); and
- Community Engagement/Day Programs

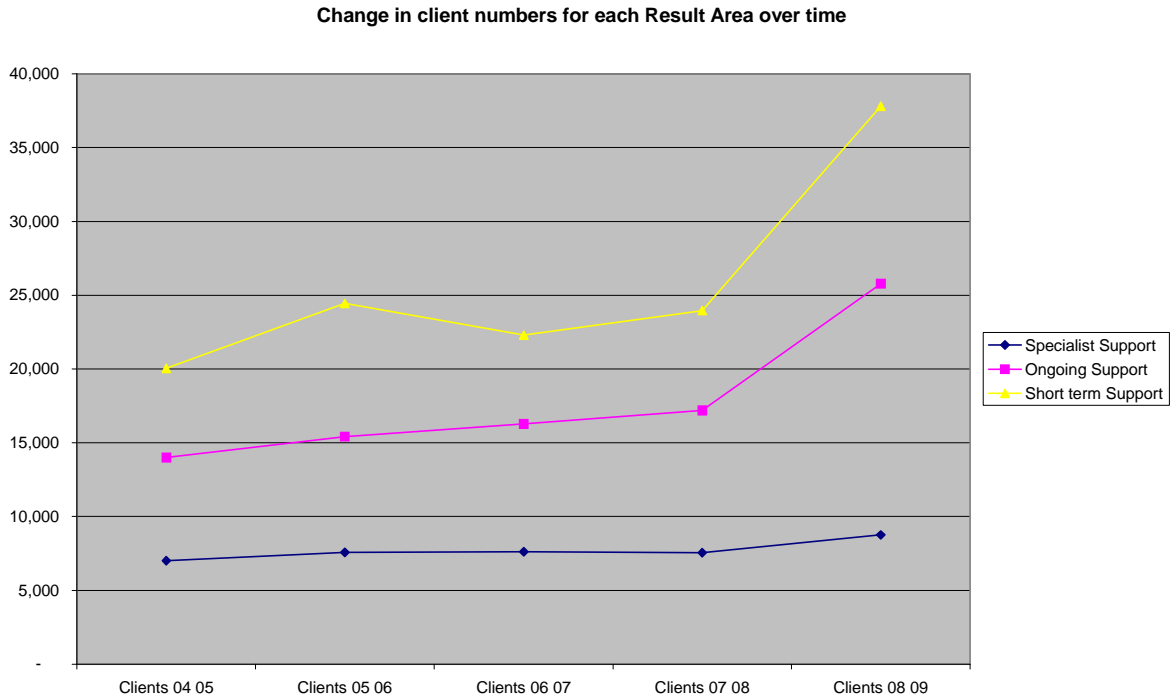
**Short term support**

People who received support (usually short term) under the following programs:

- Support for families and Children
- Therapy and Prevention
- Transition to Work

More importantly, the number of people receiving short term and ongoing community supports has increased significantly. The number of people receiving short term supports has increased from 20,000 to over 35,000, whilst the number of people receiving ongoing supports has increased from 15,000 to over 20,000 (see Fig. 18).

**Fig. 18 -**



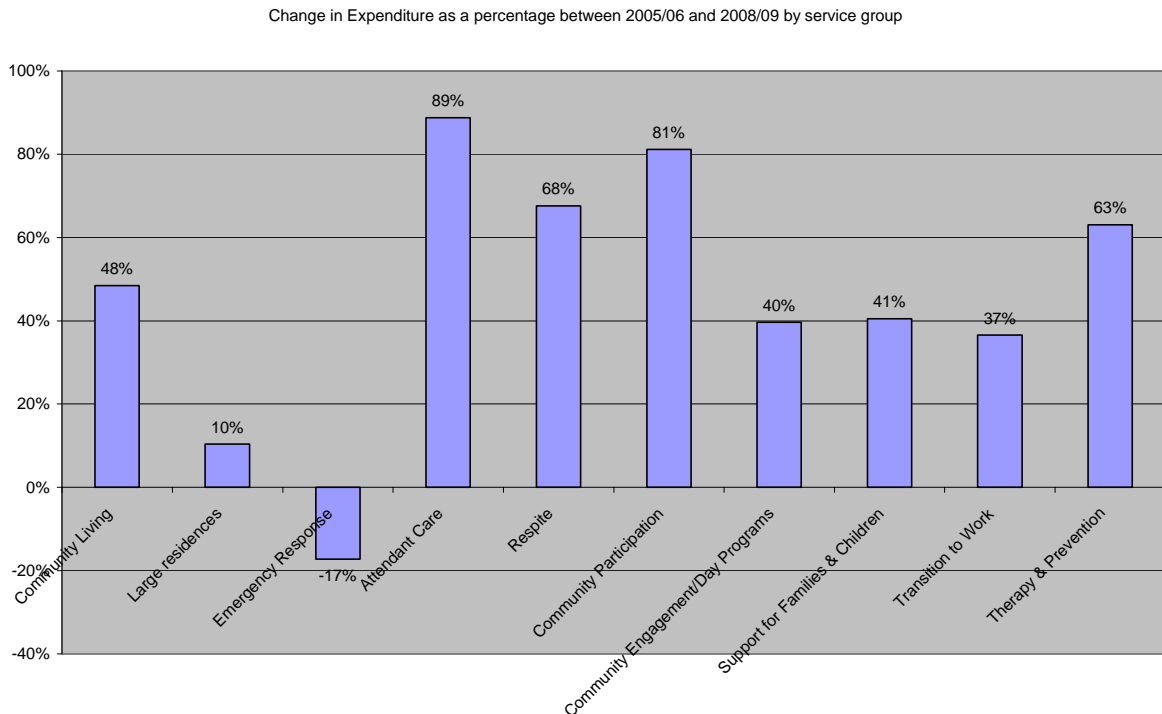
A breakdown of this data by region is available at *Appendix 9*.

Being able to assist more people with a disability and their carers in a wider variety of circumstances has led to reduced reliance on Emergency Response funding and fewer respite bed blockages. Emergency Response services are designed to provide a short term response to people with a disability who are homeless, or are at risk of homelessness. Expenditure in this service type reduced by 17% between 2005/06 and 2008/09 and continues to do so with 2009/10 and 2010/11 allocations. This represents a 67% reduction in the number of people with a disability receiving emergency response services. At the same time, places and expenditure in service groups such as respite, community participation and attendant care have increased substantially. For example, the number of people accessing respite increased by 125%. See Figures 19 and 20.

Similarly, the number of people blocking centre based respite beds has reduced to its lowest level in over 10 years. Currently fewer than 5% of beds are temporarily unavailable due to clients overstaying their planned period of respite, compared with up to 20% in 2006. If the 2006 trend had continued, each year some 1,000 families would have had their respite withdrawn or severely disrupted. Lack of access to planned respite is a main contributing factor to families being unable to continue to care.<sup>10</sup>

In addition to delivering better outcomes for people with a disability and their families, the *Stronger Together* strategy has reduced the average unit cost per service user by investing efficiently; this has enabled NSW to acquire the equivalent of an additional \$150 million in services annually by the end of 2010/11.<sup>11</sup> For example, between 2006 and 2009, respite expenditure increased by 68% and the number of people receiving respite services increased by 125%.

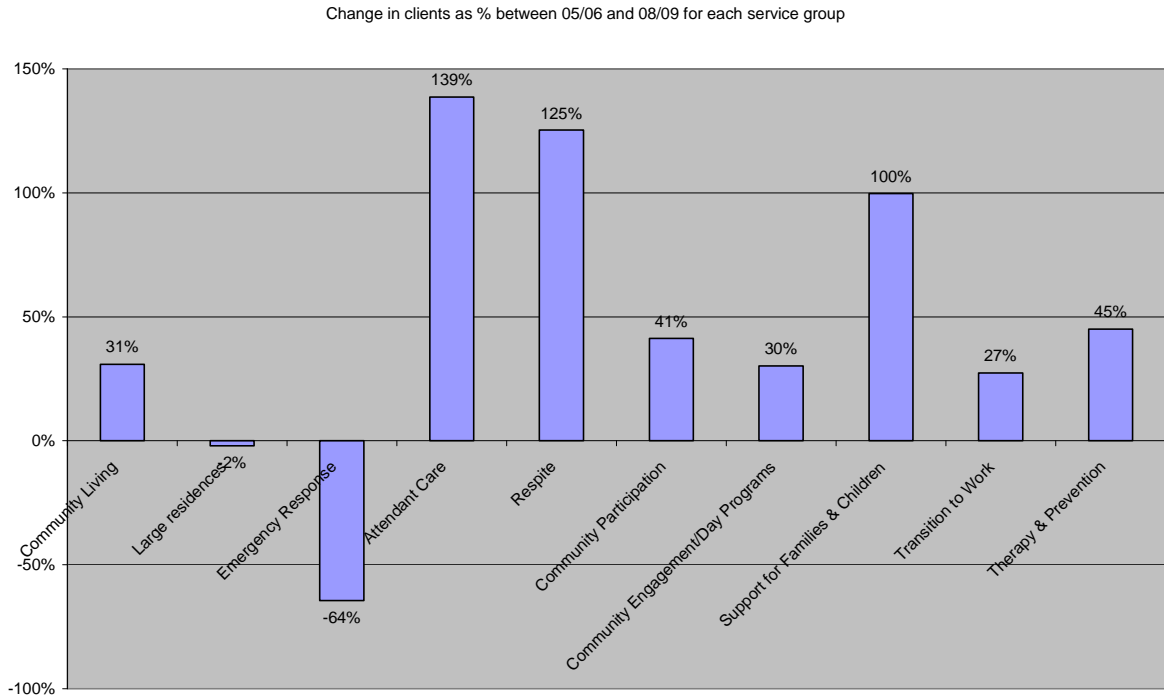
**Fig. 19**



<sup>10</sup> Nankervis et al (2009, RMIT)

<sup>11</sup> PriceWaterhouse Coopers uses a service mix analysis to estimate savings of \$150 million or almost 12 % in the first five year phase of Stronger Together through a reduction in average cost per client from \$27,700 in 2004/05 to \$24,950 in 2010/11 (2010).

**Fig. 20**

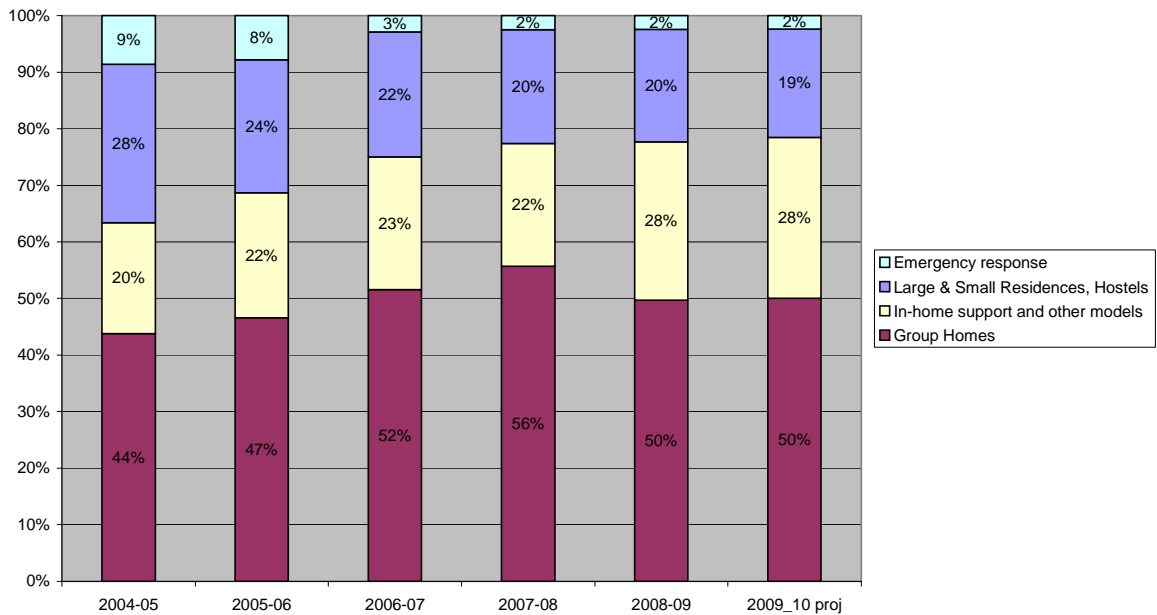


The focus on ensuring that people with a disability are supported to live as independently as possible is reflected in the change of specialist accommodation models being utilised. ADHC has increased the availability of in-home supported accommodation models whilst continuing to invest in 24 hour group homes, and significantly reduced reliance on Large and Small Residential Centres and emergency responses.

Between 2004/05 and 2009/10, the proportion of specialist accommodation support clients receiving in-home support increased from 20% to 28%, while the proportion of clients receiving emergency responses fell from 9% of accommodation clients down to 2% (refer to Figure 21).

**Fig. 21**

**Changes in clients in each Supported Accommodation Group as a percentage of all clients over the period 2004/05 to 2009/10**



More information on the successful implementation of the first phase of *Stronger Together* is at *Appendices 6 and 7*.

## **Demand for Disability Services in NSW**

### **Data Limitations**

There are no authoritative data sources that enable us to determine the level of need in the population that is not being met by government funded interventions and which requires such an intervention. In recognition of this, at a meeting on 4 June 2010, State and Australian Government Disability Ministers endorsed the methodology for the development of a National Need and Supply model. Ministers noted the potential of such a model to assist jurisdictions with strategic planning for the long term sustainability of disability service systems in several ways, including:

- As a basis for expanding or changing service delivery approaches;
- To forecast trends in growth, changes in the care support structures, and associated fiscal impacts;

- Improving accountabilities between service providers and users; and
- As an evidence base to support why certain actions have been taken, and to evaluate the outcomes of those actions.

The proposed model will build on work developed for NSW by PriceWaterhouse Coopers and will be overseen by NSW officials. It will include a baseline of current demands of people with a disability in Australia, and a projection model that quantifies future potential demand through to 2031. The model will provide national estimates by Level of Assistance required, Age, Disability type, Formal and informal assistance received, and Carer status.

The model matches need to supply to determine the extent to which formal services met the need within the potential population. The model is constructed to allow a projection of need into the future, to test various supply side scenarios against this future need and to estimate potential cost implications for each scenario.

Despite the lack of authoritative data sources, there are several sources which indicate that there is substantial demand not met by government funding and that demand for services will grow. Each of these has qualifications and none enables a simple identification of the level of need which has to be met from the government funded specialist disability system.

- Performance to date – current growth in services as a result of *Stronger Together* investment appears to have kept pace with demand – as evidenced by the reduced use of Emergency Responses and blocked respite (see earlier section on pp. 40-41).
- Cross-jurisdictions – The Report on Government Services 2010 suggests that, on average, fewer people in the NSW disability population access government funded disability services than in other jurisdictions.<sup>12</sup> In 2007/08, an estimated 15% of people with a disability in NSW accessed services, compared with 32% in Victoria and a national average of 21%. See Figure 22. However, interpreting this data needs to take account of jurisdictional variations in data quality,

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<sup>12</sup> Australian Government Productivity Commission. *Report on Government Services 2010*.



methodology and the mainstream services and supports available. Whilst the NSW rate appears lower than the national average, the national average is distorted by Victorian data which includes service types not included in the NSW data collection.

**Fig. 22**

State/territory only Disability Service 2007/08									
	NSW	Vic	Qld	WA	SA	Tas	ACT	NT	Aust
Unique users (excl psychiatric clinical only) (a)	35,923	56,321	20,112	15,600	19,350	4,172	3,675	1,912	156,343
Estimated potential population (b)	237,599	174,558	149,535	75,114	54,368	17,856	11,702	10,704	731,550
Users/PP	15%	32%	13%	21%	36%	23%	31%	18%	21%

Sources  
 ROGS 2010 Table 14A.12  
 ROGS 2010 Table 14A.15

- The Australian Institute of Health and Welfare (AIHW) estimates that the number of people in NSW with unmet supported accommodation needs is around 10,000.<sup>13</sup> However, the methodology used to assemble this data reflects support needs without taking account of existing informal care supports.
- Population dynamics
  - Numbers of people with a disability. This is relatively easily quantifiable; actuarial advice indicates that the population of people with a disability is growing at around 2-3% a year.<sup>14</sup> This is due to general population growth and people with a disability living longer. This does not take account of demographic and social factors that impact on the role and capacity of carers.
  - Numbers of carers and their capacity. It is clear that changes in this component are contributing to increasing need. Long term trends in carer capacity modelled by The National Centre for Social and Economic Modelling (NATSEM) signal a decline in carer capacity over time, mainly due to the ageing of the carer population as people with a disability live longer, and other demographic factors such as the tendency towards smaller families and increased female workforce participation. 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.<sup>15</sup>

<sup>13</sup> Australian Institute of Health and Welfare 2007. *Current and future demand for specialist disability services*. Disability series. Cat. No. DIS 50. Canberra: AIHW. Note: This figure is extrapolated from the national total of 27,800. The NSW share based on the 2003 ABS SDAC survey is 1/3 or approximately 10,000.

<sup>14</sup> PriceWaterhouse Coopers (2010) estimates that the population of people with a severe or profound disability is increasing at a rate of approximately 2.6% per year as a result of more people having disabilities and increasing life-spans.

<sup>15</sup> (Ranmuthugala, Binod & Brown. NATSEM. Australian Family Physician Vol 38. No. 8. 2009)

Nonetheless, quantifying the contribution this component will make to need cannot be undertaken objectively on current data as it needs to take account of issues such as changing expectations of the respective roles of governments and carers and the long term effectiveness of carer support interventions and interventions to build the capacity of people with a disability.

- Administrative data – Information from ADHC Need Registers and other sources is dealt with in more detail in the following section.

### **Administrative data – ADHC Need Registers**

ADHC operates a range of services for people with a disability and has needs registers for clients requesting assistance from ADHC operated services where those services cannot meet requests immediately. In the case of 24 hour supported accommodation, the needs register is for both ADHC operated and funded services. However, the greater proportion of disability community support services are provided through funding to the non-government sector and ADHC does not have a consolidated picture of people who request assistance from non-government providers. Whilst ADHC is working to further improve intake and allocation of resources,<sup>16</sup> with the exception of supported accommodation, intensive in-home support and post school programs, generally each non-government service provider works directly with people with a disability who request assistance from them.

### **Demand for Supported Accommodation**

ADHC is building more comprehensive and accurate administrative data on demand for supported accommodation.

The focus of this work is to quantify the number of people who have indicated a need for supported accommodation, be it government operated or funded services. In addition the register records the type of support the person will require, ranging from 24 hour support through to drop in support in their own home, as well as the demographic characteristics of these people.

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<sup>16</sup> For example, the NSW Auditor General indicates in the performance audit, "Access to Overnight Centred-Based Disability Respite" (May 2010) that ADHC has improved the management of respite since 2006/07, and that the Respite Assessment and Booking System under development will further improve performance.

As at 30 July 2010, the Register of Requests for Supported Accommodation records over 1,729 people who have indicated the need for 24 hour supported accommodation now or in the future. It is only recently that ADHC has begun capturing this information in a consistent and comprehensive way. To date the emphasis has been on identifying those who are willing to take up a 24 hour supported accommodation place immediately it is offered. As a result the data on need for non 24 hour supported accommodation are limited.

Of the 1,729 people on the Register, 723 are identified as needing a 24 hour supported accommodation place and are willing to take up a place immediately on offer. The remaining 1,006 have indicated an anticipated future need for supported accommodation.

**Fig. 23 People requesting supported accommodation by Region**

Need	Hunter	Metro North	Metro South	Northern	Southern	Western	Total
Willing to take up a place immediately on offer	198	153	146	111	69	46	723
Anticipated future requirement	179	435	70	10	58	254	1006
<b>Total</b>	<b>377</b>	<b>588</b>	<b>216</b>	<b>121</b>	<b>127</b>	<b>300</b>	<b>1729</b>

As at 30 July 2010

Figure 24 below provides information on the primary disability of the people on the Register. Over 60% of clients on the register are in the “Intellectual” Primary Disability Group. This rises to almost 70% for those clients who would take up a place immediately on offer.

Of the individuals identified as willing to take up a place immediately on offer, 432 (or 60%) currently live in private residences. See Figure 25.

Approximately 63% of people on the Register have a primary carer. In the case of individuals identified as willing to take up a place immediately on offer, 96 have carers in the 65 years plus age group. Available data suggests that 40% of those with an immediate need have carers who are aged 55 years and above. See Figure 26.

Fig. 24 Individuals requesting supported accommodation by disability type

Primary Disability Group	Anticipated	Immediate	Total
Acquired Brain Injury	39	62	101
Autism	30	25	55
Deaf/blind		1	1
Hearing	3		3
Intellectual	597	494	1091
Neurological	32	20	52
Not stated	5	1	6
Physical	82	55	137
Psychiatric	31	43	74
Speech	1		1
Vision	17	2	19
Not Completed	169	20	189
<b>Total</b>	<b>1006</b>	<b>723</b>	<b>1729</b>

Fig. 25 - Current Residential Settings of Individuals requesting supported accommodation who are willing to accept a place immediately

Residential Setting	Hunter	Metro North	Metro South	Northern	Southern	Western	Total
Boarding house/private hotel	5	1	8	1		1	16
Crisis accommodation facility	1	5	34	1	2	1	44
Domestic-supported facility		2		5			7
Group Home	6	10	10	6	5	10	47
Hospital	10	2	9			1	22
Not stated	3	3					6
Other	9	7	5	3	1	1	26
Private residence	111	94	64	83	56	24	432
Psych/mental health facility		1	5	1	2	1	10
Public place/temporary shelter	1	1					2
Residence in an ATSI Community					1		1
Residential aged care facility	24	5		3	1	3	36
Retire village independent unit		1					1
Supported accomm facility	8	6	7	5	1	4	31
Not Completed	20	15	4	3			42
<b>Total</b>	<b>198</b>	<b>153</b>	<b>146</b>	<b>111</b>	<b>69</b>	<b>46</b>	<b>723</b>

Fig. 26 – Primary Carers by Age for Individuals requesting supported accommodation who are willing to accept a place immediately (data items only available in 439 cases)

Client Age Group	Primary Carer Age Group							Unknown	Total
	18-24	25-34	35-44	45-54	55-64	65-74	75+		
Under 18			7	9	1	1	1	11	30
18-24		1	11	50	15	5	6	26	114
25-34		1	1	23	38	11	4	47	125
35-44		1	3	1	15	21	7	28	76
45-54	1			5	2	11	16	24	59
55-64				1	4	2	11	16	34
65-74								1	1
<b>Total</b>	<b>1</b>	<b>3</b>	<b>22</b>	<b>89</b>	<b>75</b>	<b>51</b>	<b>45</b>	<b>153</b>	<b>439</b>

## **Demand for ADHC Operated Respite**

ADHC does not have a consolidated register of demand for respite across ADHC operated services and funded services. ADHC operates only centre based respite and records demand for this type of respite on its Client Information System (CIS).

As at 30 June 2010, there were 31 people on the register awaiting the allocation of an ADHC provided respite service. This relatively low number of people does not reflect a lack of demand for respite. Rather, it reflects people who are involved in respite orientation processes prior to their first use of respite. It is not a measure of unmet need.

ADHC-operated services have generally tried to provide some respite to all clients rather than completely meeting the needs of a few. As a result clients may not always receive the level of respite they want.

On 5 May 2010, the NSW Auditor General released a Performance Audit on access to overnight centre-based disability respite. Its recommendations relate to better utilisation of services based on need and improved performance monitoring. It also recommended that ADHC speed up the development of its Respite Assessment and Booking System to improve consistency in planning and delivering respite across the State. ADHC fully accepts the Auditor-General's recommendations.

## **Demand for ADHC Operated Community Support Services (Therapy, Behaviour Support and Case Management)**

ADHC does not have a consolidated register of unmet demand for therapy services across the ADHC direct and the funded sector. Actions are underway to establish Regional processes to monitor demand across the whole sector. The data provided below relate to the needs register for ADHC-operated services only.

At present, ADHC's Client Information System (CIS) records 13,686 distinct requests for a Community Support Team (CST) service (therapy, assessment, behaviour

support, case management, and other services). Because of the complex and significant support needs of many people with a disability, an individual can have more than one request for service at any time and / or receive more than one service at any time (a request for therapy and a request for behaviour support may be on the register whilst a request for case management is being met). Consequently, these 13,686 requests are requests from a total of 8,851 distinct people.

**Fig. 27**

<b>ADHC Register of Need for Community Support Team services</b>	
Number of distinct requests for service	13,686
Number of clients who are waiting for service	8,851

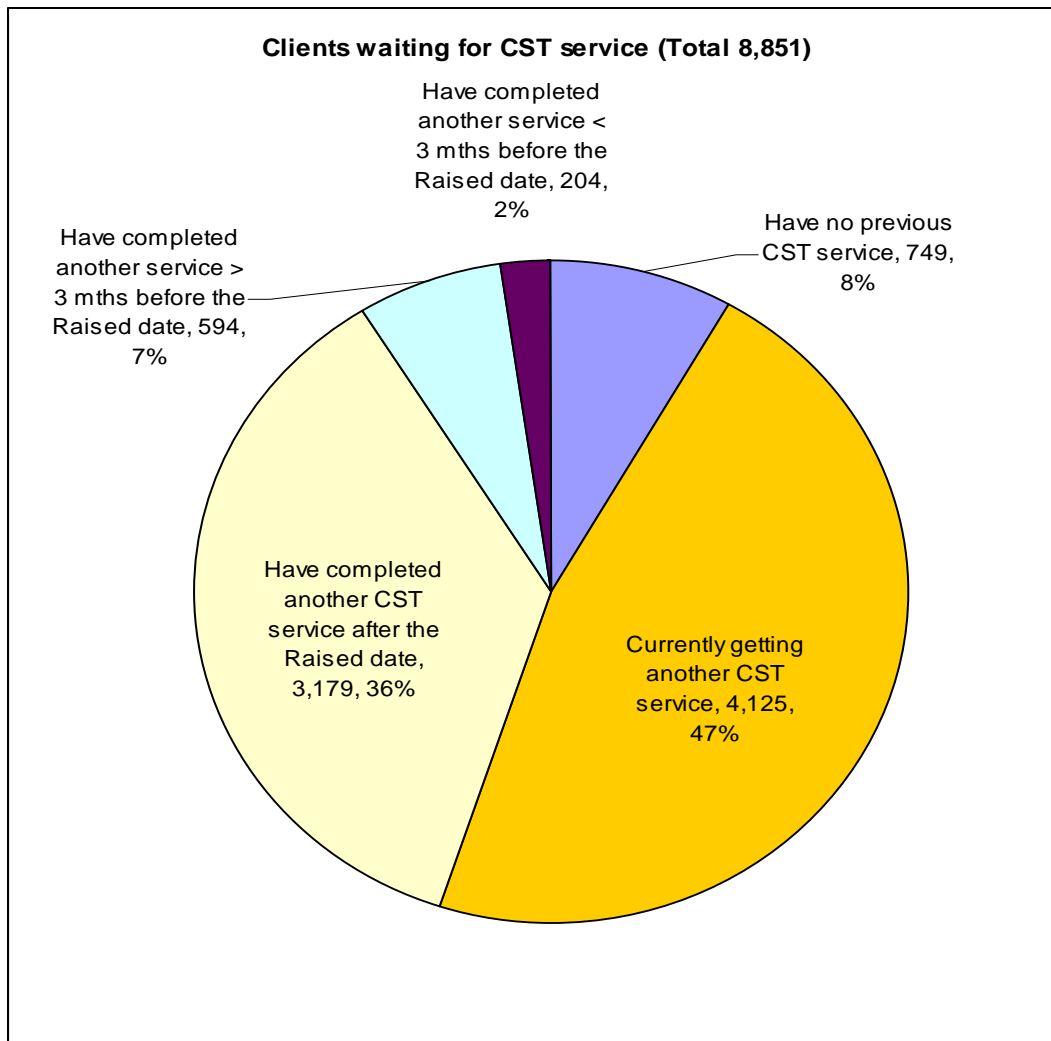
Although all 8,851 people have a need for assistance which is waiting to be met, 4,125 (47%) of them are currently receiving another CST service and a further 3,179 (36%) have already received another service whilst waiting for this service. Another 204 (2%) are people who received a service less than three months before the current service request was made.

Of the remaining clients, 749 (8%) have never received a CST service and a further 594 (7%) last received a service more than 3 months before the current service request was made. The numbers are summarised in the Figures 28 and 29 below.

**Fig. 28 – The Circumstances of Clients waiting for an ADHC CST service**

<b>Clients waiting for an ADHC CST service who:</b>	<b>No.</b>
Have no previous CST service	749
Currently getting another CST service	4,125
Have completed another CST service while waiting	3,179
Have completed another service > 3 mths before the current service request was made	594
Have completed another service < 3 mths before the current service request was made	204
<b>Total</b>	<b>8,851</b>

**Fig. 29 - The Circumstances of Clients waiting for an ADHC CST service**



Based on the above analysis, 15% of people waiting for a CST service from an ADHC operated service are not receiving any other ADHC CST service or have not received one for at least 3 months. It should be noted, however, that these clients may be receiving other services, such as respite, or receiving services from ADHC funded therapy services.

Figure 30 provides a more detailed breakdown of those 749 clients who are not receiving any services by age and the time that they have waited for a service. More than half of these clients have been waiting less than 3 months for a service. Yet a significant proportion has been waiting more than 12 months for a service. This group typically reflects people who have been given a low priority during the intake process.

**Fig. 30 The Circumstances of Clients waiting for an ADHC CST service who are in receipt of no other services**

People waiting for service who received no other services					
	Time since the service was requested				
Age Group	Less than 3 months	Less than 6 months	Less than 1 year	More than 1 year	Grand Total
0-5 years	170	51	31	21	273
6-15 years	115	27	28	36	206
16-17 years	12	8	3	3	26
18-25 years	27	9	7	10	53
26-34 years	17	3	6	14	40
35-43 years	13	9	11	19	52
44-64 years	31	14	11	37	93
65+ years	2		1	3	6
Grand Total	387	121	98	143	749



**Demand for Intensive In-Home Support**

Intensive in-home support programs are an important part of the NSW Government’s commitment to enable people to live as independently as possible in their home environments. Services are packaged in response to the individual needs of clients, with most support being in the form of personal care (assistance with activities of daily living such as showering, toileting and eating). The majority of clients using these services have spinal cord injuries, neurological or degenerative conditions. On average, supporting someone with an in-home package is half the recurrent cost of a specialist accommodation place.

Increasing demand for these kinds of programs has resulted in a doubling of our investment through *Stronger Together*, with an additional 300 places established since 2006. Nevertheless, 373 more people are on the service needs register for this program (as illustrated in Fig. 31).

**Fig. 31 -**

<b>Eligible Applicants Waiting on Intensive In-Home Support Service Need Register as of 31 July 2010*</b>							
<b>Region</b>	<b>Number of Applicants</b>	<b>Disability Conditions</b>					<b>16-64 years</b>
		<b>ABI</b>	<b>Intellectual</b>	<b>Neurological</b>	<b>Physical</b>	<b>Others</b>	
Hunter	45	10	1	11	22	1	45
Met North	98	22	5	23	39	9	98
Met South	97	34	7	26	30	0	97
Northern	61	8	8	16	29	0	61
Southern	40	10	2	7	20	1	40
Western	32	5	3	5	17	2	32
<b>Total</b>	<b>373</b>	<b>89</b>	<b>26</b>	<b>88</b>	<b>157</b>	<b>13</b>	<b>373</b>

\* People aged 65 years or over are not eligible for this form of assistance. Complementary HACC or Aged Care programs may be available to them.

**People transferring from other government systems**

Demand projections also need to consider people with a disability transferred from other systems who may or may not be currently known to ADHC. These people

represent a pool of potential new entrants to the formal disability services system that needs to be taken into account when identifying demand and appropriate service responses. An estimate of additional clients per annum is at Figure 32.

**Fig. 32 -**

<b>People transferring from other government systems</b>	
<i>estimated number of additional clients per annum</i>	
Young people leaving school	1,000
Young people leaving care	90
People leaving corrective services / juvenile detention	20
People with acquired brain injury	250

For example, each year, some 1,000 young people leave NSW schools and are unable to enter the workforce or further education because of the severity of their disability. Currently post school programs capture the most vulnerable young people with a profound or severe disability as they leave school. These programs maximise opportunities for young people to transfer to employment, or to be able to live independently in the community, at the same time giving respite to their families. Replacing the respite effect of school with a post school program is an important component in our support of families in their caring role.

Likewise, continued support for people with a profound or severe disability taken into care as children is a continuing priority in NSW. Through *Stronger Together* growth funding ADHC has been able to work closely with Community Services to ensure that young people with a disability leaving the care of the Minister for Community Services are receiving support tailored to their individual needs and circumstances to enable a successful transition into adulthood. Despite the best effort of both agencies, many of these young people require high cost continuing supports through specialist accommodation arrangements.

A significant number of people with a disability come into contact with the criminal justice system. Without appropriate support, upon release, this group is prone to recidivism, creating an ongoing cycle of release and re-offence that puts pressure on the justice, health and disability service systems. Many of these people present a danger to themselves and the community through their patterns of offending behaviour.

Over 100 people with an intellectual disability leaving the criminal justice system and at a high risk of recidivism have received case management, clinical and accommodation support services in the last three years through the newly created Criminal Justice program (CJP) as part of *Stronger Together* implementation. Preliminary performance data suggests that the average offending rate of participating clients is falling from an average of seven offences to two offences per year.

### **Non Traditional Disability Type Groups**

Historically access to specialist disability services has largely been restricted to people with an intellectual disability. Therefore, those who require high levels of physical and/or cognitive support were limited to supports available through the mainstream health systems and Residential Aged Care Facilities (RACFs). 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 are no longer able to provide care as before.

*Stronger Together* has 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.

Typically, these are people with adult-onset disabilities such as cognitive impairment arising from Acquired Brain Injury (ABI) and/or severe Physical Disability arising from neurological degenerative conditions such as Motor Neurone Disease (MND), Multiple Sclerosis (MS) 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. Clients such as Ventilator Dependent Quadriplegics, require a joint service response from Health and ADHC.

The table below indicates the number of people with an ABI discharged from the NSW Brain Injury Rehabilitation Program (BIRP) over a nine month period, who may require some assistance from ADHC and other support agencies at some point in their lives. Only people with significant ABI are admitted to BIRP units. There is no robust data on the vast majority of people with ABI who are discharged from other locations, a proportion of whom can be expected to also have needs for ongoing or episodic service.

**Fig. 33**

<b>People Exiting NSW Brain Injury Units in 2008</b>	
Number discharged 01/10/07 – 30/06/08 (9 months)	367
Number discharged eligible for assistance from LTCS Scheme	63
Number discharged eligible for compensation	33
Number remaining who may require some assistance from ADHC and other support agencies at some point in time	271
<i>Source: GMCT: Brain Injury Rehabilitation Directorate, April 2009</i>	

## **Conclusion**

Prior to the commencement of *Stronger Together* in 2006, the NSW disability services system was responding to increased levels of demand in a crisis driven way. High-cost interim solutions were being used to support people with a profound or severe disability when their community support networks failed and they were at risk of homelessness. A significantly disproportionate amount of resources was being spent on a small number of people.

There was little capacity to work with other NSW and Australian government agencies to respond in proactive and constructive ways to the needs of some of the most vulnerable people in our target groups, such as families at risk of relinquishing care of their children, young people leaving care, people in contact with the criminal

justice system, and younger people in or at risk of entry to residential aged care. As a result many people were receiving high-cost, inappropriate supports (often in other government systems such as health, justice, or aged care) that were unsustainable, and not receiving the best outcomes for clients or the service system as a whole. Whereas those needing some help to continue to care received no support until their situation reached a crisis point.

In 2006 almost 600 people with a profound or severe disability were receiving high-cost emergency type responses because their community supports had broken down. One in five centre based respite beds was blocked as a result of abandonment. The pressure on the service system was so intense that it faced more respite bed closures, and the diversion of resources from other prevention and early intervention programs such as therapy and day programs to fund the unmet need for crisis support. Even though this would, in turn, lead those displaced from therapy, respite and day programs to enter crisis, thereby creating an ongoing cycle of abandonment, respite blockages, and demand for high cost supports.

The disability services system only had the capacity to offer services that people had to 'fit' into rather than services designed around the needs and circumstances of individuals and families.

The real and tangible benefits of *Stronger Together* investments since 2006 will be more evident over the longer term as early intervention and prevention initiatives and community supports produce better outcomes for people with a disability and their families and carers. Nevertheless, four years of investment has enabled us to begin the shift in our service system approach to reach a greater proportion of the target population with planned and sustainable solutions.

There are signs that demand for government funded specialist disability services is continuing to grow. It is important that options for meeting this demand are considered within the context of the long term sustainability of the disability services system in NSW.

## **CHAPTER THREE**

### **The effectiveness and efficiency of the NSW Disability Services System**

Evidence is critical to our work. It provides a foundation for informed decision making and future planning. There are many gaps in the evidence base for disability services in general, and for our work specifically. NSW has worked to improve the evidence base by influencing the national agenda and by improving our own research, data and knowledge management processes. Some progress has been made in recent years, but there is still much to be done.

#### **The Disability Evidence Base**

As a human services agency, ADHC relies on many sources of evidence including academic research, program evaluation, input and output data, performance monitoring data, national data collections (such as census data and the Survey of Disability Ageing and Carers - SDAC), and the expertise and experiences of practitioners working in the field. In general terms, evidence assists us to:

- Understand the environment and the challenges that we face. For example, we need to understand the population, social and economic trends and how these will affect informal care networks, the demand for specialist services and the availability of an adequate workforce;
- Make decisions about how best to meet the needs of people with a disability, their families and carers;
- Reconfigure our programs and services, through both short and long term activities, to create an effective and sustainable service system; and
- Measure our performance.

The disability services sector does not have a well-established research evidence base or team of dedicated researchers like those in the aged care and health sectors.<sup>17</sup> Historically, comparatively little research has been undertaken specifically in the area of a sustainable disability services system, except for work on the

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<sup>17</sup> Australian Disability Research Agenda Collaboration (2009) Discussion Paper on Australian Disability Research Agenda, Disability Studies Conference, Australia, UNSW, Sydney

devolution of institutions into community living settings or work at a secondary level in health and ageing research or as part of a medical model of disability study.

National disability research activities have often been driven reactively by the immediate needs of the day. There has been no consolidated national effort to explore basic questions on people with disabilities, their present and future needs or the best ways to serve their needs. Therefore, there is no rich body of knowledge for policy makers and practitioners to draw upon to shape our practices and our plans for the future. There is a need to take a more deliberate and considered approach to creating a robust evidence base for disability services.

Disability research also suffers from limited systematic data collection and information on disability has not been high on the national statistical agenda for generic collections such as general social and health surveys. This has impacted on the potential to understand our clients and their needs beyond the existing client base. There are also issues with the National Minimum Data Set (MDS), the detailed data collection on ADHC direct and funded clients, which requires data development to better reflect current practice. These issues limit the ability to review past experience and to plan strategically for the future needs of people with disabilities.

Measuring performance enables us to establish benchmarks and to identify and promote best practices, thus improving performance in the longer term. Disability services are delivered through providers that are diverse in size, organisational capacity, the range of services involved, staff skill levels, and geographic coverage. Program evaluation and performance monitoring are crucial in providing evidence for any service improvement initiatives.

## **Improvements through *Stronger Together* implementation**

Improving and consolidating the disability evidence base has been an integral part of the planning and implementation of *Stronger Together*. Since 2005 we have sought to:

- Gain a better understanding of the demand and supply of disability services;
- Understand what is most important to clients, carers and their families;
- Expand the range of service responses available to meet the needs of clients, carers and families;
- Measure our performance in meeting client needs, through program evaluations; and
- Improve data collections and analysis capacities.

In doing so ADHC has established:

- A research program that supports strategic, rigorous, innovative research and that works in collaboration with other organisations to support our Priority Initiatives and Business Plans;
- An Evaluation Program that promotes systematic and robust evaluation and that is responsive to program and service improvement needs;
- A Performance Indicator Framework that is timely and action driven to improve effectiveness and efficiency in service provision; and
- A Data Improvement Strategy that aims at improving quality data capture and analysis.

The details of our key initiatives in these areas are set out below.

### **Better Understanding of Demand and Supply of Disability Services**

#### **PriceWaterhouse Coopers (PwC) actuarial modelling**

The PwC actuarial project studied the demand and supply of disability services in NSW along the lines discussed in Chapter 2. At its core the project mapped service supply data from health, specialist disability, HACC and residential aged care



systems to the best data on the population of people with a disability (the ABS 2003 Survey on Ageing, Disability and Carers). It showed that approximately one sixth of estimated support required by the whole population (across all ages) was met by funded services in 2003/04.

The limitations discussed in Chapter 2 meant that the project could not identify what part of estimated support should be met by government funded services. However, it provided a valuable model to determine the projected growth in demand that would arise from population growth, changing prevalence of different types of disability and increasing longevity of people with a disability. As identified in Chapter 2, this is in range of 2 and 3 percent.

The project also enabled modelling of various scenarios about the possible impact on growth in demand arising from changes in the capacity of the carer population and the impact of interventions to support carer capacity and the independence of people with a disability. As discussed in Chapter 2, the limitations on data meant that this modelling is largely theoretical only, but it is a valuable tool and is informing judgements about the appropriate aggregate investment level required for *Stronger Together*.

The national Disability Policy and Research Working Group (DPRWG) has recently commissioned PwC to extend the NSW project to estimate the national unmet need for disability services. This further demonstrates its relevance to policy and the validity of its methodology. The national project will make a major contribution to two national priorities ('better measurement of current and future need' and 'population benchmarking for disability services').

### **Census analysis of people with disabilities and their carers in NSW**

The 2006 Census of Population and Housing, for the first time, collected information on people with a need for assistance because of a health condition, a disability or old age. It also gathered data on the people who provide the assistance – unpaid carers. It provides, for the first time in Australia, statistics that allow detailed profiling of the people with a need for assistance and their carers. It includes a wide range of

demographic factors including age, sex, indigenous status, living arrangements, education and labour force status.

ADHC has produced a report, *Census Report on People with Disabilities and their Carers in NSW*, using published and unpublished data. The report contains two parts: Part 1 focuses on people with a need for assistance; and Part 2 on people who provide the assistance. The findings offer important insights into our targeted population.

### **Improving strategic information availability**

ADHC has also been lobbying for changes where the limited statistical information available has become a barrier to building quality evidence. One outcome is that the 2009 SDAC doubled its sample size and some questions have been modified to better reflect sectors needs.

ADHC has been working with ABS and AIHW, the national statistical agencies, to improve the other statistical collections (such as ABS Community Service Survey) that would be beneficial to disability sector.

## **Appropriate Responses to Meet Needs**

### **Resource allocation formula**

Resource allocation formulae provide a critical tool for ensuring that resource allocation is as equitable as possible across NSW and that the process is transparent.

In NSW, HACC provides basic services to frail older people and people with disabilities to support them to live independently in the community at a cost of about \$550 million annually.<sup>18</sup> A HACC resource allocation formula was developed in 2008/09. It was based on the latest demographic and service utilisation statistics and

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<sup>18</sup> Although a large proportion of HACC clients are older people, the eligibility for HACC services is based on whether the individuals "have difficulties in carrying out tasks of daily living and need assistance or supervision due to an ongoing moderate, severe or profound functional disability" (HACC national Program Guidelines, 2007).

gives special consideration to Indigenous and CALD status and locational factors. This formula benchmarks the equitable distribution by LPA and allocates expansion funds to achieve equity in a given time span according to HACC planning cycles. New information on services, the amount of expansion funds available and other data can be used each year to update the allocations.

A similar disability resource allocation tool is under development to address the complexity of planning processes for specialist disability services. Again, the statistical information on the potential target population, their demographic characteristics and the existing service supply will be key pieces of supporting evidence.

### **Planning data package**

Each year regional planners are provided with an updated data package to support their planning activities. The package contains the latest statistics on target client profiles, service profiles and population projections. It provides vital quantitative evidence to support local planning and decision-making. At this stage, it is primarily used to support HACC planning. It is also a rich source of information for regional planners when they deal with disability planning issues and can assist to inform external stakeholders.

### **Research program and annual grants**

Under a formal Research Policy, ADHC engages in and supports research that contributes to the achievement of improved outcomes in areas identified in its corporate priorities.

The increased resource commitment since 2005 (through *Stronger Together*) demonstrates recognition of the importance of research in providing an evidence base to inform continuous improvement in policy as well as in program design and service delivery. Priorities for the current program include:

- Person centred care.

- Drivers of changing expectations and how to respond and influence decisions.
- Disability accommodation.
- Action on ageing.

In many cases the results of research projects funded by ADHC support its decision-making and plans for the future. For example, research, evaluation and local knowledge in the area of respite has been critical in identifying priorities for the reconfiguration of existing services and the allocation of new resources. Likewise, a study on blocked respite beds is helping ADHC to understand the factors and issues that lead to this outcome and what we can do to prevent this from happening.

Another example is a study interrogating ADHC client and service provision data, designed to help us gain an understanding of how people are bundling supports and establish an evidence base for the development of Packaged Support.

### **University Chair in Disability and Mental Health**

Under *Stronger Together*, ADHC has established the Office of the Senior Practitioner (OSP) to improve specialist support services, especially behaviour support and support for people with complex medical needs. One initiative managed by the OSP is the establishment of a Chair in Disability and Mental Health at the University of NSW. The Chair's responsibilities include the development of a research program in relation to people with an intellectual disability and mental health issues.

### **Online library**

ADHC established an Online Library facility to provide staff with high quality research results in a cost-effective way. Usage of the Online Library has exceeded expectations and there is no doubt that ADHC staff want and need access to evidence and published research. During the first 60 days of the Online Library:

- A total of 26,852 searches were undertaken by 3,911 individual users, indicating that a large proportion of staff member use the Library; and
- Staff indicated that they found the Online Library useful and effective.

## **45 and Up Study**

Together with several other NSW State Government Agencies, ADHC is a study partner in the 45 and Up Study (led by the SAX Institute). The study is developing an open data source on people aged 45 and over for the research community. Although the study has a healthy ageing focus, there are also opportunities in the area of disability; the study has recently included several disability questions in a planned sub-study (as requested by DADHC).

## **Cross agency and cross jurisdictional efforts**

ADHC engages in and supports disability research projects that have statewide and national significance. For example:

- Nationally, NSW is working to enhance the interjurisdictional evidence base development by working in partnership with other Departments and across States.
- ADHC leads the collaboration on disability research across NSW agencies committed to in *Better Together*. The Disability Research Collaboration Group (formed under *Better Together*) was established and led by ADHC as a coherent interagency approach to improve collaboration and information sharing regarding disability research. The group aims to coordinate research efforts, expand disability research networks between government agencies and universities and avoid duplicated research.
- ADHC, NSW Health and the Office of Children and Young People have recently become industry partners with the Social Policy Research Centre at the University of NSW in a major, long-term project examining the life course impact of caring on children and young adults. In this arrangement government agencies are contributing access to data and staffing expertise plus a cash contribution. Similar research initiatives have also recently been entered into with the University of Sydney.

## **Evaluation program**

The evaluation of ADHC programs provides strong evidence for ADHC to assess three key questions:

- Are we achieving the results we set out to achieve?
- Is the way that we work the most effective and efficient way to achieve those results?
- Are our clients and communities better off as a result of our services?

The ADHC Evaluation Policy and Guidelines provide a robust framework and a quality improvement approach central to the evaluation program. An annual program evaluation schedule was developed in 2007; twenty-five evaluation projects have been completed since 2007.

Program evaluations to date have generally established effectiveness and impact of programs and made specific recommendations for individual programs. Some key findings are outlined at *Appendix 10*.

## **Performance Indicator Framework**

ADHC's Performance Indicator Framework focuses on measuring performance using indicators of equity of access, program effectiveness and cost effectiveness.

Equity of access indicators focus on monitoring whether people with a disability have equitable access to service irrespective of where they live in the State, their age, and their Aboriginal and CALD status. Inequities in the regional supply of services relative to disability population prevalence were identified for each service type in the rollout of *Stronger Together* phase one funding and funding allocated accordingly. See Figures 9, 10 and 11 in Chapter two.

ADHC monitors and measures its service delivery activity in relation to equity of access to services by Aboriginal people and people with a culturally and linguistically

diverse (CALD) backgrounds on an ongoing basis. Evidence suggests that there is a strong correlation between the proportion of Aboriginal people receiving services in a region and the number of Aboriginal people in that region. Similarly, for example, Metro South Region has the highest concentration of people from a CALD background and also has the highest representation of CALD clients compared to other Regions.

Program effectiveness indicators focus on measures of timeliness in relation to access, the appropriateness of services being delivered and the quality of service delivery. In addition to measuring the number of clients receiving services and the amount of services being received, there are additional measures of program effectiveness. For example, the post school programs have been assessed both in relation to client satisfaction and program effectiveness. High levels of satisfaction were reported with the Community Participation program, and the success rate of people with a disability transitioning to further education and/or employment has been significant (further information is outlined in the *Stronger Together* implementation report at *Appendix 10*).

The Community Justice Program is another example where program effectiveness has been measured. This program provides supported accommodation and clinical supports for people exiting the criminal justice system. Whilst this program has only been underway since the inception of *Stronger Together*, it has achieved one of its primary outcomes, significant reductions in offending behaviour of the people involved in the program (Refer to *Appendix 11*).

Cost effectiveness indicators assess cost per user, cost per place and cost per hour measures to ensure that the programs being delivered are cost effective. *Stronger Together* with its greater emphasis on early intervention and prevention, has already resulted in significant savings to ADHC with the average cost per client being reduced from \$27,700 in 2004/05 to \$24,950 in 2010/11.<sup>19</sup> The change in service mix enabled an additional 20,000 people to receive services for the same level of

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<sup>19</sup> PriceWaterhouse Coopers (2010).

investment had the service mix remained the same as pre-Stronger Together investment.

In 2008, ADHC established the Operational Performance Committee It is charged with the responsibility of reviewing the performance of ADHC's:

- Programs and services.
- Workforce management.
- Financial and asset management.
- Acquisition and contract management of funded services.

The regular OPC meetings have a clear focus on assessing program and regional performance, and determining priority actions to enable improvements. They also explore options for the provision of better services at the local level and how to remove impediments to the delivery of responsive service delivery.

### **Client focused service delivery**

In recent years there has been a shift in the provision of disability services from individual planning to person centred planning. Traditionally, service provision has been characterised by diagnosis, assessment of needs and actions to address the needs.

Person centred planning requires a change of thinking about people with disabilities and service provision so that the person and what is important to them is at the centre of all thinking.

Person centred approaches require the flexible use of resources to achieve outcomes that are important to the person. The fundamental difference with traditional approaches to service provision is that services and support adjust to providing what the person wants in life, rather than the person being expected to fit into an existing service.



Additionally person centred approaches work primarily with the generic mainstream services located within the community rather than limiting actions to what can be provided by the specialist disability sector.

The body of research on person centred approaches has been growing in recent years and clearly demonstrates that this approach can be effective. Typically this research has found that the introduction of person centred approaches results in positive changes for people with a disabilities in regards to their social networks, contact with family, contact with friends, engagement in community based activities and options for making choices.<sup>20</sup>

An important contributor to the delivery of person centred programs is the development and implementation of flexible programs with individualised support. ADHC already provides, or is developing, a number of programs that offer individualised support to give people with a disability greater choice in the types and mix of services they receive.

Programs with individualised support options include:

- Direct Funded and Cooperative Models for the *Attendant Care Program*.
- *Family Assistance Fund*.
- Self Managed Models for *Community Participation; Life Choices* and *Active Ageing* day programs.
- *Extended Family Support*.
- *Flexible Respite*.
- *The Younger People in Residential Aged Care Program*.

Programs with individualised support that are currently operating as pilots or which are planned for introduction include:

- *my plan, my choice: EarlyStart*.

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<sup>20</sup> Trudy van Dam, Australian Catholic University for NSW Department of Ageing, Disability and Home Care: Person Centred Planning: A review of the literature Strengthening person centred planning in the Community Participation program (2008)

- *my plan, my choice: Older Carers.*
- *Individual Accommodation Support Packages.*
- *Services Our Way*, an individualised support model being developed to improve response to needs of Aboriginal people.

These programs and pilots are examining the effectiveness of the different elements of individualised supports including:

- Individually tailored supports provided across a range of service types which are matched to the needs of the person and their family/carer (bundled services).
- Service users have choice of their service provider and move between providers if required (portability).
- In the most individualised programs service users may choose their own staff and employ them directly (self-managed).

Direct payment to clients and their families is another emerging model of funds management available to people with a disability.

All individuals who access the Attendant Care Program may select the Direct Funded Model. Currently 18 clients do so. The participants receive payments directly into their individual bank accounts. Clients may choose the services they purchase and the people who are employed to provide them.

Some service users have chosen to purchase adaptive technology to enable greater independence in preference to seeking the assistance of a support worker.

ADHC will continue to develop a range of funding mechanisms that people with disabilities and their families can choose from and which best suit their needs.

ADHC has adopted a measured approach to expanding options for individualised support to ensure that families and individuals with a disability receive high quality

services and that the views of all stakeholders such as service providers are considered.

It has been necessary to develop procedures to address important administrative issues such as taxation, the payment of award wages to support staff, occupational health and safety requirements and insurance coverage.

To survey and resolve potential issues that may arise for stakeholders in the expansion of programs with individualised support ADHC has commissioned a number of evaluations. They include:

- 2008 Evaluation of Attendant Care Direct Funded Model.
- 2009 Evaluation of the Self Managed Model for Community Participation.
- 2010 Supplementary Evaluation of the Self Managed Model for Community Participation.
- 2009-10 Evaluation of ADHC Services.

ADHC is also using a Participatory Action Research project to review details about best practice for individualised approaches to inform the development of other flexible programs.

Information from these evaluations, the pilot programs, the operation of Self Managed Model day programs and the Extended Family Support Program will inform the way forward.

To assist stakeholders build capacity for individualised support ADHC has established a \$17 million NSW Industry Development Fund administered by National Disability Services (NDS) for sector development and provided \$600,000 for the Resourcing Families Project to provide information and seminars for families of children aged 0-18 about using self directed and self managed funding.

Evidence of the effectiveness of individualised funding models and person centred approaches is not entirely consistent, but generally demonstrates positive outcomes for government and importantly for people with disability and their families. Evaluations of overseas self directed funding models (England, Scotland, United Kingdom, Germany, Austria) highlight the potential benefits of people choosing to self direct their own services with less reliance on service models offered by the state.<sup>21</sup> In some instances, as in the case of Germany, direct funding support for disability service provision aimed at supporting the person with a disability to remain living at home represents half the cost of the equivalent formal service option. In the UK evidence indicates that personal budgets cost approximately 10% less than comparable traditional services and generate substantial improvements in outcomes, although one study found that care package cost between 12 and 45% less when someone went onto a personal budget.<sup>22</sup>

Positive outcomes for people with a disability and their families are also evident from evaluations. The results of the *Our Health, Our care, Our Say* evaluation in the UK showed that:

- Almost half of people surveyed reported improvements in their general health and well-being.
- 55% reported spending more time with people they liked.
- 77% said their quality of life had improved.
- 63% said they took part in and contributed to their communities more when they went onto self-directed support.
- 72% said they had more choice and control.
- 59% said they felt their lives had more dignity.
- 36% estimated their economic well-being had improved, with 60% reporting no change.

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<sup>21</sup> Social Policy Research Centre (2008) *Approaches to Packaged Support – Draft Final Report*

<sup>22</sup> Leadbeater C., Bartlett, J., Gallagher, N.

A 2010 study by the Social Policy Research Centre into individualised funding approaches to disability supports in Australia reports similar findings.<sup>23</sup> Individual funding has not increased the total specialist disability support cost to government in that some individual funding is more cost effective than other models of organising support, particularly where it supplements social housing and informal care. Quality of life outcomes highlight personal wellbeing, and physical and mental health experiences at levels similar to both the Australian population norm and the Victorian norm of people with intellectual disabilities. Most people were happy with their social relationships and community participation attributed to the whole of life approach taken to providing support for people with disabilities who have individual funding.

Locally under *Stronger Together*, evaluations of self-managed models of support, including of the Community Participation and Attendant Care programs, have proven the benefits of enabling greater levels of flexibility, choice and control for people with a disability, their families and carers.

ADHC conducted a comprehensive evaluation of services, including substantial consultation with stakeholders, about the types of services they need and their preferences for how they are accessed. This independent review made nine recommendations that form the basis of a framework for expanding person centred approaches while also maintaining an appropriate level of traditional specialist services.<sup>24</sup>

The benefits to be derived from increasing the range of person centred service options within the overall service mix include:

- A more appropriate and efficient mix of services for people with a disability (more closely matching the support levels that people with a disability need).
- Leveraging individual strengths.
- Developing services within the context of people's lives.
- Complementing established informal and family support networks.

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<sup>23</sup> Department of Families, Housing, Community Services and Indigenous Affairs (2010) *Occasional Paper no. 29, Effectiveness of individual funding approaches for disability support*

<sup>24</sup> Allen Consulting (2010) *Choice and Control: Moving to an Individualised Approach, Summary Report* (2010),

- Tailoring services to specific individual and group needs – including Aboriginal and culturally and linguistically diverse people.

Person-centred planning and individualised supports recognises the needs of individuals change over time, that the type and mix of supports people need differ across the lifespan and across different backgrounds, and the benefits that a lifespan perspective to planning can deliver more certainty to people with a disability, their families and carers.

There is also evidence of the efficacy of planning that is future focused and covers the whole-of-life and transitional support needs of people with a disability. The lifespan approach is an important conceptual approach that represents a proactive approach to assisting people with key life stage transitions so that developmental progress is sustained and to avert crises that are often precipitated by a lack of transitional support. For example, transition from school to post-school programs is a critical period that can impact on the life chances of people with a severe or profound disability. Under *Stronger Together*, transitional support models such as the leaving care program have demonstrated the importance in using a permanency planning approach.

### **Aboriginal Clients**

Aboriginal people are twice as likely (1.5 to 3.0 times depending on age) to have a severe or profound core activity limitation.<sup>25</sup> At the same time, Aboriginal people are far less likely access formal services. The challenge of the formal system is 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 such a strong feature of Aboriginal culture.

ADHC has been working with Aboriginal communities to better understand the most appropriate and effective approach to improving supports. Services should be

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<sup>25</sup> ABS- The Health and Welfare of Australia's Aboriginal and Torres Strait Islander Peoples, 2008

delivered on their terms and in ways which foster independence rather than reliance on formal care and lifetime support.

ADHC is continually working towards innovative and responsive models of service delivery that respect cultural values, meet community expectations and build the confidence of Aboriginal families to access services.

The Aboriginal Service Development and Delivery Directorate has been established by ADHC to provide leadership, co-ordination, and support across the agency for improved responsiveness of our programs and services to Aboriginal people. The new Directorate is working on the following initiatives to bring about systemic structural reforms to improve disability services for Aboriginal people now and into the future:

- Establishing a Cultural Inclusion Framework that forms the overarching platform for accountability and monitoring systems to support ADHC programs and funded services to deliver culturally inclusive services.
- Implementing a range of employment strategies and support mechanisms to increase the capabilities across the agency to deliver quality services to Aboriginal communities. Some examples are: the Home Care Aboriginal Trainee Project, the Enhanced Aboriginal Residential Support Workers Program and the Aboriginal Assistant in Nursing Program. A cultural mentoring program is put in place to support workplace adjustment and retention of Aboriginal trainees.
- Development and implementation of an innovative and flexible service delivery model to improve the access of Aboriginal people to disabilities services. The trial implementation sites are Metro North, Southern and Northern Region. This service delivery module places strong focus on community consultation and engagement, on flexibility and choice and on having a key Aboriginal worker supporting Aboriginal people with a disability, their families and carers throughout the service delivery continuum.

ADHC also funds a range of Aboriginal specific disability programs and mainstream programs tailored to support Aboriginal people with a disability and their families. Descriptions of these are at *Appendix 13*.

### **Clients with culturally and linguistically diverse 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. Responding to the challenges and opportunities of cultural diversity is not at the margins or a hurdle to jump – it is a core part of our business and an opportunity to improve our practices and person and family centredness.

Nevertheless, 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.<sup>26</sup>

ADHC is committed to providing accessible, inclusive and responsive services to meet the diverse needs of its client target group who include people from culturally and linguistically diverse (CALD) backgrounds.

There are a broad range of issues and barriers that are involved in providing services to ADHC's culturally diverse client base that are experienced on both the service user and service provider levels. These issues and barriers include:

- Inadequate access to interpreters for service users and services.
- A lack of trained interpreters and translators for some new and emerging community languages.

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<sup>26</sup> Australian Government Productivity Commission 2008



- Differences in cultural norms, understanding of and attitudes towards illness, disability and ageing between the general and the CALD community.
- Different perceptions of the 'carers' role and concept of what a 'carer' is between the general and the CALD community.
- The impact of pre and post migration and settlement experience on a person/family; a reluctance to deal with Government agencies by some migrants due to negative experiences of war, conflict, trauma and state-sanctioned persecution in their country of origin.

Working with diversity necessitates the implementation of flexible, innovative and responsive approaches to service provision. It involves working within different contextual frameworks and ability to work cross culturally from a culturally competent skill base.

*Valuing and Managing Diversity: Cultural Diversity Strategic Framework 2010-2013* sets an action agenda to better equip ADHC and ADHC funded services to address many of the issues outlined above in relation to providing services to people from CALD backgrounds.

Its three priorities are to:

1. Integrate cultural and linguistic diversity into planning, monitoring, reporting and evaluation.
2. Build organisational capabilities to work with a culturally and linguistically diverse community.
3. Provide culturally and linguistically responsive services and programs.

A number of CALD specific disability initiatives have been initiated through *Stronger Together*, including:

- The CALD Innovative Accommodation Support Initiative to facilitate service access for people with a disability from CALD backgrounds.

ADHC funds two Drop-in Support Services for people with an intellectual disability from CALD backgrounds (one in St George and the other covering the Bankstown, Liverpool and Fairfield Local Government areas). These services provide flexible support of up to 35 hours per week for people living in their own homes. As part of this initiative ADHC also funded a two-year Accommodation support development project to work across the ADHC Metro South Region. This project provides training and support to ADHC funded accommodation service providers to facilitate the delivery of services that are culturally appropriate and responsive.

- In 2008 ADHC funded a project that explored the meaning of 44 commonly used English terms in the disability sector in 14 other languages. The project developed fact sheets that went beyond literal translations and considered the clarity and appropriateness of meaning in a cross-cultural context. The project was voted runner up finalist of the Outstanding Contribution to the Translating and Interpreting Industry Awards 2009. The fact sheets are available on the ADHC website.
- In 2008/09 ADHC provided \$148,000 to the Lady Gowrie Child Centre to develop a DVD – ‘Starting School: Stories from parents of children with a disability’. The DVD identifies strategies to ease the transition to school process for children with a disability. The DVD is produced in Arabic, Cantonese, Dari, Dinka, English, Korean, Mandarin and Vietnamese.
- In 2008 ADHC invested \$270,000 for the development of the information kit ‘Raising kids together’. The kit was developed in partnership with peak multicultural organisations and was translated into Arabic, Assyrian, Dari, Dinka and Juba Arabic. ‘Raising kids together’ won the Government category of the National Multicultural Marketing Award from the Community Relations Commission in 2009.

## **CHAPTER FOUR: Compliance with Disability Standards**

### **Framework for Monitoring Compliance**

There are a number of internal and external mechanisms that are used to monitor policy implementation and improve compliance in ADHC operated and funded services.

Internal mechanisms include:

- Quality and Safety Framework (for direct services).
- Quality Assurance and Improvement Program (for direct services).
- Annual Compliance Return (for funded services).
- Integrated Monitoring Framework (for funded services).
- Staff training programs and professional development reviews.
- Business assurance and auditing activities arising from the Department's Business Improvement Directorate.

External mechanisms include:

- NSW Ombudsman.
- Official Community Visitors.
- NSW Office of Children - Children's Guardian (OCCG).
- Auditor-General.

Continuous improvement underpins ADHC's approach to monitoring and reviewing its services and policies. ADHC works collaboratively with service providers to deliver improved performance and outcomes for clients by ensuring that:

- Monitoring activities are consistent and transparent.
- Effective, efficient quality services are delivered to achieve the best outcomes for clients and their carers.
- Sound business principles are practiced.

- Service providers are accountable for the services that they are funded to deliver.

The Department aims to review its policies within a 3-5 year cycle, or earlier where necessary. For example, a policy review may be brought forward as a result of legislative changes or a recommendation in the NSW Ombudsman's Review of Disability Deaths. Each business area is responsible for maintaining and reviewing the policies that belong to them.

### **National Context**

A key priority under the new National Disability Agreement (NDA) is to develop a national quality framework, with the aim of achieving a nationally consistent approach to improving the quality of services and improving outcomes for people with disability. ADHC represents NSW on the National Quality Framework Working Group.

An Interim National Quality Framework (NQF) based on the current National Standards has been developed and the architecture of the interim framework provides context for the National Standards, incorporating the principles of human rights, outcomes of the NDA, legislation, quality management principles, and processes to continuously improve services. The introduction of a NQF includes exploring opportunities to introduce, where appropriate, streamlined monitoring and assessment by acknowledging the steps being taken by jurisdictions to reduce the regulatory burden faced by service providers. ADHC has taken all these issues into consideration when developing its approach to monitoring compliance with the standards.

ADHC recently led a comprehensive process of consultation on the revision of the National Standards for NSW and worked with peak bodies and other agencies to develop innovative ways for people with disability, carers and service providers to have their say. Numerous workshops were held across NSW with TAFE NSW conducting pre-consultation training and support to enable people with disability to express their views about what was important to them when they use a disability

service. Workshops for culturally and linguistically diverse communities and Aboriginal communities were held in ways that made it easier for them to have a say. ADHC worked in partnership with NSW Fair Trading Information Centre so that people could express their views using a toll free number. SBS radio was engaged to broadcast an advertising campaign in specific community languages to promote workshops and the toll free telephone line. Approximately 600 people participated in the consultation on the revision of the National Standards.

ADHC has considered the feedback from the workshops which confirmed the sector's view of the usefulness and value of the current resources available in NSW to support service providers in compliance against the standards.

### **NSW Standards**

It is a condition of ADHC's Funding Agreement that service providers comply with the NSW Disability Service Standards (copy at *Appendix 11*). The standards are high-level aspirational statements designed to ensure that services are provided in a way that fulfils international, national and state commitments to people with disabilities and their carers. As well as developing policies that formally translate the standards into requirements imposed on staff and service providers, ADHC is committed to promoting a culture of respect for the rights of people with disabilities. Workers who provide services directly to clients need to understand the principles on which standards are based and the way they should inform their day to day work.

ADHC is developing a series of fact sheets and simple language resources that will assist residential support workers, staff of funded service providers and other front-line staff to own the standards.

These resources will draw on the Convention on the Rights of Persons with Disabilities, existing and new National and NSW Disability Service Standards and the Principles and Application of Principles under the *Disability Services Act*. They will explore the way that standards relate to good governance, privacy, respect for culture, social participation, complaint handling, freedom from abuse and how they

link up with other laws and Government policies that elaborate these commitments to the community as a whole.

Fact sheets will aim to break down the issues into manageable summaries that help staff to define the basic principles, where they come from, why they are important and where further resources can be found.

### **Compliance and Monitoring for direct and funded services**

ADHC's approach to ensure that service providers comply with legislative, policy and reporting requirements is through the Annual Compliance Return (ACR). The ACR is a service provider self-assessment at the organisational level and requires the Chair of the Board of Management and/or Management Committee and CEO to confirm that they are aware of all ongoing responsibilities and contractual obligations for compliance. Service providers rate their level of compliance with the terms and conditions of the Funding Agreement.

ADHC is seeking ways to streamline the regulation of the funded services sector and reduce reporting requirements, whilst maintaining the accountability of service providers. ADHC is introducing a risk identification and monitoring approach when engaging with service providers. This approach balances the burden of monitoring compliance with the desire to have maximum resources directed towards service provision. The approach utilises a risk identification matrix to identify potential risk - defined as a possible disruption to the achievement of client outcomes - from available information sources. This guides the selection of an appropriate monitoring response taking into account urgency and available resources. Unresolved issues may be escalated to be managed as formal non-compliance with the conditions of funding.

ADHC will engage the sector in the implementation of the risk monitoring approach and develop a series of Fact Sheets and tools for ADHC regional staff in the application of the risk identification matrix.

ADHC is moving to an output-based acquittal process as another way of reducing reporting requirements for service providers. The model is being developed with the sector and will be an alternative to the current annual financial acquittal system. It will provide incentives to service providers to meet agreed service outputs and submit accurate and timely Minimum Data Set (MDS) returns. Where this is achieved, service providers will not be required to financially acquit and will be able to retain any surplus funds for reinvestment in the service program. There will be a phased implementation for the new process with clear messages to service providers so they can position their organisations to participate in the new model.

### **Historical Integrated Monitoring Framework (IMF) performance information**

In the 2006 to 2009 funding period, all ADHC Non Government Organisations (NGOs) and Local Government providers were monitored under the Integrated Monitoring Framework (IMF). The framework comprised various monitoring activities, including:

- Financial Acquittals-submitted annually.
- Annual Compliance Return: an annual statement by all service providers of their compliance with the Funding Agreement.
- Quarterly CSTDA/HACC MDS Reports-submitted by all CSTDA and HACC funded output services.
- Service Reviews—a triennial assessment of a service provider's provision and quality of services, and organisational capacity.

During this period, the majority of providers submitted Annual Financial Acquittals and Annual Compliance Returns (94% to 97% for Acquittals and 83% to 95% for Annual Compliance Returns). MDS reporting improved in each quarter throughout this period, from only 14% CSTDA and 37% HACC reports being submitted in the first quarter of 2006, to current compliance rates of 87% and 90% respectively.

The IMF approach has been superseded by 1) the quality framework and third party accreditation and 2) risk identification and compliance monitoring as promoted by the recommendations of the Productivity Commission.

The IMF performance results identified the following areas of strength: how service providers develop networks and partnerships with relevant stakeholders, and promote client independence and participation in the community through service provision. Areas identified as having lower than average ratings were: the ability of clients to access services, and organisational governance.

### **ADHC Direct Services - Quality Assurance and Improvement Program**

The Quality Assurance and Improvement Program (QAIP) is the quality management system for ADHC-operated accommodation and centre-based respite services to improve and monitor service delivery.

To continually improve services, QAIP uses a number of audit tools to identify areas for improvement to incorporate into ADHC's improvement plans, including the Quality and Safety Framework, Quality Assurance Reviews and participation in the NSW Office for Children - the Children's Guardian Accreditation Program.

### **Quality and Safety Framework**

The Quality and Safety Framework (QSF) is ADHC's internal audit to monitor the quality of services delivered in ADHC operated accommodation and centre-based respite services.

Comprising of 24 Key Performance Indicators (KPI), the QSF monitors the development and review of client care plans, levels of incident reporting, completion of health and safety inspections and levels of staff and service usage.

Data is collected at a unit level by staff within accommodation and respite service outlets on a quarterly basis. At this level, the data is used to raise awareness amongst staff of the review cycles for client care plans and other reporting processes carried out at the unit level.



Unit level data is then collated by regional officers for reporting to the Regional Executive. At the regional level the data is used to track patterns of improvement or decline in levels of compliance and developing strategies and directing training to address these areas.

Regional reports are aggregated to the state level by the Accommodation Policy and Development (APD) Directorate and reported to the Executive on a quarterly basis. The state-wide data is used to inform performance monitoring and strategic planning across the regions and the state as a whole.

To further improve the measuring of services, in November 2009, the Group Home and Respite (GH&R) QSF scorecard was redesigned to produce a separate Respite QSF scorecard and a Group Home (GH) QSF scorecard. In total, three state-wide reports are now available, one for respite, one for group homes and a third for large residential centres.

### **QSF Results: Client Care Plans**

**Fig. 34 - Group Home: Completion of client plans within the required timeframe**

	<b>Jan-Mar 08*</b>	<b>Jan-Mar 09</b>	<b>Jan-Mar 10</b>
<b>Individual Plans</b>	<b>87%</b>	<b>88%</b>	<b>88%</b>
<b>Health Care Plans</b>	<b>89%</b>	<b>91%</b>	<b>92%</b>
<b>Nutrition Plan</b>	<b>84%</b>	<b>89%</b>	<b>91%</b>
<b>Epilepsy Management Plan</b>	<b>86%</b>	<b>89%</b>	<b>93%</b>

\*combined group home and respite score

**Fig. 35 - Group Home: Completion of review of client plans with the required timeframe**

	Jan-Mar 08*	Jan-Mar 09	Jan-Mar 10
Individual Plans	72%	72%	73%
Health Care Plans	79%	79%	82%
Nutrition Plan	n/a	n/a	n/a
Epilepsy Management Plan	n/a	n/a	n/a

\*combined group home and respite score

**Fig. 36 - LRC: Completion of client plans within the required timeframe**

	Jan-Mar 08*	Jan-Mar 09	Jan-Mar 10
Individual Plans	96%	96%	95%
Health Care Plans	93%	99%	98%
Nutrition Plan	92%	97%	99%
Epilepsy Management Plan	93%	98%	98%

**Fig. 37 - LRC: Completion of review of client plans with the required timeframe**

	Jan-Mar 08*	Jan-Mar 09	Jan-Mar 10
Individual Plans	41%	80%	86%
Health Care Plans	92%	97%	97%
Nutrition Plan	n/a	n/a	n/a
Epilepsy Management Plan	n/a	n/a	n/a

**Fig. 38 - Respite: Completion of client plans within the required timeframe**

	Jan-Mar 08*	Jan-Mar 09	Jan-Mar 10
Respite Plans	77%	76%	86%
Health Care Plans	89%	87%	67%
Nutrition Plan	84%	84%	74%
Epilepsy Management Plan	86%	79%	77%

\*combined group home and respite score

**Fig. 39 - Respite: Completion of review of client plans with the required timeframe**

	Jan-Mar 08*	Jan-Mar 09	Jan-Mar 10
<b>Respite Plans</b>	61%	67%	70%
<b>Health Care Plans</b>	79%	77%	63%
<b>Nutrition Plan</b>	n/a	n/a	n/a
<b>Epilepsy Management Plan</b>	n/a	n/a	n/a

\*combined group home and respite score

### **Quality Assurance Reviews**

As part of QAIP, a sample of 120 units will have a Quality Assurance Review (QAR) conducted by an external auditor between 2008 and 2011.

Each unit is assessed against the following domains:

- **Client systems:** This group of indicators addresses systems and specific procedural requirements for the management of client information, planning and care at the unit level.
- **Staff systems:** This group of indicators addresses systems and specific procedural requirements for the support and supervision, selection and training and management of unit staff.
- **Agency systems:** These systems include support procedures and administrative requirements that link the unit to state-wide and regional/centre-based reporting and outcomes.
- **QSF Validation:** Test the accuracy and reliability of the unit's reported quarterly QSF data against the review findings.

Each system reviewed is given an improvement rating from 1 to 5 with 1 being no improvement required to 5 being a significant number of improvement required.

The first year of Quality Assurance Reviews have been completed and the findings indicated the majority of units reviewed would require a small to moderate amount of improvement within each of the systems reviewed.

**Fig. 40 - 2008/09 State-wide Improvement Ratings**

	<b>Client Systems</b>	<b>Staff Systems</b>	<b>Agency Systems</b>	<b>QSF Validation**</b>
<b>Group Homes*</b>	2.87	2.55	2.41	2.2
<b>LRCs*</b>	2.2	1.8	1.4	2
<b>Respite*</b>	2.5	2.4	2.5	2.3

\* 40 units reviewed: 29 group homes, 6 respite units and 5 LRC units

\*\* In a number of units the external reviewer reported better performance than that recorded by the unit in their QSF return.

### **Key Improvement Priorities**

While it was difficult to draw specific systemic issues from the first round of audits, due to the small sample of units reviewed, the QAR state-wide report has provided sufficient information to identify domains of service delivery that require attention including client records, stakeholder communication and regional data collection and reporting systems.

### **Client Records**

The key findings from the QAR state-wide summary report correlated with the key findings from the state-wide QSF results regarding the completion of client plans. The external auditor identified a number of factors that relate to this issue:

- Completion of reviews within the required time-frames.
- Timely access to skilled support to complete client plans.
- Quality of unit administrative processes including the signing off on plans and audits. It was noted a correlation between formal unit administrative processes and the completion of client plans.

The key recommendation from the 2008/09 state-wide QAR summary report was to consider the implementation of the database and electronic QSF tracking system to

enable managers to track the status of client plans, provide a prompt when a plan is due for review and record the reasons why a plan is not up-to-date.

Work is underway to improve staff usage of the Client Information System to track the status of client plans.

### **QSF Reporting**

Each unit reviewed has received a report with recommendations and the Regional Managers are using the feedback to improve the quality of their QSF data collection and reporting systems.

To further improve the quality of audit reporting, the QSF scorecard is being reviewed to improve the descriptor for each KPI and to develop quality requirements for each KPI in the client care domain to help measure the quality of client plans.

### **Stakeholder Communication**

To improve communication with families, the APD Directorate is developing good practice guidelines to guide staff on effective communication and how to build productive relationships with families.

The charter and information pack describes the expected service experience for clients and families accessing ADHC operated accommodation support services.

It will update and enhance the existing policy statement, “*Our Commitment to Residents*” and include:

- Information about the type of accommodation and range of support provided.
- Rights and responsibilities of ADHC staff, clients and families.
- Communication guidelines.
- Information about key ADHC policies and procedures.
- Advice on feedback and complaint mechanisms.

## **Industry Development**

Non Government Organisations (NGOs) are the major source of the growth in services delivered under *Stronger Together* and are central to ensuring an effective and efficient specialist disability service system.

*Stronger Together* recognises the need to work in partnership with the sector to ensure that we have an integrated and sustainable service system with the capacity to deliver more services and to respond to a broader range of client choices.

We have a long term strategy to improve value for money in the sector by working with NGOs to develop their governance and management capacity, and equipping them to operate more efficiently. Reforms to funding arrangements and predictable longer term growth are providing certainty and sustainability for existing and new providers.

The Industry Development Fund was established in 2009 to assist the NGO sector to implement service improvements and reforms. The governing board of the fund includes representatives of government and industry.

The Fund will support sector development through access to training, service improvement measures, merger support and exploring shared services models. The Fund has three components:

1. Sector Reconfiguration and system upgrades to prepare for:
  - Quality reform implementation.
  - Individual support options and person / family centred approaches to service delivery.
  - Changes to eligibility / intake / access and prioritisation processes.
2. Achieving Third Party Accreditation - assist in preparing for third party quality accreditation.

- Sector capacity building - build capacity to meet ADHC and sector development requirements and improve the cost-effectiveness of their operations.
  - Tailoring support to client need
3. Assisting NGOs to meet future expanding workforce demands through a two year project designed to grow the pool of labour available to government and non-government providers of disability and community care services in NSW.

The NSW Government, through Ageing, Disability and Home Care (ADHC), and in partnership with National Disability Services (NDS) has allocated \$17M for an Industry Development Fund (IDF) to assist service providers improve the effectiveness of their operations and enhance their service quality.

ADHC and NDS engaged KPMG to undertake extensive consultation with the sector in relation to priorities for disability services' industry development and priority initiatives for the IDF. Sector consultation workshops were held during November and December 2009.

A Directions Paper *NSW Disability Services Sector – Directions for Industry Development Final Report* (The Report) was published on 30 June 2010. The Report details recommended priority initiatives for the IDF derived from consultations with the sector in the following key areas:

- People with a disability at the centre of service delivery.
- People with a disability have access to the information and range of supports they need to live the lives they choose.
- High-performing organisations achieving real outcomes for people with a disability.
- Robust planning and resource allocation decisions based on accurate data and evidence.
- Effective governance, leadership and management of the sector.

- The workforce is skilled, capable and focused on people with a disability.

The Report is a major achievement in terms of a sector-led strategy that will support it in responding to major changes to direct care consistent with the reform areas outlined by the Productivity Commission in its report, *Contribution of the Not-for-Profit Sector*.

An IDF Implementation Group will be established to support the IDF Governance Board on industry development initiatives that support an integrated, efficient, innovative, robust and responsive service system to achieve quality outcomes for people with disability and their families in NSW.

The IDF Board recently approved enhancement funds for the following projects:

- Aboriginal Resources and Pathways – one-off funding of \$592,000 across three years (2009-2011) to expand and replicate the pilot project and establish new practical models of local networks to open clear communication and consultation pathways between ADHC, disability services and Aboriginal communities.
- Disability Safe – one-off funding of \$527,000 for 2009-10 to develop strategies to address identified gaps in the Disability Safe Model and improve service providers' efficiency gains through better management of Occupational Health and Safety issues.

In addition to the IDF, ADHC is also leading funding administration reform across the Department of Human Services (DHS) NSW in an effort to improve efficiency and cut red tape for funded organisations. Projects include:

- Establishing a DHS Forward Purchasing Plan which will provide the sector with a simplified tool for forward planning and make the process more transparent.
- Developing a DHS Risk Framework for NGO funding selection processes which will standardise and therefore improve the effectiveness of this process.



- Undertaking a DHS funding contract review which will provide a foundation “minimal model” for effective funding contracts that can be adapted across DHS agencies to reflect individual service models.

Successful outcomes from this program will:

- Reduce the burden on NGOs in preparing their applications for funding assistance, by streamlining the process and providing more readily available assistance to NGOs negotiating the process.
- Enable NGOs to engage more constructively with planning for the future using the expanded range of information that will be made available on websites. This will assist them to better understand their competitors and their comparative strengths and weaknesses, thereby allowing them to identify their most productive market niche and make longer term decisions in areas such as asset deepening and/or expansion into other areas more suitable for their operational experience and infrastructure.
- Help to make the sector more efficient by allowing quality NGO performers to focus more on providing services and less on paperwork. Through the availability of better market knowledge it will also support better targeted investments in assets and staffing.

Statewide Consultation for Revision of National Disability Services Standards

- \$90,000 has been allocated for state-wide consultations which consist of four discreet strategies: workshops; an on-line survey; face-to-face interviews; and, establishment of telephone interview service which took place in April to June 2010.
- An additional \$25,000 allocated for disability peak activity to cover nine workshops for people with disability across NSW delivered by TAFE NSW between May and June 2010.

Employment Probity is a key risk for disability service providers. In response to this, ADHC recently increased funding in disability peak activity by providing a non-recurrent amount of \$98,184 to support the development of resources and conduct

23 regional forums on Probity in Employment across NSW between 2010 and June 2011. These resources and forums will provide information to disability service providers on employment requirements and practices.

### **Workforce Development (Care Careers; SACS award increase)**

The Workforce Recruitment Strategy (WRS) is designed to grow the pool of labour available to Not For Profit, Government and Non Government Organisation providers of disability and community care services in NSW.

The WRS has received three funding allocations:

- \$3.3 million, one year (2008 – 2009)
- \$1.0 million, one year (2009 – 2010)
- \$4.273 million, two years (2010 - 2012)

The strategy aims to raise the profile of the sector within the NSW community and attract new employees to the care sector. The strategy is targeted at three primary groups within the community, parents returning to work, education leavers and career changers. It will also target potential employees in Aboriginal and CALD communities.

The strategy aims to assist employers to fill an estimated 38,000 vacancies, including over 10,000 new jobs, over the five year period to 2014.

There are two sub projects in the strategy – carecareers and project ABLE:

- Carecareers is an internet based recruitment initiative and its fully staffed Careers Centre has been established to help job seekers and hiring managers in the community care and disability sector to meet their recruitment needs.

- Achievements to date (June 2010):

Job applications to date	4697
User registrations	3048
Organisations on board	728
Jobs advertised to date	1144
Live jobs today	104
Vacancies having carecareers candidates in their selection process	668
Hires already made	Over 50 from gardeners and volunteers, to occupational therapists.

- project ABLE is designed to inspire students in secondary schools and university allied health programs to engage in an experiential program with a service provider and ultimately attract more young people into the sector.
  - To date 320 secondary students from 26 schools (public and private) have enrolled in the program. The first workshop was held on 20 May at Sunnyfield. Four disability and community care organisations have signed on to host students.
  - The project ABLE concept is transferable to other key areas of workforce interest – Aboriginal and Torres Strait Islanders and Culturally and Linguistically Diverse populations. Plans are in development for these two project components in 2010-12.

## **A Quality Framework for Disability Services in NSW**

Ageing, Disability and Home Care (ADHC) is working with National Disability Services (NDS) NSW to develop a Quality Framework for Disability Services in NSW. The Quality Framework aims to ensure that people with a disability, their family and carers receive high-quality services that deliver positive outcomes and support them to participate as valued members of the community. The Quality Framework is built on the UN Convention on Rights of Persons with Disabilities and is underpinned by the National Standards for Disability Services.

In NSW, all funded service providers are required to comply with the *NSW Disability Services Act 1993* and the NSW Disability Standards (standards) as a condition of their Funding Agreement. The Quality Framework outlines ways in which service providers can review, refine and continuously improve service delivery. It embeds a culture of continuous improvement as an ongoing process for service providers as they strive to improve outcomes for service users.

The Quality Framework aligns with ADHC's strategic objective to develop a unified, regulated sector with service users at the centre and has the capacity to respond effectively. The application of the Quality Framework will also streamline reporting requirements for the sector through the recognition of the findings of independently assessed systems (third party accreditation).

The Quality Framework is built on a partnership approach that recognises and supports the role of Boards of Management. It places the responsibility on service providers to demonstrate compliance against the standards through a process of self-assessment, independent assessment or accreditation by a third party. It allows service providers to assess the effectiveness of service operations and identify areas for improvement.

ADHC is currently establishing a program to refresh, enhance and develop tools and resources to support the implementation of the quality framework. This work is being undertaken with the sector through the Industry Development Program. These

resources will provide service providers with information on recognised assessment tools, quality management systems and a guide on recognised third party accreditation bodies. One resource will include an interactive model of the Standards in Action guide with hyperlinks to policy and good practice so service providers can continuously improve service delivery outcomes for people with disability.

### **Equal Remuneration Order**

The Social and Community Services Senior Officers Group (SACS SOG), led by ADHC, DHS NSW and comprising the Office of Industrial Relations (on behalf of other government agencies including the Department of Premier and Cabinet, Treasury, Attorney Generals) NSW Health, and Community Services are collaborating to determine the impact on NSW Government funding to the non-government community services sector arising from a Pay Equity Order currently before Fair Work Australia.

Research has been commissioned to address a critical gap in knowledge about the size and nature of the community services workforce. In particular, there is currently little information on gender, employment status, job classification, SACS award grade /year, and the range of services provided by organisations under government-funded contracts.

Key commitments have been made by the Sector to lead the development of:

- A productivity strategy; and a
- Workforce strategy.

The Equal Remuneration Order is one of a number of complex changes in the Industrial Relations environment for disability service providers that bring opportunities to transform the workforce and affect organisational productivity and efficiency gains.

## **CHAPTER FIVE: Complaint handling, grievance mechanisms and ADHC funded advocacy services**

### **Complaints Handling**

Complaints and grievances form part of ADHC's overall risk management approach where key risk issues are reported, monitored, analysed and managed to improve business processes, systems and services.

ADHC responds to requests for information and accepts feedback and complaints about all aspects of its business. ADHC seeks to respond to all complaints in a timely manner and to handle them in a fair and professional way. Whenever possible, issues are resolved at a local level in an effort to preserve the relationship between staff, the client and the client's representatives.

ADHC's *Feedback and Complaint Handling Policy, Principles and Guidelines* outlines the principles ADHC uses in the handling of complaints and to provide guidelines to assist ADHC employees to respond to complaints received. All ADHC staff as well as contractors and volunteers are required to respond to complaints according to the principles and guidelines outlined in the policy.

ADHC monitors and analyses complaints handling information including feedback and complaint handling processes, complaints data, and implementation of recommendations made by the Ombudsman or the National Disability Abuse & Neglect Hotline to ensure that policy requirements are met and to identify systemic improvements to ADHC services and support systems.

A recent complaints data analysis for the period between January and March 2010 showed that 246 complaints were received by ADHC. Of these about 90% of complaints were related to services provided by Home Care. Detailed analysis is provided at *Appendix 12*.

Improvements are being made to simplify and streamline processes for reporting complaints which will increase consistency, timeliness to respond and resolve and improve customer satisfaction with the handling of complaints. This will ensure ADHC meets all elements of current industry standard.

### **Internal Grievances**

No statistics are held on the number of grievances lodged by ADHC staff either regionally or centrally. The ADHC grievance policy requires employees to approach the person with whom they are aggrieved in the first instance. For this reason many grievances are addressed and resolved directly at the cause and are not escalated to a level where management can record that a grievance has been lodged.

Where grievances are escalated to frontline management, such grievances are managed at the front line by negotiation and mediation. Where grievances are not resolved to the satisfaction of the grievant, the region may choose to appoint an external mediation consultant to negotiate an outcome. In a small number of instances where the grievant is still not satisfied that the matter has been adequately addressed, the policy provides for the matter to be referred to the Executive Director Human Resources for review. The policy requires that such matters are referred to the Ethics and Professional Standards Unit (EPSU) in the first instance, however this is not always the case.

In the 2009/2010 financial year EPSU received 43 enquiries concerning grievances. Four of these were enquiries by individuals who wished to lodge a grievance about the process to be followed. The remaining matters were reported to the EPSU were assessed as to whether they entailed possible allegations of misconduct. All 39 matters were referred back to the respective region for local management.

### **Advocacy Services**

Advocacy enables people with a disability to increase the power and control they have over their lives in order to enjoy what they see as a 'good life' for themselves. It encourages and assists people with a disability to achieve and maintain their rights

as citizens and to achieve equity of access and participation within their communities. An advocate listens to the person so that they can accurately reflect their views and act fairly on their behalf. Advocacy also aims to increase the person's independence and confidence.

Information services provide accessible information to people with a disability and their families and carers as well as to the broader community. This support provides specific information about access to the community, disability supports and equipment and promotes the development of community awareness.

In 2009/2010, \$7.9 million was distributed across 39 service providers for 67 disability advocacy and information services including 16 advocacy only services (\$1.9 million), 24 Information only services (\$2.9 million) and 27 combined advocacy/information services (\$3.0 million).

In addition, in 2009/10 \$4.3 million was allocated to thirteen Peak Organisations to undertake initiatives in the six core peak activity areas of:

- Developing Policy and Advocacy (systemic advocacy)
- Providing Advice and Information
- Consulting Broadly
- Building Sector Capacity
- Promoting Partnerships and Collaborations and
- Demonstrating Leadership and Innovation.

Over recent years, reforms to NSW Advocacy and Information Services and Peaks Bodies have achieved distinction between systemic advocacy (with peaks) and individual advocacy (through services) and have ensured more equitable distribution of resources across NSW.




New Program Guidelines have been developed for both Advocacy and Information Services (for implementation from August 2010) to improve quality, accountability and contract management.

Reforms to Advocacy services in NSW are in line with emerging directions under the draft National Disability Advocacy Framework (Framework). This Framework responds to the commitment under the National Disability Agreement that all governments consider improvements in administration of advocacy services, with a focus on improving service delivery and access to advocacy services for people with disability.

Consultation on this Framework was held in July 2010 through written submissions, managed by Families, Housing, Community Services and Indigenous Affairs (FaHCSIA).

To complement this, NSW also held a face-to-face consultation on 2 July 2010 with NSW State and Commonwealth funded disability Advocacy services.



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