

Standing Committee on Social Issues

**Services provided or funded
by the Department of
Ageing, Disability and Home
Care**

Ordered to be printed 11 November 2010

New South Wales Parliamentary Library cataloguing-in-publication data:

New South Wales. Parliament. Legislative Council. Standing Committee on Social Issues

Services provided or funded by the Department of Ageing, Disability and Home Care : [report] / Standing Committee on Social Issues. [Sydney, N.S.W.] : the Committee, 2010. – [xxxii] 285 p. ; 30 cm. (Report ; no. 44)

“Ordered to be printed November 2010”.

Chair: Hon. Ian West MLC.

ISBN 9781920788315

1. Older people—Services for—New South Wales.
2. People with disabilities—Services for—New South Wales.
3. Caregivers—Services for—New South Wales.
4. Home care services—New South Wales.
5. Human services—New South Wales.
6. Social service—New South Wales.
- I. Title
- II. West, Ian.
- III. Series: New South Wales. Parliament. Legislative Council. Standing Committee on Social Issues. Report ; no. 44

362.409944 (DDC22)

How to contact the Committee

Members of the Standing Committee on Social Issues can be contacted through the Committee Secretariat. Written correspondence and enquiries should be directed to:

The Director

Standing Committee on Social Issues

Legislative Council

Parliament House, Macquarie Street

Sydney New South Wales 2000

Internet www.parliament.nsw.gov.au

Email socialissues@parliament.nsw.gov.au

Telephone 02 9230 2898

Facsimile 02 9230 2981

Terms of reference

1. That the Standing Committee on Social Issues inquire into and report on the quality, effectiveness and delivery of services provided or funded by the Department of Ageing, Disability and Home Care (ADHC), and in particular:
 - (a) the historical and current level of funding and extent of unmet need,
 - (b) variations in service delivery, waiting lists and program quality between:
 - (i) services provided, or funded, by ADHC,
 - (ii) ADHC Regional Areas,
 - (c) flexibility in client funding arrangements and client focused service delivery,
 - (d) compliance with Disability Service Standards,
 - (e) adequacy of complaint handling, grievance mechanisms and ADHC funded advocacy services,
 - (f) internal and external program evaluation including program auditing and achievement of program performance indicators review, and
 - (g) any other matters.
2. That the Committee report by 11 November 2010.

These terms of reference were referred to the Committee by Legislative Council on Thursday, 24 June 2010.

Committee membership

Hon Ian West MLC	Australian Labor Party	<i>Chair</i>
Hon Trevor Khan MLC	The Nationals	<i>Deputy Chair</i>
Hon Greg Donnelly MLC	Australian Labor Party	
Hon Marie Ficarra MLC	Liberal Party	
Dr John Kaye MLC	The Greens	
Hon Helen Westwood MLC*	Australian Labor Party	

* The Hon Helen Westwood MLC replaced the Hon Mick Veitch MLC as a Social Issues Committee member on 2 December 2009, as per the resolution of the House (Legislative Council Minutes No. 132, Item 18).

Committee Secretariat

Ms Rachel Simpson, Director

Ms Emily Nagle, Principal Council Officer

Ms Kate Mihaljek, Senior Council Officer

Ms Lynn Race, Assistant Council Officer

Table of contents

	Chair's foreword	xii
	Executive summary	xiii
	Summary of recommendations	xxi
	Acronyms	xxx
Chapter 1	Introduction	1
	Terms of reference	1
	Conduct of the Inquiry	1
	Submissions	1
	Public hearings	1
	Public forum	2
	Report structure	2
Chapter 2	Background	5
	Ageing, Disability and Home Care	5
	Regions	8
	Funded organisations	9
	Disability in NSW	9
	International framework	9
	National framework	10
	NSW framework	14
	Stronger Together	18
	Definition of 'disability'	19
	Data and prevalence of disability	19
	Service provision	20
	Definition of unmet need	23
	Quality and evaluation processes	24
	ADHC provided services	24
	ADHC funded services	25
	Evaluation	26
	Complaint handling mechanisms	27
	ADHC complaint handling process	27
	NSW Ombudsman	27
	Official Community Visitor Scheme	28
	The Independent Commission Against Corruption	29

Chapter 3	Funding	31
	Ageing, Disability and Home Care funding	31
	The adequacy of funding and unmet need for disability services	31
	Stronger Together II	36
	Procurement of services funded by ADHC	38
	Compliance requirements	40
	Funding and procurement inconsistencies	41
	Funding inequities between regions	42
	Individualised funding	42
Chapter 4	Planning for future service needs	47
	Service planning experiences	47
	ADHC service planning	47
	Service users' experience	49
	Disability sector organisations' experience	50
	What can be done to improve planning of disability services?	51
	Planning for transition	55
	Education	55
	From hospital to home	59
	Into accommodation placements	64
	Cross-agency service planning	67
Chapter 5	Service availability	73
	Accessing services	73
	Intake and assessment	76
	Vacancy management	82
	Disability service information	85
	Service eligibility	89
	Waiting lists	94
	Culturally appropriate services	98
Chapter 6	Unmet and under-met need	107
	Overview	107
	Supported accommodation	110
	Home care services	116

	Community Transport	122
	Attendant Care Program	125
	Equipment program	127
Chapter 7	Large Residential Centres	133
	Support for LRCs	135
	Opposition to LRCs	138
Chapter 8	Home modification and maintenance	147
	Home Modification and Maintenance	147
	Service quality	150
	Waiting lists	153
Chapter 9	Quality monitoring and evaluation	157
	Disability standards and legislation	157
	Disability Service Standards	157
	<i>Disability Services Act 1993 (NSW)</i>	163
	How could compliance with legislation and the NSW DSS be improved?	164
	Complaint handling	168
	Access to complaint handling	169
	What is required to improve ADHC's complaint handling process?	174
	Evaluation and monitoring	180
	Conflicts of interest	183
	Disability services data and research	186
	Licensed boarding houses	192
Chapter 10	Carers	195
	Recognition of carers	196
	Supported accommodation	200
	Respite	203
	Person-centred service provision	206
	Access to future planning services	209
	Communication and navigating the disability service sector	211
	Complaints handling and grievance mechanisms	212

	Impact on family relationships	213
	Child relinquishment	217
	Older carers	219
	Culturally and Linguistically Diverse (CALD) carers	223
	Aboriginal carers	225
Chapter 11	Disability services staffing	229
	The number of staff	229
	The importance of good staff	230
	Attracting and Retaining Staff	232
	Attracting staff	232
	The workforce recruitment strategy	234
	The retention of staff	236
	Differing pay rates between government and non-government providers	238
	Professional development of staff	240
	Rude and abusive staff	243
	The special problems in regional and remote areas	245
Appendix 1	Submissions	249
Appendix 2	Witnesses	253
Appendix 3	Tabled documents	257
Appendix 4	Answers to questions on notice	258
Appendix 5	Disability Service Standards, Principles and Applications of principles	259
Appendix 6	Minutes	262

Cases

Case study 1 – Name suppressed	61
Case study 2 – Ms Valerie Noone	66
Case study 3 – Name suppressed	91
Case study 4 - Ms Estelle Shields	112
Case study 5 – Name suppressed	118
Case study 6 - Mr Martin Boers	129
Case study 7 – Name suppressed	148
Case study 8 – Name suppressed	161
Case study 9 – Spinal Cord Injuries Australia	161
Case study 10 – Ms Valerie Noone	173
Case study 11 - Ms Janice Marshall	201
Case study 12 - Ms Sayde Sarkis	214
Case study 13 - Ms Jackie Dufty	215
Case study 14 - Lyn	218

Figures

Figure 2.1 Administrative regions of Ageing, Disability and Home Care	8
---	---

Tables

Table 2.1	ADHC's key result areas	6
Table 7.1	Redeveloped Large Residential Centres in NSW	134

Chair's foreword

There is a significant opportunity for constructive change to be embedded in the NSW disability service system in the coming years. Following the many achievements of the first phase of Stronger Together, there is anticipation of what the second phase will bring. The importance of services being planned and delivered in a way that enables people to live with maximum choice, flexibility and control over their lives cannot be underestimated. This is a goal that all disability services should strive to achieve as the priorities of Stronger Together II are announced and implemented.

The terms of reference for the Inquiry asked the Committee to examine the quality, effectiveness and delivery of services provided or funded by Ageing, Disability and Home Care (ADHC). Throughout the Inquiry we were reminded of the enormous responsibility and important role played by ADHC in the coordination, planning, service delivery, regulation and funding of disability services. The services funded and provided by ADHC touch the lives of many people, both directly and indirectly, and effective planning is essential in ensuring that the system develops in a way that best serves the needs of these people. It is essential that the disability service system recognises and supports the contribution of the numerous unpaid carers on which the system depends. There must be processes established to prevent carers from reaching breaking point before being eligible to receive support.

While the move towards a person-centred approach to disability service provision is unarguably supported, there are still many people who do not receive essential planning, services, support and quality of care they require. Unfortunately, there are many service users and carers for whom the current service system creates additional challenge, rather than helping to ease the burden these people face on a daily basis. I hope that the recommendations made through this Inquiry can help improve the support provided to these service users and carers, improve the rate of compliance with the Disability Service Standards and prevent the situations we have observed from occurring in the future.

On behalf of the Committee I would like to thank all the participants for contributing their valuable time and knowledge during Inquiry, particularly the inspiring service users and carers who shared their often difficult experiences with the Committee at the Public Forum.

I would also like to thank the Committee secretariat – Rachel Simpson, Emily Nagle, Kate Mihaljek and Lynn Race – for their efforts in managing the Inquiry process and preparing this report. I also thank my fellow Committee members for their efforts in examining the diverse and often challenging issues presented and for identifying options to improve this vital area of service and support.

I commend this report to the Government, which is supported unanimously by the Committee, and call on it to ensure that *all* disability services comply with the Disability Service Standards and that they are planned and delivered in a person-centred way.



Ian West MLC
Chair

Executive summary

This Inquiry was referred to the Committee on 24 June 2010, to examine the quality, effectiveness and delivery of services provided or funded by Ageing, Disability and Home Care (ADHC). The extent of unmet need for disability services was required to be examined, including whether there were regional or other variations in the capacity and quality of disability services. We received 112 submissions and 8 supplementary submissions, which reflected a range of experiences, views and recommendations to improve the current disability service system.

The important role that ADHC plays in the provision of essential services to the lives of many people was highlighted through the Inquiry. This includes both service users who directly access services and their carers and families who depend on supports such as advocacy and respite. Recent improvements in the disability service system were acknowledged by some participants, however, a significant amount of evidence also identified the desperate need for further improvement in some key areas.

Many service users and carers made an important contribution to this Inquiry. The Committee's deliberations are indebted to their courage in coming forward and sharing often difficult experiences. Through sharing these experiences we were able to learn more about the disability service system and ensure that the recommendations made would assist the system to develop in a way that best serves the needs of the very people who depend upon it.

Funding

In order to effectively examine issues regarding services provided and funded by ADHC, the Committee considered the current funding of disability services. We consider that funding provided through Stronger Together has noticeably improved the provision of disability services in NSW, however, it is clear that funding does not meet the current demand for many services and as such there is a significant amount of unmet need. The demand for disability and ageing services is not likely to decrease in future, in fact the Committee heard evidence of a growing and ageing population. This means that pressure on the service system is likely to grow, which increases the urgency for the development of a well-planned and responsive, rather than reactive, service system.

We agree with ADHC and the many participants who identified that measurement of unmet need is a serious issue and should be addressed as a priority. However, for areas of service provision that clearly demonstrate a significant level of unmet need, data should not be used as an excuse for inaction. Stronger Together II provides an opportunity to increase the funding to disability services, plan a responsive service system and address the issues identified through this Inquiry. The Committee has recommended that at least \$2.5 billion is provided for Stronger Together II to meet these goals (Recommendation 3).

Individualised funding options have the potential to provide improved choice, flexibility and control for service users. While we acknowledge that individualised funding may not be suitable for all service users, for many people this person-centred funding approach will improve their quality of life through providing improved autonomy, flexibility and choice. The Committee commends the Government for providing individualised funding options through phase one of Stronger Together, and also through committing to delivering personalised funding arrangements during phase two. We support this approach and have recommended that Stronger Together II includes the development of a

comprehensive strategy to make individualised funding models available for all people who receive services from ADHC, who wish to utilise them (Recommendation 6).

Person-centred planning and supported accommodation

The move towards a person-centred service system will significantly improve the quality of services available. ADHC is moving away from a one-size-fits-all approach towards person-centred service planning and delivery, which is supported by the Committee. ADHC has already made some progress, however, there is still a long way to go before all service planning, delivery and funding is provided with the service user at the centre of decisions.

Some aspects of services provided and funded by ADHC are inflexible and cause unnecessary stress for service users. The inflexibility of the system that is encountered by many people makes planning for their future services very difficult and causes additional anguish, fear and frustration for service users and their families. While this issue was experienced in many service types, we heard this issue most profoundly in peoples' experience of supported accommodation. We are greatly concerned for the service users and families who are currently required to reach a point of crisis before supported accommodation is available to them. We are disappointed that the service system has let these people down.

Given the shortage of supported accommodation placements available, we have recommended that improved support is provided to all service users and their families who register on ADHC's *Register of Request for Supported Accommodation* (Recommendation 36). We have also recommended that additional supported accommodation placements are made available through Stronger Together II and that a comprehensive service planning framework is developed to forward plan service delivery, rather than continuing to provide services such as these on a crisis basis (Recommendation 9).

Individualised planning is not currently required to take place for people who reside in long-term respite placements. This is of great concern to the Committee. It is an example of a significant gap and unmet need in person-centred planning and service delivery. We recommend that *all* service users who are in, or are likely to remain in, long-term placements have access to individualised planning, in-line with the Government's commitment to a person-centred approach (Recommendation 7). We have also recommended that a person-centred approach is developed and implemented for all funding programs and service types during Stronger Together II (Recommendation 10).

Eligibility, intake and assessment

Significant challenges are created for people who attempt to navigate the disability service system through unclear and poorly communicated eligibility criteria and intake and assessment rules. There is a lack of consistency across and within ADHC regions, no tracking system for referrals for many service types, poor communication with service users and an unnecessary duplication of needs assessments being completed by ADHC. People with disability can face many challenges and well functioning intake and assessment process is required to adequately support, rather than provide challenge, to the lives of these people.

We heard evidence that ADHC complete a needs assessment, even when the agency has a comprehensive one that has been completed by a professional. The lengthy delay that this can cause with regard to accessing services is unnecessary and a waste of scarce resources. We have recommended that a review of ADHC's intake and assessment process is undertaken, which reduces

duplicate needs assessments being completed, through not requiring ADHC to complete an assessment when one has been completed by the referring professional (Recommendation 21).

An issue regarding financial eligibility relates to the lack of assessment of expenses incurred by people with disability who access multiple services, as part of means testing requirements. We believe that the inclusion of assessment of expenses in means tests would provide a more comprehensive picture of people with disability's financial position and ensure that these people are not further disadvantaged by this process. We have recommended that ADHC's means testing policy is reviewed with view to including assessment of expenses (Recommendation 19).

ADHC has committed to creating a consistent and streamlined intake and assessment process for accessing specialist disability services, specifically committing to reviewing different intake models, the number of entry points and developing a single set of priority of access criteria. We believe that this review could significantly improve the intake and assessment process and that it should be expedited. We have recommended that the review of the intake and assessment process for disability services is expedited to address entry to the system, prevent duplicate needs assessments being completed where possible, improve notification of eligibility and entitlements to services, improve consistency in intake and assessment processes and improve navigation of the system (Recommendation 21).

Transition planning

We received a great deal of evidence regarding a lack of planning that takes place during times of predictable transition in the lives of service users'. The Committee has recommended that ADHC's transition policy is reviewed and amended to improve the support available to people who transition, the timing of support provided, service user awareness of transition programs and intake rules and to reduce delays and absence of planning (Recommendation 11). We have also recommended that improved co-ordination be implemented across Government agencies, such as ADHC and NSW Health, to assist people who transition from hospital to home (Recommendation 12). Improvement is also required in the transition of service users into group homes. It is vital that ADHC funded and provided service staff understand and implement transition policy to ensure that a person-centred approach is implemented, for both the person who is transitioning into accommodation options and existing residents.

Large residential centres

Although Large Residential Centres (LRCs) have been redeveloped by the Government, too many people continue to live in these centres. LRCs do not comply with the NSW Disability Service Standards, the *Disability Services Act 1993* or the United Nations Convention on the Rights of People with Disabilities. While the Committee agrees that an appropriate 'mix' of accommodation options is required in order to best meet the diverse needs of service users, we also believe that all options made available to service users must comply with the relevant disability service policies and legislation. For the vast majority of service users, congregate care settings will not be the most appropriate, person-centred option suitable for their needs.

We have recommended that the devolution of LRCs is maximised through providing person-centred planning and support for *every* service user who is currently housed in these centres (Recommendation 42). The Committee believes that if every service user received person-centred planning, a very small number who had extremely high support needs may remain in congregate settings.

Home modification and maintenance

Home modification and maintenance services are essential in enabling service users to live in their own home in the community. There are delays in accessing these services due to a lack of Occupational Therapists and long waiting periods to access NSW Health Occupational Therapy assessments. Issues regarding a lack of funding and poor quality of service provision are also significant for this program. The possibility that unlicensed builders may be used to modify service users' homes is of great concern to the Committee. Although we have not received sufficient evidence to be able to determine whether all service providers are either licensed or use licensed builders, the lack of certainty is a significant concern. The requirement for service providers to indicate that they comply with legislation through the Annual Compliance Return has not provided the Committee with the required level of assurance that home modification and maintenance services comply with relevant legislation. ADHC should be able to report *with certainty* that their services comply with the *Home Building Act 1989*.

We have recommended that the current home modification and maintenance service review includes consultation with stakeholders to address potential non-compliance with the *Home Building Act 1989*, including the use of unlicensed builders, funding levels and shortages, waiting lists and options to streamline the application process (Recommendation 44).

Culturally appropriate service provision

There are many additional challenges faced by people with disability from non-English speaking backgrounds when attempting to access disability services and support. The provision of culturally appropriate services is an area of disability service provision that has improved; however, it has a long way to go before it adequately meets the needs of these people. There is a significant under-representation of people with disability from non-English speaking backgrounds accessing ADHC services, with approximately 36 per cent of people from non-English speaking backgrounds having disability, but only around 5 per cent of these people accessing ADHC services. The barriers these people face include a lack of culturally appropriate information and services, cultural differences towards 'disability', lack of appropriately trained staff and a focus on managing disability rather than supporting people who happen to have disability.

We also sadly heard that Aboriginal and Torres Strait Islander people with disability are some of the most disadvantaged people in Australia. Again, there have been improvements in this area, for example through changes to the Aboriginal Home Care Service resulting in the provision of more culturally appropriate services. However, until there is a significant shift in the way that services are able to be accessed by Aboriginal people, towards a more flexible, person-centred and culturally appropriate model, we feel that there will be little improvement. This includes developing a service system that allows Aboriginal workers to work in a culturally competent way rather than imposing a system on them that may work for other groups, but is inappropriate for them.

The commitment by ADHC to increase the number of Aboriginal staff may assist the agency to provide more culturally appropriate services. We have recommended that this is completed in conjunction with cultural competence training for *all* employees (Recommendation 33). This training would result in more staff being able to provide appropriate services and it would improve the choice that Aboriginal people have regarding who they receive services from.

We have questioned whether there are adequate advocacy organisations and services available to represent the needs of people with disability from Aboriginal communities and from non-English speaking backgrounds. There is currently only one advocacy organisation funded by ADHC that

provides services for people with disability from non-English speaking backgrounds. We have recommended that ADHC incorporate diversity measures and outcomes in all program guidelines, to convey the importance and requirement to provide culturally appropriate services (Recommendation 34). We also believe that the lack of free interpreter services to people with disability from a non-English speaking background is a barrier to them receiving services and recommended that this is made available (Recommendation 32).

Licensed boarding houses

Boarding houses are an accommodation option for both people with and without disability, and house approximately 800 residents in NSW. They are monitored by ADHC licensing officers and are visited by Official Community Visitors. We are concerned that unlicensed boarding houses have neither of these safeguards and that some may be operating illegally, reducing the quality of care that may be provided to some of the most vulnerable and marginalized people in society. The referral of people with disability to unlicensed boarding house accommodation in the absence of other accommodation options is particularly disturbing to the Committee.

We have recommended that people who reside in boarding houses receive person-centred planning and assurance that the services they receive comply with the NSW Disability Service Standards.

Equipment and aids

The importance of having appropriate aids and equipment for people with disability is acknowledged by the Committee. Access to equipment is critical in enabling people to undertake regular activities, such as moving around, personal care, attending school or generally accessing the community. Both ADHC and NSW Health play a role in relation to aids and equipment through case management, occupational therapy assessment and referral (ADHC), and for the administration of disability support programs such as Enable NSW (NSW Health).

We are very concerned at the reports of service users having to wait up to two years between assessment of their need for a piece of equipment and receiving it. This is unacceptable and is a huge area of unmet need. It is ADHC's responsibility to ensure that their service users receive essential equipment when they need it, and to remove any barriers to this access. Lengthy waiting periods for equipment can have a devastating impact on service users and carers. We sympathise with their frustration in observing the provision of equipment on a crisis basis. In most cases the provision of equipment is not managed in line with ADHC's person-centred approach to service planning and delivery, and requires significant improvement.

We have recommended that the implementation of a program of interest free loans for equipment and aids for ADHC service users and other people with disabilities is investigated (Recommendation 41). These loans would allow for greater flexibility and a more person-centred approach to service provision.

Standards of quality and complaint handling

The NSW Disability Service Standards (NSW DSS) and the *Disability Services Act 1993* (NSW) provide the foundation for the quality of services provided to people with disability in NSW. However, some services provided or funded by ADHC do not comply with this important policy and legislation. Services are also sometimes not provided in accordance with the United National Convention on the

Rights of People with Disabilities (UNCRPD). The poor monitoring of service compliance with this policy and legislation is one of the most significant issues identified through the Inquiry. We are concerned that ADHC is not able to respond to breaches of the NSW DSS in a reasonable time frame or in a reasonable manner in some cases

Services such as LRCs, tools such as ADHC's vacancy management system and the behaviour of some staff are examples of non-compliance with NSW DSS. There is variation between ADHC central office and local implementation of NSW DSS policy and a lack of staff knowledge and training in the use and implementation of the NSW DSS. We have recommended that the NSW Government establish an independent agency to monitor the compliance of disability service provision with the NSW DSS, the Act and the UNCRPD (Recommendation 47). This agency would reduce the potential for conflict of interest to occur and also be responsible for handling complaints and managing third party accreditation of disability service providers.

On numerous occasions, service users and their families experienced poor complaint handling when attempting to provide feedback and resolve issues about services received by ADHC or funded organisations. Adequate policies and processes are required to effectively handle complaints and to ensure compliance with the NSW DSS. We have recommended that ADHC's complaint handling policy is reviewed to ensure that complaints are addressed in a timely manner, the policy is accessible to all service users, implements staff training and develops appropriate resources for funded organisations to improve understanding of complaint handling processes (Recommendation 46). As outlined, we have also recommended that an independent organisation is established to, amongst other responsibilities, handle complaints about disability service provision.

Conflict of interest

There is the potential for a conflict of interest to occur through ADHC's incompatible responsibilities of funder and regulator of disability services, while also being a major service provider. The NSW Law Reform Commission recommended many years ago that an *independent* organisation is required to accredit and monitor disability services. We support this recommendation and believe that it would reduce the potential for a conflict of interest to occur while improving the quality of disability services provided (Recommendation 47). Having an independent organisation whose sole responsibility is service provision quality, would address many of the issues identified through this Inquiry including complaint handling, quality monitoring, compliance with the NSW DSS, third party accreditation and conflict of interest.

Advocacy services are currently funded by ADHC which reduces the ability for independent advocacy services to be provided to service users. A conflict results from advocates being funded by the organisation they may inadvertently criticise through their role of supporting people with disability to access appropriate services. As ADHC also fund and provide services, ADHC funded advocacy services are not impartial or independent. This may impact upon the ability for advocates to provide the most appropriate advice to service users. We have recommended that the funding for advocacy services is moved to a Department that is independent of disability service provision (Recommendation 48). This would free advocates to provide the most appropriate services and support to individual service users' needs without fear of 'biting the hand that feeds them'.

Carers

The important social and financial contribution of the approximately 750,000 unpaid carers in the disability system in NSW cannot be underestimated. The system depends on these people who often provide care to their loved ones under very challenging circumstances. Many carers are not well supported and may even have their situation made worse by the current disability service system, through poor planning, a lack of support services and an inflexible service system. We acknowledge the steps the Government has taken to recognise and support the important role carers play in the community, although evidence received through this Inquiry suggested that there is still a long way to go.

We are deeply concerned by the stress and fear experienced by the many carers whose attempts to plan for the future of their children have not been well supported by ADHC. We are disappointed that access to supported accommodation is largely provided in response to crisis and emergency, rather than in a planned way. A system that requires its families to reach breaking point before providing adequate support and services is unacceptable. A summary of our recommendations to improve access, support and provision of supported accommodation are identified in 'person-centred planning and supported accommodation' on page xiv.

Staff

People with disability and their families place a high value on staff that are highly professional, experienced and caring. There are many thousands of hard working and caring employees who work in the ageing and disability support sector. The positive comments that persons with disability and their families expressed towards their carers were some of the few positive comments that we received during this Inquiry.

ADHC's Workforce Recruitment Strategy is supported by the Committee, in addition to the proactive recruitment work undertaken by ADHC and non-government service providers to assist in attracting people to the profession. As funding for this program is not allocated beyond 2012, we recommended that the strategy is reviewed with a view to extending it for a further two years, six months prior to the end of current funding (Recommendation 51). The high turnover of disability service staff is of concern to the Committee as it reduces the quality of care provided to service users and their families. We have recommended that ADHC convene a cross sector working party to develop a workforce retention strategy (Recommendation 52).

We strongly support the principle of equal pay for staff delivering the same service, no matter whether a carer is an employee of ADHC or a non-government provider. We acknowledge that the successful outcome of the pay equity case before Fair Work Australia will have funding implications, which will need to be addressed by the Government.

The level of training for Home Care workers is of concern to the Committee. Examples of clients being injured by poorly-trained, ill-equipped staff are unacceptable, so we recommended that the Home Care Service of NSW undertake an evaluation of training levels for all care workers (Recommendation 53). The majority of ADHC care workers provide outstanding work, which allows people with disability to participate more fully in community life and offers respite for carers. However, we received evidence of carer staff who are rude, abusive and sometimes neglect service users. We strongly believe that both ADHC and funded organisations need to strengthen reporting and accountability mechanisms, so that clients can report inappropriate staff behaviour and have confidence that their concerns will be dealt with promptly and appropriately.

The extra challenges that both service providers and service users face in rural and remote communities is acknowledged. The challenges relate to geographical distance, recruitment of suitably qualified people and the provision of training. The Committee received evidence that the provision of disability and ageing services is more expensive in rural and remote areas. We have recommended that ADHC investigate these concerns, with a view to increasing the funding for services in rural and regional areas if required (Recommendation 55).

Data and research

Infrequent Australian Bureau of Statistics data collection is a significant issue for disability service system planning in NSW. This makes it difficult for ADHC to best plan for the needs of people with disability and for phase two of Stronger Together. We acknowledge the work that ADHC is undertaking to make good use of other relevant statistical data collection. We have recommended that the existing data that is collected by both ADHC and through other means is audited so that data gaps can be identified regarding unmet need for disability and ageing services in NSW (Recommendation 1).

A survey of service users, carers and their families is recommended to be completed by ADHC every three years to improve ADHC's understanding of the population that is receiving a service, the level of unmet need and any other relevant issues that are not captured through other means (Recommendation 49).

Summary of recommendations

- Recommendation 1** **35**
 That the Minister for Disability Services audit the existing data that is collected by ADHC and data that is available to ADHC, identify any additional data that is required to accurately assess unmet and under-met need for ageing and disability services in NSW.
- That the NSW Government amend the *Disability Services Act 1993* to require the Minister for Disability Services to table a biannual report into unmet and under-met need for ageing and disability services in NSW.
- Recommendation 2** **35**
 That ADHC prioritise the attainment of its targets for supported accommodation places, as identified in the first phase of Stronger Together.
- Recommendation 3** **38**
 That the NSW Government commit at least \$2.5 billion to deliver phase two of Stronger Together. That phase two funding is provided in addition to the \$1.3 billion in funding that was provided during phase one and is announced by the end of December 2010.
- Recommendation 4** **38**
 That the Minister for Disability Services table an annual report to Parliament on the implementation of, and expenditure on, Stronger Together II.
- Recommendation 5** **41**
 That the Minister for Disability Services report publicly on ADHC's implementation of the recommendations of the NGO Red Tape Reduction report by November 2011 including the level of third party outsourcing by ADHC NGO-contracted service providers.
- Recommendation 6** **46**
 That the next phase of Stronger Together include development of a comprehensive strategy to make individualised funding models available for all people who receive services from ADHC, who wish to utilise them.
- Recommendation 7** **53**
 That the Minister for Disability Services ensure that all service users who are in, or are likely to remain in, long-term placements have access to individualised planning.
- That this is achieved through:
- conducting a review of service users who have been in, or are likely to remain in, placements long-term and have not received individualised planning
 - completing individualised planning for these service users as a matter of priority
 - ensuring that individualised planning is provided for all accommodation placements that are, or are likely to be, long-term.
- Recommendation 8** **53**
 That the Minister for Disability Services develop and implement an outreach approach for the planning of disability services for Aboriginal and Torres Strait Islander communities.

Recommendation 9**54**

That the Minister for Disability Services convene a Working Group made up of government Departments, NGO service providers, representatives of the Disability Council of NSW and other stakeholders, to develop and implement a comprehensive service planning framework, in consultation with disability service stakeholders, to identify how the disability service system will develop over the next five years.

That the framework:

- identifies how and when policy priorities, including person-centred planning, will be incorporated into service provision
- integrates planning at a state, regional, local and organisational level and provides tools to strengthen planning at an organisational level
- demonstrates how data and research will be used to inform development of the disability service system over time
- is published on ADHC's website.

Recommendation 10**54**

That the Minister for Disability Services work in collaboration with the non-government sector and other relevant stakeholders to develop and implement a person-centred approach for *all* funding programs and service types during phase two of Stronger Together.

Recommendation 11**59**

That the Minister for Disability Services, in consultation with the Department of Education and Training, review and amend transition planning policies as part of phase two of Stronger Together.

That the review:

- is conducted in consultation with relevant stakeholders including services users, carers and their families
- increases awareness of the Transition to School program
- ensures that all people with disability leaving school are able to access transition planning as early as possible
- improves transition support and planning provided to people with disability from non-English speaking backgrounds who are leaving school
- provides clear resources for service users, carers and their families who are seeking information on how to access transition planning services
- ensures that people with disability receive appropriate support upon entering the education system and that access to education does not result in adverse consequences such as a reduction in necessary services or supports.

That the review and actions resulting from the review are published on ADHC's website.

Recommendation 12**64**

That the NSW Government review and amend transition policy and processes for people with disability who transition from hospital to home.

That the outcome of the review ensures that people have appropriate, accessible and well-coordinated support available prior to transitioning out of hospital and during the period of readjustment to their home. The review should consider existing successful programs and models, such as the South East Sydney Illawarra Area Health Service Agency for Clinical Innovation Transition Model.

Recommendation 13**64**

That the NSW Government review and clarify current staff responsibilities in transition planning, including reviewing whether hospital social workers are the most appropriate role to conduct this planning and whether there is a greater coordinating role for ADHC caseworkers.

That the review identifies clear staff roles responsible for providing support to service users while they complete transition planning in hospital and as they re-settle in their home. That the outcomes of the review are communicated to all relevant staff.

That the review identifies safeguards to prevent people with disability from being discharged from hospital with inadequate support.

Recommendation 14**64**

That the Minister for Disability Services provide ADHC case management to all ADHC service users who are being discharged from hospital.

Recommendation 15**64**

That the NSW Government consider the Spinal Cord Injuries Response initiative for relevance to the NSW disability service sector.

Recommendation 16**67**

That the Minister for Disability services ensure that current policy regarding transition planning in accommodation services is understood and implemented by all relevant staff, to ensure that a person-centred approach is implemented, for both the person who is transitioning into accommodation options and existing residents.

Recommendation 17**72**

That the NSW Government review and amend the process by which ADHC and NSW Health share sensitive information about service users who access both agencies.

That the review:

- develops and applies a common understanding of the meaning of 'confidential information' in the context of health and disability service user information sharing
- identifies how confidential information can be shared between agencies to improve the quality of services provided, including considering issues of consent
- learns from the successful models of information sharing between ADHC and NSW Health that exist in some regions
- learns from the achievements of information sharing in Keep Them Safe and applies them as appropriate.

That the report resulting from the review and ADHC response to recommendations are published on the website.

Recommendation 18

72

That the NSW Government amend the requirement for people with disability to obtain multiple statements from General Practitioners to confirm their disability when accessing ADHC services, to allow the General Practitioners statement to be valid for varying periods of time that are relevant to the disability and needs of the individual.

Recommendation 19

75

That the NSW Government review and amend means testing policy for people with disability attempting to access services, to include assessment of expenses, so that people with disability are not disadvantaged through being required to provide an incomplete picture of their financial position.

That the amended policy is communicated to ADHC staff, funded organisations and disability service users.

Recommendation 20

75

That the Minister for Disability Services introduce standardised income/means testing forms across all ADHC provided and funded programs and ensures forms are available in multiple languages and formats.

Recommendation 21

81

That the Minister for Disability Services expedite the review of the intake and assessment process for disability services to:

- develop a single, well-defined and clear entry point into the service system
- prevent duplicate needs assessments being completed, through not requiring ADHC to complete an assessment when one has been completed by the referring professional
- provide immediate notification of eligibility and entitlement for ADHC provided and funded services
- develop and implement a consistent intake and assessment policy across regions
- improve navigation of intake and assessment, including the provision of clear information about service options, eligibility and support
- review the eligibility criteria for the Attendant Care Program.

That the outcomes of the review, recommendations and ADHC's response to the recommendations are published on ADHC's website.

Recommendation 22

85

That the Minister for Disability Services review and amend ADHC's vacancy management system for supported accommodation in consultation with stakeholders. That the review considers:

- person-centred policy
- access to supported accommodation based on need rather than disability type
- complexity of the application process
- the distance that service users are placed from their family and community
- the compatibility of people placed together in supported accommodation
- the level of choice that service users have regarding where they live, who they live with and who supports them
- compliance with the NSW Disability Service Standards and the United Nations Convention on the Rights of Persons with Disabilities

- provision for information sharing and co-ordination of data exchange between ADHC and NGO service providers.

That the outcomes of the review, recommendations and actions are published on ADHC's website.

Recommendation 23

88

That the Minister for Disability Services improve access to disability service information for all service types, programs and supports. That this is achieved through:

- ensuring information is available and easily accessible on all ADHC provided and funded services, including locations where the services are provided, eligibility criteria and how to access the service
- providing information in a variety of formats, including Easy Access, non-English languages, electronically and in hard copy
- providing references to other reputable sources of information, such as websites and organisations, that can provide support and general information to service users, carers and their families.

Recommendation 24

89

That the Minister for Disability Services improve the availability of information to people who are deaf or those with vision disability through making available disability service information in relevant formats.

Recommendation 25

93

That the Minister for Disability Services convene a Working Group made up of government departments, NGO service providers, representatives from the Disability Council of NSW and other stakeholders, to complete a review of eligibility criteria for all services, based on an internationally valid framework such as the WHO's International Classification of Disability Functioning and Health. That revised eligibility criteria determine service eligibility based on need rather than disability.

That the Working Group undertakes consultation with a range of ADHC service users and ensure eligibility criteria are consistent with the UN Convention on the Rights of Persons with Disabilities.

That the outcomes of the review, recommendations and actions are published on ADHC's website.

Recommendation 26

93

That the Minister for Disability Services develop (or revise as appropriate) and consistently implement eligibility policy for all funded and provided service, including the development and implementation of a common eligibility screening tool, and that the policy ensures that service users' are immediately notified of their eligibility and entitlement to ADHC funded and provided services.

Recommendation 27

94

That the Minister for Disability Services amend the eligibility criteria of the attendant care program as a matter of urgency to include people who are deaf and blind.

- Recommendation 28** **94**
That the Minister for Disability Services ensure that appropriate services are available for people who are deaf blind, through funding and training interpreters and guides for deaf and blind service users.
- Recommendation 29** **97**
That the Minister for Disability Services develop a policy regarding the use of waiting lists in ADHC provided and funded services, to improve transparency and understanding of waiting list through:
- providing clear direction on when waiting lists will be kept by ADHC and funded organisations
 - providing direction on how waiting lists will be maintained
 - identifying when, how and the frequency that service users will be communicated with regarding their position on the waiting list
 - reducing the amount of red tape in accessing waiting lists
 - communicating that waiting lists will not negatively impact funded organisations' relationship with ADHC
 - being circulated to service providers, ADHC staff and peak organisations so there is a common understanding across the sector.
- Recommendation 30** **105**
That the Minister for Disability Services consider the Western Australia local area coordinator model of service delivery and implements the model in NSW if appropriate.
- Recommendation 31** **106**
That the Minister for Disability Services provide culturally appropriate disability services information.
- Recommendation 32** **106**
That the Minister for Disability Services provide free interpreter services to people with disability from non-English speaking backgrounds.
- Recommendation 33** **106**
That the Minister for Disability Services ensure that all staff in ADHC funded and provided services receive cultural competency training to enable them to work effectively with Aboriginal and Torres Strait Islander people and people from a non-English speaking background.
- Recommendation 34** **106**
That the Minister for Disability Services incorporate diversity measures and outcomes in all program guidelines.
- Recommendation 35** **116**
That the Minister for Disability Services increase the number of supported accommodation options available as a priority, through phase two of Stronger Together to meet the need on the Register and the anticipated ongoing, growing demand.

Recommendation 36**116**

That Ageing, Disability and Home Care regularly communicate with all families on the Register of Requests for Supported Accommodation to assess their eligibility for supported accommodation, communicate how long the anticipated wait is and to ensure that families receive an appropriate level of support while waiting for accommodation.

That in cases where a family has remained on the Register of Requests for Supported Accommodation for more than six months, ADHC is to advise the Minister of the unfulfilled request.

Recommendation 37**121**

That the Minister for Disability Services establish an out-of-office hours staff member in all regions to coordinate after hours changes to service delivery for all ADHC provided home care programs. That this staff member communicates with service users when there are after hours changes to service provision.

Recommendation 38**121**

That the Minister for Disability Services ensure that all relevant staff are aware of current policy and procedures in the home care program, to improve consistency in this program across regions, through the implementation of regular training.

Recommendation 39**122**

That the Minister for Disability Services ensure that there are HACC staff available in every region who are trained to communicate with, understand and respond to the needs of deaf people.

Recommendation 40**125**

That the Government ensures community transport concerns are addressed, particularly the need to make the service more person-centered, as a priority through the phase two of Stronger Together.

Recommendation 41**131**

That the NSW Government investigate the implementation of a program of interest free loans for equipment and aids for ADHC service users and other people with disabilities.

Recommendation 42**144**

That the Minister for Disability Services maximise the devolution of Large Residential Centre through providing person-centered planning and support for every service user who is currently housed in these centres, and that:

- accommodation needs and preferences of individuals are the centre of decisions to relocate residents.
- all accommodation options offered to service users transitioning out of Large Residential Centres, complies with the NSW Disability Service Standards, *Disability Services Act 1993* and the United Nations Convention on the Rights of Persons with Disabilities.

Recommendation 43**145**

That the Minister for Disability Services ensures that service users who are transitioned out of Large Residential Centres are adequately supported during the transition period and while they settle into their new accommodation.

Recommendation 44**156**

That the NSW Government ensure that the current evaluation of the ADHC funded Home Modification and Maintenance program includes consultation with stakeholders and includes review of:

- funding levels and shortages
- waiting lists, including for Occupational Therapist assessments
- potential non-compliance with the *Home Building Act 1989*, including the use of unlicensed builders
- options to streamline the application process for home modification services so that only one application is required from service users for assessment, quotation and home modification
- quality evaluation of services provided through the program
- options for home modification and maintenance service providers to provide waiting list information to ADHC, for example regarding unmet need
- review of all outstanding applications that have received an assessment and quotation but have not been completed.

That the evaluation and ADHC's response to the recommendations is published on ADHC's website once finalised.

Recommendation 45**167**

That the Minister for Disability Services revises the NSW Disability Service Standards to include a new standard that requires culturally appropriate services to be delivered.

Recommendation 46**180**

That the Minister for Disability Services conduct a review of complaint and grievance handling policy and procedures for disability services in NSW, and that the review:

- be conducted in consultation with relevant stakeholders including service users and carers
- provides ADHC complaint policy in a format that is accessible to all service users, including people who are deaf and visually impaired
- ensures ADHC complaint policy is easy to locate on the internet
- develops processes to ensure that complaints are addressed in a timely manner
- refers to the NSW Ombudsman Complaint Handling at Universities: Best Practice Guidelines when identifying how to improve complaint handling policies and processes
- identifies and addresses gaps in complaint handling between agencies such as ADHC and the NSW Ombudsman
- implements staff training and develops appropriate resources for funded organisations to improve understanding of complaint handling processes.

That the review report and actions resulting from the review are published on ADHC's website.

Recommendation 47**180**

That the NSW Government establish an independent organisation to:

- monitor the quality of disability services provided and funded by ADHC
- handle complaints about the provision of services (for issues that are not within the responsibility of organisations such as the NSW Ombudsman)
- monitor compliance with the NSW Disability Service Standards and the *Disability Services Act 1993* through providing accreditation to organisations that provide disability services in accordance with the standards.

- Recommendation 48** **186**
 That the NSW Government move funding administration of advocacy services to a Department that is independent of disability service provision.
- Recommendation 49** **191**
 That the Minister for Disability Services conduct a survey of all service users, carers and their families who receive services from ADHC and funded organisations every three years to improve ADHC's understanding of issues in the disability service system.
- That the results of the survey and ADHC's response to the results are published within six months after completion of the survey.
- Recommendation 50** **193**
 That the Minister for Disability Services ensure that people with disability who reside in boarding houses receive person-centred planning and that the services provided to people who reside in boarding houses comply with the NSW Disability Service Standards.
- Recommendation 51** **236**
 That six months before the end of funding of the Workforce Recruitment Strategy, ADHC, with the assistance of stakeholders, review the strategy in consultation with stakeholders, with a view to extending it for a further two years.
- Recommendation 52** **238**
 That ADHC convene a cross sector working party to develop a workforce retention strategy. This strategy should include, but not be limited to, issues of:
- career pathways
 - professional development
 - working conditions
 - appropriate remuneration levels.
- Recommendation 53** **243**
 That the Home Care Service of NSW undertake an evaluation of training levels of all care workers, which identifies training gaps and how these will be addressed.
- Recommendation 54** **243**
 That ADHC coordinate and share training programs and opportunities with both their own staff and that of non-government service providers in each of the six ADHC regions.
- Recommendation 55** **247**
 That the Minister for Disability Services investigate the cost of providing ageing and disability services in metropolitan and rural areas of NSW, with a view to increasing the funding allocation to ensure equity of service provision in rural areas, if required.

Acronyms

A & E	Accident and Emergency
ABS	Australian Bureau of Statistics
ACAT	Aged Care Assessment Team
ACD NSW	Association of Children with a Disability
ACI	Agency for Clinical Innovation
ACP	Attendant Care Program
ACR	Annual Compliance Return
ADHC	Department of Human Services, Ageing, Disability and Home Care
ADIDD	Association of Doctors in Developmental Disability
ADN	Aboriginal Disability Network
AIHW	Australian Institute of Health and Welfare
BM HMMS	Blue Mountains Home Modification and Maintenance Service
CALD	Culturally and Linguistically Diverse
COAG	Council of Australian Governments
COTA	Council on the Ageing
CSDA	Commonwealth-State Disability Agreement
DET	Department of Education and Training
DHS	Department of Human Services
DisQAC	Disability Quality Assurance Council
DoCs	NSW Department of Community Services
DSA	Disabled Surfers Association
DSA Cth	<i>Disability Services Act 1986</i> Cth
DSNSW	Deaf Society NSW
ED	Emergency Department
FaHCSIA	Department of Families, Housing, Community Services and Indigenous Affairs
GPs	General Practitioners
HACC	Home and Community Care
HEN	Home Enteral Nutrition
HRT	Health Related Transport
ICAC	Independent Commission Against Corruption
ICF	International Classification of Disability Functioning and Health
IDF	Industry Development Fund
IMS	Integrated Monitoring System
ISO	International Standards Organisation
KPI	Key Performance Indicators
LGA	Local Government Area
LRCs	Large Residential Centres
MDAA	Multicultural Disability Advocacy Association
MDS	Minimum Data Set
MOU	Memorandum of Understanding

NCOSS	Council of Social Service NSW
NDA	National Disability Agreement
NDS	National Disability Service NSW
NESB	Non-English speaking backgrounds
NGO	Non-Government Organisations
NHHNA	National Health and Hospitals Network Agreement
NRS	National Relay Service
NSW CID	The NSW Council for Intellectual Disability
NSW DSS	NSW Disability Service Standards
NSW HMMS	NSW Home Modification and Maintenance Service
OT	Occupational Therapists
PADP	Program of Appliances for Disabled People
PDCN	Physical Disability Council of NSW
PWD	People with Disability
QAR	Quality Assurance Review
QARP	Quality Assurance Rectification Program
QSF	Quality and Safety Framework
RASAIID	Ryde Area Supported Accommodation for Intellectually Disabled
RFW	Royal Far West Children's Health
SCI	Spinal Cord Injury
SCIR	Spinal Cord Injuries Response
SDAC	Survey of Disability, Ageing and Carers
SESAHS	South East Sydney Illawarra Area Health Service
SWAHS	South West Sydney Area health Service
The Act	<i>Disability Services Act 1993</i> (NSW)
TTW	Transition to Work
TTY	Telephone Typewriter
UNCRPD	United Nations <i>Convention on the Rights of Persons with Disabilities</i>
WHO	World Health Organisation
YPIRAC	Younger People in Aged Residential Care

Chapter 1 Introduction

This chapter provides an overview of the manner in which the Inquiry was conducted and the structure of the report.

Terms of reference

- 1.1 The Inquiry was referred to the Committee by the Legislative Council on 24 June 2010 to examine the quality, effectiveness and delivery of services provided or funded by Ageing, Disability and Home Care (ADHC). The extent of unmet need for disability services and whether there are regional or other variations in the capacity and quality of disability services and providers was also required to be examined.
- 1.2 The Committee adopted the terms of reference on 24 June 2010, which are reproduced on page iv of this report.

Conduct of the Inquiry

Submissions

- 1.3 The Committee advertised a call for submissions in *The Sydney Morning Herald* and *The Daily Telegraph* on 7 July 2010. A media release announcing the Inquiry and the call for submissions was sent to all media outlets in NSW. The Committee also wrote to a number of relevant stakeholders inviting them to participate in the Inquiry process.
- 1.4 The closing date for submissions was initially 6 August 2010, however the Committee resolved to continue to accept submissions and supplementary submissions to the Inquiry after the closing date.
- 1.5 The Committee received a total of 112 submissions to the Inquiry, including 8 supplementary submissions. 36 submission authors requested that their name be suppressed from publication or for some content of their submission to remain confidential. Five submissions were kept fully confidential by resolution of the Committee. A list of all submissions is contained in **Appendix 1**.
- 1.6 The Committee considered this report on 5 November 2010. Minutes of the deliberative are included in **Appendix 6**.

Public hearings

- 1.7 The Committee held five public hearings at Parliament House on 9 and 26 August, and 3, 27 and 30 September 2010.

- 1.8** A list of witnesses is set out in **Appendix 2** and published transcripts are available on the Committee's website.¹ The list of documents tabled at the public hearings is provided in **Appendix 3**. A list of witnesses who provided answers to questions taken on notice during the hearings is provided in **Appendix 4**.
- 1.9** Australian Sign Language (Auslan) interpreters were available at each public hearing to translate the proceedings for deaf people who viewed proceedings from the audience and also appeared at witnesses. The use of Auslan interpreters was publicised on the Committee's website and informally through the Deaf Society of NSW.
- 1.10** The Committee would like to thank all those who participated in the Inquiry, whether by making a submission, giving evidence or attending the public hearings.

Public forum

- 1.11** The Committee held a public forum at Parliament House on 30 September 2010, to hear people share first hand their experiences of the disability service system. There was a high level of interest in the forum with regard to the number of participants and audience members in attendance.
- 1.12** The Committee heard from 13 individual submission authors who had previously provided submissions to the Inquiry. A light lunch was shared by the Committee with participants and audience members at the conclusion of the forum. A list of witnesses is set out in **Appendix 2** and published transcripts are available on the Committee's website.¹
- 1.13** Auslan interpreters were available at the forum to translate the proceedings for deaf people who attended in the audience.
- 1.14** The Committee considered the public forum a very useful part of the Inquiry and would like to thank all those who participated in the public forum, for sharing often difficult experiences, views and recommendations.

Report structure

- 1.15** Chapter 2 provides an overview of the disability service system in NSW, including the international and national framework within which it sits.
- 1.16** Chapter 3 details the current funding arrangements of ADHC and the services it provides. Issues regarding measurement of unmet and 'undermet' demand are also examined. ADHC's procurement of services provided by other agencies and non-government organisations is also discussed in this chapter, along with possible alternative models of funding.
- 1.17** Chapter 4 examines issues regarding the planning of disability services. The move towards a person-centred planning approach is examined, including the ability to plan for services at key transition points and barriers that may prevent effective planning from taking place. Issues regarding processes used to share sensitive client information between agencies are also examined.

¹ The Committee's website can be found at <www.parliament.nsw.gov.au/socialissues>

- 1.18** Chapter 5 considers the delivery of disability services, focusing on the availability and access to different service types across NSW. Issues regarding intake and assessment, vacancy management processes and service eligibility are examined, as is the role of waiting lists in the provision of services. This chapter also examines issues regarding access to and availability of culturally appropriate services to people with disability.
- 1.19** Chapter 6 examines issues regarding the level of unmet need in the provision of disability services in NSW. The level of unmet need in specific service types is examined, including in supported accommodation, home care, community transport, equipment programs, attendant care and services for people in the criminal justice system. The impact of unmet need on service users, carers and their families is examined, including challenges regarding effective measurement of unmet need.
- 1.20** Chapter 7 considers the Government's policy to redevelop rather than devolve Large Residential Centres.
- 1.21** Chapter 8 examines issues regarding ADHC's administration and implementation of home modification and maintenance services. Issues regarding long waiting periods in the program are examined, including the impact of a lack of funding and a shortage of Occupational Therapists. The quality of work completed through the program is also examined, including the use of unlicensed builders.
- 1.22** Chapter 9 examines compliance with the NSW Disability Service Standards and the *Disability Services Act 1993*, including mechanisms to monitor and act upon non-compliance and the effectiveness of complaint handling. Current monitoring processes for disability services, access to disability services data and the quality of services provided in licensed boarding houses are also considered.
- 1.23** Chapter 10 considers the role of carers and their contribution to the disability service sector. Issues examined include the provision of respite and supported accommodation services, person-centred service delivery and future planning services and the stress placed on family relationships when caring for a person with disability. The specific needs of older carers and culturally and linguistically diverse and Aboriginal carers are also explored.
- 1.24** Chapter 11 examines issues regarding disability services staff who are paid for or funded by ADHC, including the ability to attract staff to the carer profession, staff training, retention and pay.

Chapter 2 Background

This chapter provides an overview of disability service provision in NSW. The role of the Department of Human Services, Ageing, Disability and Home Care (ADHC) is described, as is the role of funded organisations. Additionally, the relevant international, national and state policy and legislation are explained, including the definition of disability. Service quality and evaluation processes are described, including complaint handling mechanisms that are available for service users.

Ageing, Disability and Home Care

- 2.1** This section provides background on ADHC, including identifying the key responsibilities of the agency, administrative regions, staff information and annual funding. An overview of governance arrangements is also provided.
- 2.2** ADHC is the NSW government agency "... responsible for delivering a wide and diverse range of community support and specialist care services ..." ² to older people, people with disability, their families and carers. ³ Key services and supports provided to these groups include:
- early intervention, skill development, therapy, community participation
 - respite and support for carers
 - advocacy and information
 - personal assistance and intensive in-home support
 - supported accommodation in the community and specialist facilities. ⁴
- 2.3** Services are also provided by the agency through the statutory authority, the Home Care Service of NSW. ⁵ A background on services provided through ADHC funded organisations is provided from section 2.19.
- 2.4** In its submission, the NSW Ombudsman explained that over 72,000 children and young people live with a disability in NSW. ⁶ The NSW Ombudsman reported that "[m]ost of these children live in the community with their families, and many of these families rely on the services and support provided by government and funded agencies to help meet the needs of their child." ⁷
- 2.5** ADHC described its purpose in its submission to the Inquiry, stating that the agency "... 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." ADHC continued:

² Submission 31, ADHC, p 9

³ Submission 31, p 7

⁴ Submission 31, p 7

⁵ Submission 31, p 9

⁶ Supplementary Submission 100a, NSW Ombudsman, p 1

⁷ Supplementary Submission 100a, p 1

We seek to make a difference by recognising the value that people contribute to 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.⁸

2.6 The two key result areas that ADHC measure success of the organisation against are summarised in the following table:⁹

Table 2.1 ADHC's key result areas

Result Area	Definition
1. Community Support	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.
2. Specialist Support	Provides services to ensure that people with ongoing intensive support needs are living in suitable accommodation and participating in the community.

2.7 ADHC is one of thirteen agencies that form the Department of Human Services (DHS), which was created in July 2009. In the ADHC submission, Mr Jim Moore, Chief Executive of ADHC, advised that the DHS was created "... 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."¹⁰

2.8 Specifically, the 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.¹¹

⁸ Submission 31, pp 6-7

⁹ Submission 31, p 7

¹⁰ Submission 31, p 6

¹¹ Submission 31, p 6

Governance

- 2.9** ADHC is one of the largest human services organisations, providing or funding services to more than 260,000 people and employing more than 13,000 people, "... 80 per cent of whom work in direct client services". The total budget for ADHC is \$2.5 billion in 2010/11.¹²
- 2.10** A corporate governance framework is used by the agency to "... support executive decision making and the management of ... strategic goals and operational objectives." Due the size and complexity of the agency, ADHC has devolved operations across the state.¹³
- 2.11** ADHC advised that "[d]ecision making and implementation oversight reflects a cross section of views and responsibilities with the agency." The ADHC submission advised that:
- an *Executive* oversees committees, sets directions and maintains an overview of Agency performance.
 - an *Operational Performance Committee* reviews operational performance against specific indicators that relate to regional and business stream performance.
 - *Standing Committees* are based around key infrastructure.
 - an *Ageing 2030 Implementation Committees* oversees implementation of ADHC-led initiatives.¹⁴
- 2.12** The Chief Executive is responsible for overseeing the governance activities of the agency, to the Minister for Ageing and Disability Services and to the Director General of the DHS.¹⁵
- 2.13** In its submission to the Inquiry, ADHC advised that an Audit Committee assists "... 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."¹⁶
- 2.14** The Audit Committee is considered to function as an "... independent oversight and review mechanism" as it has an independent Chair and an independent member. Potential conflicts of interest are required to be declared by members of the Committee and members "... remove themselves from proceedings in relation to these matters."¹⁷

¹² Submission 31, p 6

¹³ Submission 31, p 10

¹⁴ Submission 31, p 11

¹⁵ Submission 31, p 11

¹⁶ Submission 31, p 11

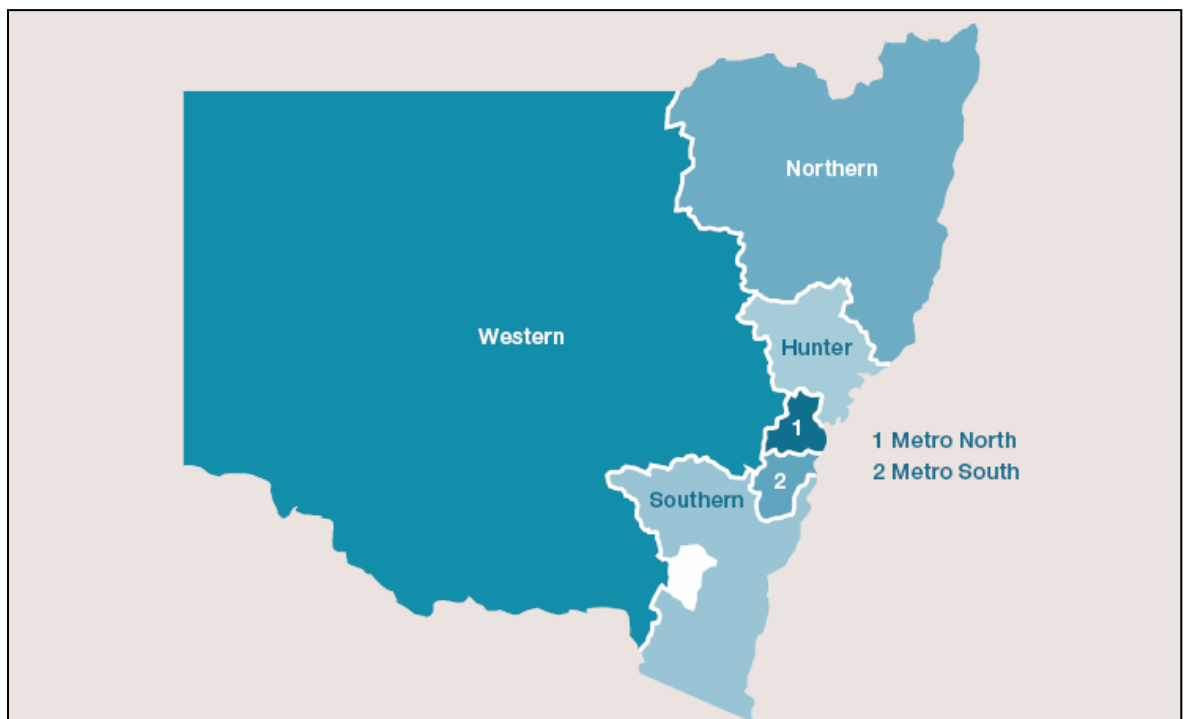
¹⁷ Submission 31, p 12

- 2.15 Findings and recommendations that arise from the Audit Committee are reported to the Chief Executive and Corporate Management Board.

Regions

- 2.16 ADHC and the services it provides and funds are administered through six regions - Metro North, Metro South, Hunter, Northern, Southern and Western.¹⁸ **Figure 2.1** illustrates the location of these regions in NSW.¹⁹
- 2.17 Each region has four business streams that manage the services provided to clients, including accommodation and respite, community access, the Home Care Service of NSW and service development and planning. ADHC advise that this regional structure enables the organisation to "... foster closer ties with local communities and more effectively manage intake and vacancy services."²⁰
- 2.18 The ADHC central office is located in Sydney. It is responsible for developing state-wide policies and programs and also for providing corporate support to the rest of the agency.²¹

Figure 2.1 Administrative regions of Ageing, Disability and Home Care



¹⁸ Submission 31, p 9

¹⁹ Submission 31, Appendix 3, p 55

²⁰ Submission 31, p 10

²¹ Submission 31, p 10

Funded organisations

- 2.19** Funded organisations play an increasingly important role in the delivery of disability services in NSW. There are approximately 460 ADHC funded organisations that provide specialist support services to people with disability.²² These organisations are diverse in their size, organisational capacity, range of services delivered, staff skill levels and geographic coverage.²³
- 2.20** In its submission to the Inquiry, National Disability Service NSW (NDS) reported that since 2006 the size of the NGO sector has grown by approximately 50 per cent.²⁴
- 2.21** Ms Lauren Murray, Deputy Director General of ADHC told the Committee that funded organisations provide approximately 50 per cent of all services to people with disabilities. Ms Murray said that this statistic varies depending on service type, for example most case management services are provided by ADHC directly, while the non-government sector provides a large amount of therapy services.²⁵
- 2.22** The Government announced the \$17 million Industry Development Fund in the 2009-10 Budget.²⁶ The fund is to be jointly administered by NDS and ADHC and will support NGO sector development through access to training, service improvement measures, merger support and exploring shared service models.²⁷

Disability in NSW

- 2.23** This section provides a brief overview of the legislative and policy framework for the provision of disability services in NSW. The relevant international, national and state policy and legislation is described. This section also provides a definition of disability as used in state legislation and provides an overview of the prevalence and patterns of disability in NSW.

International framework

- 2.24** The United Nations *Convention on the Rights of Persons with Disabilities* (UNCRPD) was ratified by Australia on 17 July 2008, to "... promote the equal and active participation of all people with disability".²⁸

²² Submission 31, p 16

²³ Submission 31, p 61

²⁴ Submission 32, NDS, NSW, p 7

²⁵ Ms Lauren Murray, Deputy Director General, ADHC, Evidence, 9 August 2010, p 13

²⁶ Submission 32, p 2

²⁷ Submission 31, p 92

²⁸ Australian Government Attorney Generals Department, (accessed 7 October 2010) <www.ag.gov.au/www/agd/agd.nsf/Page/Humanrightsandanti-discrimination_UnitedNationsConventionontheRightsofPersonswithDisabilities>

2.25 The eight principles that underlie the UNCRPD include:

- Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons
- Non-discrimination
- Full and effective participation and inclusion in society
- Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity
- Equality of opportunity
- Accessibility
- Equality between men and women
- Respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities.²⁹

2.26 The UNCRPD was a point of reference for many participants during the Inquiry, particularly in relation to a person's right to self-determination, choice of services and devolution from large residential centres.

2.27 Ms Therese Sands, Executive Director, People with Disability Australia noted the importance of the UNCRPD informing the work of the Government:

This inquiry provides a timely and important opportunity for people with disability in NSW as it coincides with the five-year review of the 10-year plan for Disability Services Stronger Together. UNCRPD had not been adopted by the United Nations when Stronger Together was developed. Now that Australia has ratified UNCRPD this inquiry and the five-year review should use the UNCRPD to audit and assess the services provided and funded by ADHC as it is highly likely the legislative framework and the institutional arrangements from practises that underpin those services will not conform or will only partially conform to the UNCRPD.³⁰

2.28 Similarly, Mr Moore noted that:

There is a growing expressed desire for people with a disability and their families to have much greater control of how resources available to them are applied. That is an area where, when you look at it both from a program administration perspective and also from areas like looking at it from the human rights United Nations convention which talks about enabling people with a disability to be in control of their lives, we need to change our administration quite substantially.

National framework

2.29 The Commonwealth and State are closely linked in the funding and delivery of disability services. Important Commonwealth policies include:

- National Disability Agreement (NDA)
- National Disability Strategy

²⁹ United Nations, *Convention on the Rights of Persons with Disabilities*, (accessed 7 October 2010) <www.un.org/disabilities/convention/conventionfull.shtml>

³⁰ Ms Therese Sands, Executive Director, People with Disability Australia, Evidence, 3 September 2010, p 32

- Productivity Commission Inquiry into a national disability long-term care and support scheme
- National Health and Hospitals Network Agreement.

2.30 The Commonwealth and State Governments have extensive linkages in the funding and delivery of disability services in NSW. Both levels of government work to create an appropriate legislative environment to ensure people with disabilities are able to receive the services they require to lead a 'good life'.

2.31 In its submission ADHC noted that "[t]he national disability policy arena (National Disability Agreement (NDA); 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."³¹

2.32 The separation of responsibilities for service provision between different levels of government was instituted with the signing of the first Commonwealth-State Disability Agreement (CSDA) in 1992. In 2009 the CSDA was replaced by a new NDA in 2009, which also incorporated a number of other smaller bilateral funding agreements.

2.33 Through the NDA, the Commonwealth government will provide NSW \$1.74 billion in funding over five years; this figure includes \$118 million in new funding.³² However, the bulk of funding for specialist disability programs comes from the NSW government. The NSW government currently contributes 81% of funding for specialist disability services, while the Commonwealth contributes 19% through the NDA.³³

2.34 In addition to providing services directly, ADHC also funds some 460 organisations to provide services for older people and people with disability. Organisations funded by ADHC include local governments, community-based non-profit organisations and private companies.

National Disability Agreement

2.35 The NDA commenced on 1 January 2009, replacing earlier Commonwealth State/Territory Disability Agreement. The NDA also encompasses several bilateral agreements previously held with the Federal Government. ADHC noted that the NDA seeks to "progress reforms which place people with a disability, their families and carers at the centre of services."³⁴

2.36 The NDA identifies several priority areas to underpin policy direction and reforms. These priority areas are:

- better measurement of need
- population benchmarking for disability services
- making older carers a priority
- quality improvement systems based on Disability Standards

³¹ Submission 31, p 17

³² Submission 31, p 28

³³ Submission 31, p 28

³⁴ Submission 31, p 27

- service planning and strategies to simplify access
- early intervention and prevention, lifelong planning and increasing independence and social participation strategies
- increased workforce capacity
- increased access for indigenous Australians
- access to aids and equipment
- improved access to disability care.³⁵

2.37 The new Agreement increases funding from the Commonwealth to NSW. ADHC explained the funding implications of the NDA:

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%.³⁶

National Disability Strategy

2.38 In conjunction with the NDA, the National Disability Strategy seeks to drive coordination across all levels of government to improve outcomes for people with disability, their families and carers. The National Disability Strategy has been developed under the auspices of the Council of Australian Governments (COAG) and it is expected that the strategy will be discussed at its next meeting.³⁷

2.39 In its submission ADHC explained the importance of the National Disability Strategy in framing disability services policy:

The NDS [National Disability Strategy] 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.³⁸

Home and Community Care (HACC)

2.40 The Home and Community Care (HACC) program is a joint Commonwealth-State initiative which provides funding for services for elderly people, people with disability and their carers, to assist them to live independently. HACC forms the second major stream of funding

³⁵ Department of Families, Housing, Community, Services and Indigenous Affairs, *National Disability Agreement*, (accessed 25 October 2010) <http://www.fahcsia.gov.au/sa/disability/progserv/govtint/Pages/policy-disability_agreement.aspx>

³⁶ Submission 31, p 28

³⁷ Submission 31, p 30

³⁸ Submission 31, p 30

administered by ADHC. ADHC advised the Committee that in 2008-2009, 233,640 people in NSW received services funded through HACC.³⁹ Seventy nine per cent of HACC clients were aged over 65.⁴⁰

2.41 In 2010-2011, total funding for HACC in NSW will be \$629.37 million; of this, the Commonwealth government contributes \$374.2 million (or about 60%) and the NSW government \$255 million (about 40%).⁴¹

2.42 ADHC funds over 600 service providers through the HACC program. The Department also provides HACC services directly through the Home Care Service of NSW. The Home Care Service of NSW (Home Care) is a statutory authority which is funded through HACC and is 'effectively integrated' into the Department.⁴² Home Care currently employs 4,500 staff and receives about a third of HACC funds in NSW. Mr Moore described the HACC program in NSW:

There are about 600 organisations that get those sorts of funds and the Home Care Service of NSW is around 30 per cent of the totality of the HACC sector in NSW. It is the single biggest provider in NSW and Australia.⁴³

2.43 Under the National Health and Hospitals Network Agreement (NHHNA) that was announced by the Council of Australian Governments (COAG) in April 2010, the Commonwealth government will assume responsibility for funding all services for those aged over 65 (and over age 50 for Indigenous people).⁴⁴ This will take place from 1 July 2012.

2.44 On 8 September 2010 the Minister for Disability Services told Parliament that these reforms will clarify Government roles in the provision of disability services and that transition will be carefully managed to provide continuity of care for people with disability:

The potential benefits of the Council of Australian Governments reforms for people with a disability, their families and carers are substantial. The reforms will enable the creation of a national aged care system and a national disability services system, which will clarify the roles of the Commonwealth and State in the provision of these services and enable seamless pathways for clients through both systems. For NSW the reforms will enable improved integration of services currently provided under the Home and Community Care Program with a large range of other services available for people with a disability. And this includes closer alignment with Stronger Together ... Older people with a disability and their families will benefit from the commitment of the NSW Government and the Commonwealth to flexible service arrangements.

... I am pleased that there is commitment to transition to the new arrangements in a way that will ensure there is no disruption to current clients, including younger people with a disability who are currently receiving care in residential aged care facilities. NSW maintains its commitment to the arrangements in a way that ensures minimal disruption to clients and existing providers.

³⁹ Submission 31, p 20

⁴⁰ Submission 31, p 20

⁴¹ Submission 31, p 19

⁴² Mr Jim Moore, Chief Executive, ADHC, Evidence, 9 August 2010, p 5

⁴³ Mr Moore, Evidence, 9 August 2010, p 5

⁴⁴ Submission 31, p 19

NSW will insist that the Commonwealth provide the appropriate provisions for these organisations during transition and continues to fully utilise their services. This includes holding the Commonwealth to its commitment to not substantially alter existing service arrangements before 1 July 2015.⁴⁵

- 2.45** This decision to separate responsibility for funding of services for those aged over 65 has significant implications for the future of the Home Care Service of NSW and other HACC-funded services which currently provide services to both people who ageing and younger people with disability. For example, Mr Moore said that:

Think of the Meals on Wheels organisation, which is largely a volunteer-based entity. It was a small amount of resources that come out of HACC funding. If you were to try to start breaking that up and putting it into a section for those aged under 65 and those aged over 65, you could easily disrupt that strong grassroots organisation.⁴⁶

- 2.46** In its submission to the Inquiry, ADHC argued that "... the HACC program is out of scope due to its primary focus on frail aged people, and the agreement with the Australian Government to transition arrangements."⁴⁷ However, ADHC did emphasise that it is working with the Commonwealth to ensure that transition arrangements involve minimal disruption to clients and existing service providers.⁴⁸

NSW framework

- 2.47** NSW has various pieces of legislation that look to protect and promote the rights of people with disability. The list includes:

- *Disability Services Act 1993*
- *Home Care Services Act 1988*
- *Youth and Community Services Act 1973*
- *Anti-Discrimination Act 1977*
- *Guardianship Act 1987*
- *Community Services (Complaints, Reviews and Monitoring) Act 1993*
- *Community Welfare Act 1987*.

- 2.48** Additionally, the State has a range of policy mechanisms to support the inclusion of people with disability in the wider community and to help them reach personal outcomes. These policies include:

- Disability Service Standards
- NSW State Plan
- Stronger Together

⁴⁵ NSWPD (*Legislative Council*), 8 September 2010, p 25346

⁴⁶ Mr Moore, Evidence, 27 September 2010, p 7

⁴⁷ Submission 31, p 20

⁴⁸ Submission 31, p 20

- Better Together
- Industry Development Plan
- Industry Development Fund
- Large Residential Centre redevelopment policy
- Person centred policy
- Health Reform policy.

Disability Services Act 1993 (NSW)

- 2.49** The *Disability Services Act 1993* provides for "... the provision of services necessary to enable persons with disabilities to achieve their maximum potential as members of the community."⁴⁹ ADHC described the role of the *Disability Services Act 1993*:

[the Act]...provides for the funding and provision of disability services; sets out the terms and conditions on which non-government organisations receive funding and provides for decisions made by the Minister under the Act to be reviewed by the Administrative Decisions Tribunal.⁵⁰

- 2.50** Mr Phillip French, Director of the Disability Discrimination Legal Centre, provided background to the development of the *Disability Services Act 1993*:

[the Act was]... enacted to give effect to an intergovernmental agreement (the Commonwealth State Disability Agreement 1991) which purported to rationalise responsibility for the provision and funding of disability services between the Commonwealth and State and Territory governments. As a condition precedent to the transfer responsibility for the provision and funding of particular service types between governments, and to the payment of Commonwealth incentive funding to the States and Territories, the States and Territories were required to enact legislation that was complementary to the *Disability Services Act 1986 Cth* (DSA Cth). The central requirements for complement were adherence to the objects of the DSA Cth, and to the principles and objectives formulated pursuant to s5 of that Act, and to the formulation of Disability Service Standards equivalent to the then operative Commonwealth Standards.⁵¹

- 2.51** Mr French described that the NSW Act in fact went further than the minimum requirements of the Commonwealth Act:

... by elaborating the principles and objectives of the DSA Cth into a suite of principles and applications of principles that are incorporated in the DSA NSW in Schedule 1. Schedule 1 might be conceptualised as a charter of service user rights that is made binding upon the Minister administering the Act, requiring him or her to ensure that all disability services provided or funded by the NSW Government conform to the requirements of Schedule 1. The DSA NSW has remedial and progressive elements. At the time it was enacted the Minister was required to

⁴⁹ *Disability Services Act 1993*, Section 3 (a)

⁵⁰ Department of Human Services, ADHC, (accessed 6 October 2010) <www.dadhc.nsw.gov.au/dadhc/About+DADHC/>

⁵¹ Submission 20, Disability Discrimination Legal Centre, p 1

determine within 2 months if a service conformed to the requirements of the Act. If it did not, the service was required to develop a transition plan that would bring it into full conformity with the Act.⁵²

2.52 The principles in Schedule 1 of the *Disability Services Act 1993*, as described by Mr French in section 2.51, are as follows:

Persons with disabilities have the same basic human rights as other members of Australian society. They also have the rights needed to ensure that their specific needs are met. Their rights, which apply irrespective of the nature, origin, type or degree of disability, include the following:

- (a) persons with disabilities are individuals who have the inherent right to respect for their human worth and dignity,
- (b) persons with disabilities have the right to live in and be part of the community,
- (c) persons with disabilities have the right to realise their individual capacities for physical, social, emotional and intellectual development,
- (d) persons with disabilities have the same rights as other members of Australian society to services which will support their attaining a reasonable quality of life,
- (e) persons with disabilities have the right to choose their own lifestyle and to have access to information, provided in a manner appropriate to their disability and cultural background, necessary to allow informed choice,
- (f) persons with disabilities have the same right as other members of Australian society to participate in the decisions which affect their lives,
- (g) persons with disabilities receiving services have the same right as other members of Australian society to receive those services in a manner which results in the least restriction of their rights and opportunities,
- (h) persons with disabilities have the right to pursue any grievance in relation to services without fear of the services being discontinued or recrimination from service providers,
- (i) persons with disabilities have the right to protection from neglect, abuse and exploitation.⁵³

Disability Service Standards

2.53 The NSW Disability Service Standards (NSW DSS) result from the *Disability Service Act 1993*. ADHC described the Standards in their submission to the Inquiry:

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,

⁵² Submission 20, pp 1-2

⁵³ *Disability Services Act 1993* Schedule 1

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.⁵⁴

2.54 There are ten standards, which are:

- **STANDARD SERVICE ACCESS**
Each consumer seeking a service has access to a service on the basis of relative need and available resources.
- **INDIVIDUAL NEEDS**
Each person with a disability receives a service which is designed to meet, in the least restrictive way, his or her individual needs and personal goals.
- **DECISION MAKING AND CHOICE**
Each person with a disability has the opportunity to participate as fully as possible in making decisions about the events and activities of his or her daily life in relation to the services he or she receives.
- **PRIVACY, DIGNITY AND CONFIDENTIALITY**
Each consumer's right to privacy, dignity and confidentiality in all aspects of his or her life is recognised and respected.
- **PARTICIPATION AND INTEGRATION**
Each person with a disability is supported and encouraged to participate and be involved in the life of the community.
- **VALUED STATUS**
Each person with a disability has the opportunity to develop and maintain skills and to participate in activities that enable him or her to achieve valued roles in the community.
- **COMPLAINTS AND DISPUTES**
Each consumer is free to raise and have resolved, any complaints or disputes he or she may have regarding the agency or the service
- **SERVICE MANAGEMENT**
Each service adopts sound management practices which maximise outcomes for consumers.
- **FAMILY RELATIONSHIPS**
Each person with a disability receives a service which recognises the importance of preserving family relationships, informal social networks and is sensitive to their cultural and linguistic environments.
- **RIGHTS AND FREEDOM FROM ABUSE**
The agency ensures the legal and human rights of people with a disability are upheld in relation to the prevention of sexual, physical and emotional abuse within the service.⁵⁵

⁵⁴ Submission 31, p 83

⁵⁵ Submission 31, Appendix 11, NSW DSS, p 123

2.55 It is a condition of ADHC's Funding Agreement that service providers comply with the NSW DSS.⁵⁶

2.56 ADHC is currently in the process of creating fact sheets and simple language resources to assist clients and service providers to understand the NSW DSS. In its submission, ADHC explained the importance of this process:

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 frontline 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.⁵⁷

2.57 The National Disability Services Standards are currently under review with the aim of achieving consistency across all jurisdictions. Revising the Standards is seen as an integral part of the National Quality Framework and aims to establish a consistent national approach to improving the quality of disability services and improving outcomes for people with disability.⁵⁸

Stronger Together

2.58 *Stronger Together: A new direction for disability services in NSW 2006-2016* is a state Government initiative that was announced in 2006, which provided a significant injection of new funding to disability services. Stronger Together provided an extra \$1.3 billion to the disability services system in NSW over five years⁵⁹.

2.59 By 2009-2010 \$961 million had been spent through Stronger Together,⁶⁰ in 2010-2011 Stronger Together will provide \$378 million in funding.

2.60 Stronger Together aims to provide increased places in all specialist disability service categories. ADHC advised the Committee that the first five-year phase of Stronger Together is now in its final year of implementation; targets have been met in most service categories and exceeded in

⁵⁶ Submission 31, p 83

⁵⁷ Submission 31, pp 83-84

⁵⁸ ADHC, *National Standards for Disability Services fact sheet*, <http://www.dadhc.nsw.gov.au/NR/rdonlyres/CD3588A6-5D12-4B2E--A189-28C648038FC/5354/NSW_Fact_SheetSept2010.pdf>

⁵⁹ This figure is based on 2006 projections, and has since been adjusted upwards to \$1.5 billion to allow for indexation. See Submission 31, p 33

⁶⁰ Submission 31, p 34

some. For example, Stronger Together planned to provide an additional 780 places in day programs over five years; by 2009 815 had already been provided.⁶¹

- 2.61** The Hon Peter Primrose, Minister for Disability Services told Parliament that an extra 20,000 service places were provided through the first phase of Stronger Together:

The first five-year phase of Stronger Together delivered an extra \$1.3 billion in funding for people with disabilities in NSW, providing an extra 20,000 service places in areas such as respite, supported accommodation, therapy, community participation and case management services.⁶²

Definition of 'disability'

- 2.62** In the *Initial Report under the Convention on the Rights of Persons with Disabilities* the Commonwealth Attorney-General's Department identified that there are a number of different definitions of disability in Australia. A common feature of these definitions "... is that disability is defined broadly."⁶³

- 2.63** A common and statutory definition used within NSW can be found in the *Anti-Discrimination Act 1977*:

[disability means]

- (a) total or partial loss of a person's bodily or mental functions or of a part of a person's body, or
- (b) the presence in a person's body of organisms causing or capable of causing disease or illness, or
- (c) the malfunction, malformation or disfigurement of a part of a person's body, or
- (d) a disorder or malfunction that results in a person learning differently from a person without the disorder or malfunction, or
- (e) a disorder, illness or disease that affects a person's thought processes, perception of reality, emotions or judgment or that results in disturbed behaviour.⁶⁴

Data and prevalence of disability

- 2.64** The Australian Bureau of Statistics (ABS) stated that 18 per cent of people in NSW report having disability.⁶⁵ The definition used by the ABS refers to disability as "... any limitation, restriction or impairment, which has lasted, or is likely to last, for at least six months and

⁶¹ Submission 31, p 34

⁶² NSWPD (*Legislative Council*), 1 September 2010, p 24953

⁶³ Attorney-General's Department, *Australia's Initial Report under the Convention on the Rights of Persons with Disabilities*, May 2010, p 6

⁶⁴ *Anti-Discrimination Act (1977)*, Section 4

⁶⁵ Australian Bureau of Statistics, *Disability, Ageing and Carers: Summary of Findings*, p 19

restricts everyday activities."⁶⁶ It should be noted that this definition appears to be broader than the one described in the *Anti-Discrimination Act 1977*.

2.65 The ABS also identified that there was little change in the disability rate in Australia between 1998 (20.1 per cent) and 2003 (20.0 per cent), and also between males and females over this time.⁶⁷ However, the rate of disability in Australia increases significantly with age, from 4.3 per cent in the 0 to 4 age group, to 92.1 per cent in the over 90 year age group.⁶⁸

2.66 Comprehensive disability related data in NSW is collected through survey by the ABS every six years, and was most recently collected in 2003. The gap between data collection periods was identified as an issue by Mr Moore:

... we do suffer from a paucity of data in this area. We only have a once-in-six-year chance to see the totality of the population of people with a disability in NSW, through an ABS survey, and that we do our best to try to model out an understanding of just what is the level of need and what is the right way to respond to that need in that context, but our position is somewhat limited. I put that up front because I fear that there is enormous frustration about the ability of the agency to be able to point to just how well we are doing against population data, but it is a very difficult issue which has been recognised nationally.⁶⁹

2.67 Issues regarding data are examined further in Chapter 9.

Service provision

2.68 This section provides an overview of the types of disability services that are provided by ADHC and funded organisations. These services are considered throughout the report and particularly in Chapters 4 to 8.

2.69 ADHC provides and funds a range of services to older people, people with disability, their carers and families. ADHC fund approximately 900 local government and non-government organisations to provide a wide and diverse range of community support and specialist care services across NSW.⁷⁰ Below are descriptions of the main service types provided or funded by ADHC.

2.70 **Advocacy** services assist older people, people with disability, their families and carers by directly speaking on their behalf or by providing information and advice so that a person can get what they want and need.

2.71 The **Attendant Care Program** "provides portable, flexible and individualised support for people with physical disability or who need personal help to complete activities of daily living."⁷¹ The program is funded through the National Disability Agreement.

⁶⁶ ABS, *Disability, Ageing and Carers: Summary of Findings*, p 3

⁶⁷ ABS, *Disability, Ageing and Carers: Summary of Findings*, p 3 and p 17

⁶⁸ ABS, *Disability, Ageing and Carers: Summary of Findings*, p 16

⁶⁹ Mr Moore, Evidence, 9 August 2010, p 6

⁷⁰ Submission 31, p 9

⁷¹ ADHC, Attendant Care Program, (accessed 25 October 2010)
<<http://www.dadhc.nsw.gov.au/dadhc/People+with+a+disability/Attendant+Care.htm>>

- 2.72** The **Community Justice Program** aims to "minimise re-offending in people with intellectual disability who have exited a correctional facility and facilitate appropriate community integration through the provision of specialised accommodation and support along with pre- and post-release clinical and case management services." The program was established in 2006 in an effort to encourage the Government and advocacy groups to achieve better outcomes for people with an intellectual disability who were involved in the criminal justice system.⁷²
- 2.73** **Community support teams** are usually comprised of professionals who provide a range of support services to service users, carers and families. ADHC notes that these support services include "assessment, case planning and management, counselling, referral, therapy, family support, early intervention and behaviour management."⁷³
- 2.74** **Day programs** "provide ongoing daytime activities and supports for people with a disability who have moderate to very high support needs."⁷⁴ Examples of day programs include the Active Ageing, Life Choices, Community Participation and Transition to Work.
- 2.75** **Group homes** provide community-based residential support for up to six people with disability. The accommodation is usually staffed 24-hours a day.⁷⁵
- 2.76** The **Home and Community Care (HACC) 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." ADHC currently administers the program in NSW. HACC services are delivered by over 600 service providers and rely significantly on the contribution of volunteers.⁷⁶
- 2.77** The Commonwealth will assume funding responsibility for support services to all eligible people aged 65 years and over and Aboriginal people aged 50 years and over, regardless of their location or current program in 2012. Council of Social Service of NSW (NCOSS) noted that "[a]ccordingly, states and territories will assume funding and program responsibilities for all eligible people with disability aged less than 65 years and under 50 years for Aboriginal people."⁷⁷
- 2.78** Despite ADHC maintaining funding and administrative control over the HACC program for all eligible people with disability aged less than 65 years and under 50 years for Aboriginal people, the agency told the Committee it considered the program to be out of the Inquiry's terms of reference:

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

⁷² ADHC, Community Justice Program, Program Guidelines, April 2010, p 4

⁷³ ADHC, Community Support Teams, (accessed 25 October 2010)
<www.dadhc.nsw.gov.au/dadhc/People+with+a+disability/Community+Support+Teams.htm>

⁷⁴ ADHC, Day programs, (accessed 25 October 2010)
<www.dadhc.nsw.gov.au/dadhc/People+with+a+disability/Day+Programs.htm>

⁷⁵ DADHC, *Stronger Together*, p 31

⁷⁶ Submission 31, p 18

⁷⁷ Submission 30, NCOSS, pp 4-5

older people, and the agreement with the Australian Government to transition arrangements.⁷⁸

- 2.79** The **Home Modification and Maintenance Service** industry modifies homes for older people and people with disability so they can remain living independently in their own home for longer. The industry also provides support to other HACC services. For further information of the Home Modification and Maintenance Service see Chapter 8.
- 2.80** **Large Residential Centres** are facilities that provide 24-hour residential support in a congregate setting of 20 or more people with disability.⁷⁹ For further information on Large Residential Centres see Chapter 7.
- 2.81** **Licensed boarding houses** are "[a]ny residential centre for handicapped persons' licensed or declared under the *Youth and Community Services Act 1973*." These facilities generally do not receive any direct funding from the NSW Government however residents receive certain services through the Boarding House Reform Strategy.⁸⁰ For further information on licensed boarding houses see Chapter 9.
- 2.82** The **NSW Younger People in Aged Residential Care (YPIRAC) Program** "aims to provide more appropriate living options and practical support for some younger people with a disability living in, or at risk of entry to, residential aged care." The program is jointly funded by the State and Commonwealth Governments and is managed by ADHC in NSW.⁸¹
- 2.83** **Occupational therapy** aims to enable people to participate in the activities of daily life. On its website Occupational Therapy Australia explains that "[o]ccupational therapists achieve this outcome by enabling people to do things that will enhance their ability to participate or by modifying the environment to better support participation."⁸²
- 2.84** **Other residential care centres** include facilities that specialise in housing older people and people with spinal cord injuries. For example, the Paraplegic and Quadriplegic Association of NSW operates a centre dedicated to the high-care needs of people with spinal cord injuries.
- 2.85** **Respite** is "planned short-term and time-limited breaks for families and other unpaid care givers of children with a developmental delay and adults with an intellectual disability in order to support and maintain the primary care-giving relationship." There are four different types of respite activity:
- centre-based (general and specialist)
 - home based

⁷⁸ Submission 31, p 20

⁷⁹ DADHC, *Stronger Together*, p 31

⁸⁰ NSW Ombudsman, *Community Services Division fact sheet No. 4, NSW Licensed boarding houses*, <www.ombo.nsw.gov.au/publication/PDF/factsheets/CSD%20Fact%20Sheet%204_Licensed%20Boarding%20Houses.pdf>

⁸¹ ADHC, Factsheet, *NSW Younger People in Aged Residential Care (YPIRAC) Program*, August 2010, (accessed 25 October 2010), <www.dadhc.nsw.gov.au/NR/rdonlyres/B8DD766C-5E12-4229-AE42-05F5007C0DD4/5336/approvedUpdatedYPIRACfactsheetv6August2010.pdf>

⁸² Occupational Therapy Australia, What is occupational therapy, (accessed 25 October 2010), <www.ausot.com.au/inner.asp?pageid=85>

- host family
- community-based.⁸³

- 2.86** The Government has provisions for respite in unexpected circumstances. Clients can access Emergency Short Term Respite if they need an immediate, time-limited break because of an unforeseen crisis.⁸⁴
- 2.87** **Supported accommodation** offers ongoing high intensity services that support people with disability in specialised accommodation settings. Examples of supported accommodation include group homes and large residential centres.⁸⁵
- 2.88** **Transport** allows people to move freely in their communities and enables older people, people with disability, their carers and families to access important support services. **Community transport** is funded by ADHC through the HACC program and is commonly delivered by NGOs and/or local councils to provide transport for group and individual excursions. For further information on community transport see Chapter 6.

Definition of unmet need

- 2.89** The terms of reference require the Committee to examine the extent of unmet need for services that are provided or funded by ADHC. Undermet need was also a term that was commonly used by Inquiry participants, and is defined in this section.
- 2.90** In evidence, Mr Moore advised that the definition used by his organisation for unmet need is "... the level of need for support that needs to be met by government intervention but is not being met."⁸⁶ Mr Moore clarified that unmet need does not refer to *inadequate* service delivery, rather, the term is used to describe the circumstance of "... someone not getting a service and wanting a service."⁸⁷
- 2.91** A definition for unmet need was also provided by NCOSS, who referred the Committee to the Productivity Commission's *Report on Government Services 2010*.⁸⁸ With regard to unmet need in services for older people, the report states that "[u]nmet need' is defined as the extent to which demand for services to support older people requiring assistance with daily activities is not met."⁸⁹
- 2.92** The Productivity Commission's report also stated that, "[u]nmet need' is an indicator of governments' objective of ensuring aged care services are allocated to meet clients' needs."⁹⁰

⁸³ ADHC, Respite, (accessed 25 October 2010)
<www.dadhc.nsw.gov.au/dadhc/People+with+a+disability/Respite.htm>

⁸⁴ ADHC, Respite (accessed 25 October 2010)
<www.dadhc.nsw.gov.au/dadhc/People+with+a+disability/Respite.htm>

⁸⁵ DADHC, *Stronger Together*, p 31

⁸⁶ Mr Moore, Evidence, 9 August 2010, p 7

⁸⁷ Mr Moore, Evidence, 9 August 2010, p 18

⁸⁸ Answers to additional written questions on notice, NCOSS, p 19

⁸⁹ Productivity Commission, *Report on Government Services 2010*, p 13.51

⁹⁰ Productivity Commission, *Report on Government Services 2010*, p 13.50

- 2.93** The ability to measure unmet need was identified by ADHC as a significant challenge, which is examined further in Chapter 3 and Chapter 6.
- 2.94** *Undermet* need was also identified by some Inquiry participants as a significant issue facing service users.⁹¹ The Australian Institute of Health and Welfare define undermet need as occurring when people receive some but not sufficient assistance.⁹²
- 2.95** NCOSS also provided a definition for undermet need, reporting that it is when a person "... receives some support but it is either not sufficient or inappropriate."⁹³

Quality and evaluation processes

- 2.96** The processes and programs used by ADHC to monitor the quality of services are outlined in this section. Background is also provided on how programs are evaluated by ADHC. Chapter 9 examines issues regarding quality and evaluation processes that were raised during the Inquiry and makes relevant recommendations.

ADHC provided services

- 2.97** The quality management system for ADHC provided and operated accommodation and centre-based respite services is the Quality Assurance and Improvement Program (QAIP).⁹⁴
- 2.98** A number of audit tools are used through the QAIP program to identify areas of performance that require improvement. These areas of improvement are then incorporated into ADHC 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."⁹⁵
- 2.99** A Quality Assurance Review (QAR) is also conducted for ADHC provided and operated accommodation and centre-based respite services as part of the QAIP. An external auditor will conduct a QAR of 120 units between 2008 and 2011, and provide a report with recommendations to improve the quality of Quality and Safety Framework (QSF) data collection.⁹⁶
- 2.100** The internal audit tool that is used to monitor the quality of services delivered in ADHC provided and operated accommodation and centre-based respite services is the QSF. In its submission, ADHC stated that the QSF comprises 24 Key Performance Indicators (KPI), and monitors:
- the development and review of client care plan

⁹¹ See for example Submissions 32 and 107

⁹² Australian Institute of Health and Welfare, *Disability in Australia: multiple disabilities and need for assistance*, September 2009, p 22

⁹³ Answers to additional written questions on notice, NCOSS, p 19

⁹⁴ Submission 31, p 86

⁹⁵ Submission 31, p 86

⁹⁶ Submission 31, p 89

- levels of incident reporting
- completion of health and safety inspections
- levels of staff and service usage.⁹⁷

2.101 Data is collected through the QSF on a quarterly basis by staff who work in accommodation and respite services. This information is then collated into regional reports, then state level reports where it is reported to the Executive on a quarterly basis.⁹⁸

2.102 These reports are used to inform strategic planning and performance monitoring across regions and the state. Three statewide reports are produced quarterly, for respite services, group homes and large residential centres.⁹⁹

ADHC funded services

2.103 ADHC measures the performance of funded organisations to “... establish benchmarks and to identify and promote best practices, thus improving performance in the longer term.”¹⁰⁰ Funded organisations are required to comply with the NSW Disability Service Standards as a condition of their funding agreement.¹⁰¹

2.104 Compliance with the funding agreement is monitored by ADHC 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.” In its submission, ADHC advised that this ensures service providers comply with legislative, policy and reporting requirements.¹⁰²

2.105 ADHC has commenced streamlining regulation of funded services through developing a risk identification and monitoring approach:

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.¹⁰³

2.106 The risk identification approach provides for unresolved issues to be escalated and managed as formal non-compliance with the conditions of funding. ADHC advised that it “... will engage the sector in the implementation of the risk monitoring approach and develop a series

⁹⁷ Submission 31, pp 86-87

⁹⁸ Submission 31, p 86

⁹⁹ Submission 31, p 86

¹⁰⁰ Submission 31, p 61

¹⁰¹ Submission 31, p 83

¹⁰² Submission 31, p 84

¹⁰³ Submission 31, p 84

of Fact Sheets and tools for ADHC regional staff in the application of the risk identification matrix.”¹⁰⁴

2.107 In relation to the new approach to monitoring funded services, Mr Moore stated “... we are talking about how can we get a more effective approach and how can we get an approach that does not just simply resource outsiders to come and pressure NGOs to behave in certain ways and check whether they are behaving in certain ways.”¹⁰⁵

2.108 ADHC is also moving towards an output-based acquittals process to reduce the reporting requirements on funded organisations:

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.¹⁰⁶

2.109 Mr Moore told the Committee that ADHC is developing a quality framework, which will “... outline 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.”¹⁰⁷

Evaluation

2.110 Through Stronger Together, ADHC has sought to establish “[a]n Evaluation Program that promotes systematic and robust evaluation and that is responsive to program and service improvement needs”.¹⁰⁸ This program provides a “... 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?¹⁰⁹

2.111 Evaluation and Policy Guidelines provide the framework and a “quality improvement approach central to the evaluation program.” Twenty-five evaluation projects have been completed since 2007, which act to establish the “... effectiveness and impact of programs and made specific recommendations for individual programs.”¹¹⁰

¹⁰⁴ Submission 31, p 84

¹⁰⁵ Mr Moore, Evidence, 9 August 2010, p 21

¹⁰⁶ Submission 31, p 85

¹⁰⁷ Submission 31, p 98

¹⁰⁸ Submission 31, p 62

¹⁰⁹ Submission 31, p 68

¹¹⁰ Submission 31, p 68

Complaint handling mechanisms

2.112 The options available for people to make complaints about various aspects of the disability service system are outlined in this section. Avenues for complaint include ADHC, the NSW Ombudsman, the Official Community Visitors Scheme and the Independent Commission Against Corruption. Issues raised during the Inquiry in relation to complaint handling are considered in Chapter 9.

ADHC complaint handling process

2.113 A formal process to address complaints directed to ADHC is detailed in the agency *Feedback and Complaint Handling Policy, Principles and Guidelines*.¹¹¹ This policy outlines principles and provides guidelines to assist staff in responding to complaints. In its submission, ADHC stated that "[a]ll ADHC staff as well as contractors and volunteers are required to respond to complaints according to the principles and guidelines outlined in the policy."¹¹²

2.114 ADHC also stated that "[c]omplaints 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."¹¹³

2.115 Funded organisations are required to address complaints through conditions in the funding agreement. The funding agreement requires all non-government organisations to comply with the disability service standards, which includes a standard on complaints and dispute resolution.¹¹⁴

2.116 In the event that a complaint is not been handled appropriately by a funded organisation, "... we [ADHC] would be going back to the non-government organisation to understand whether or not the complaints handling process had been done well enough."¹¹⁵

NSW Ombudsman

2.117 The NSW Ombudsman is responsible for assisting agencies, such as ADHC, to "... address problems with their performance." Problems are brought to the attention of the Ombudsman through complaints and "... scrutinising agency systems, overseeing investigations or reviewing the delivery of services."¹¹⁶

2.118 Matters dealt with by the NSW Ombudsman include, but are not limited to, complaints about how reportable allegations are handled, complaints about the provision, failure to provide,

¹¹¹ Submission 31, p 100

¹¹² Submission 31, p 100

¹¹³ Submission 31, p 100

¹¹⁴ Mr Moore, Evidence, 9 August 2010, p 19

¹¹⁵ Mr Moore, Evidence, 9 August 2010, p 19

¹¹⁶ NSW Ombudsman (accessed 7 October 2010)
<www.ombo.nsw.gov.au/aboutus/ourresponsibilities.html>

withdrawal, variation or administration of a community service and protected disclosures from public sector staff and officials about maladministration.¹¹⁷

2.119 The NSW Ombudsman addresses complaints through:

- making sure agencies are aware of their responsibilities to the public
- recommending actions for the agency to take to resolve complaints
- encouraging agencies and complainants to deal with each other directly to address issues
- referring complaints back to the agency concerned and giving them support to handle the complaint themselves
- assisting agencies to set up and maintain complaint handling systems to better handle complaints and to use the feedback to improve the way they do things
- investigate serious matters.¹¹⁸

2.120 Specific functions of the NSW Ombudsman to coordinate the Official Community Visitor Scheme are described in the following section.

Official Community Visitor Scheme

2.121 The Minister for Disability Services and the Minister for Community Services appoint Official Community Visitors under the *Community Services (Complaints, Reviews and Monitoring) Act 1993*.¹¹⁹ The scheme is coordinated by the NSW Ombudsman, however, Official Community Visitors are independent of the NSW Ombudsman and report to the Minister for Disability Services and the Minister for Community Services.¹²⁰

2.122 Ms Roz Armstrong, an Official Community Visitor, advised that “Official Community Visitors visit accommodation services for children and young people and people with a disability that are operated, funded or licensed by the DoCs [Department of Community Services] or ADHC where residents are in full time care.”¹²¹

2.123 Key responsibilities of Official Community Visitors include:

- informing the Ministers and the Ombudsman about the quality of services
- promoting service users' rights
- identifying issues raised by residents
- helping to address complaints.

¹¹⁷ NSW Ombudsman (accessed 7 October 2010)
<www.ombo.nsw.gov.au/aboutus/dealwithcomplaints.html>

¹¹⁸ NSW Ombudsman (accessed 7 October 2010)
<www.ombo.nsw.gov.au/aboutus/ourresponsibilities.html>

¹¹⁹ NSW Ombudsman (accessed 7 October 2010)
<www.ombo.nsw.gov.au/aboutus/coordnteofcommvstrprog.html>

¹²⁰ Submission 41, Official Community Visitor Scheme, p 1

¹²¹ Submission 41, p 1

The Independent Commission Against Corruption

- 2.124** The Independent Commission Against Corruption (ICAC) was established as “... an independent organisation to protect the public interest, prevent breaches of public trust and guide the conduct of public officials in the NSW public sector.”¹²²
- 2.125** Principal functions of the ICAC are set out in the *Independent Commission Against Corruption Act 1998* and include:
- investigate and expose corrupt conduct in the NSW public sector, including agencies such as ADHC
 - actively prevent corruption through advice and assistance
 - educate the NSW community and public sector about corruption and its effects.¹²³
- 2.126** Clients can complain to the ICAC about allegations of serious wrong-doing by ADHC staff. Also, the ICAC may investigate or ask ADHC to investigate matters about public sector staff.¹²⁴

¹²² The ICAC (accessed 7 October 2010) <www.icac.nsw.gov.au/about-the-icac>

¹²³ The ICAC (accessed 7 October 2010) <www.icac.nsw.gov.au/about-the-icac/overview>

¹²⁴ ADHC, Complaints, (accessed 26 October 2010)
<www.dadhc.nsw.gov.au/dadhc/Contact+DADHC/Complaints.htm#whatif>

Chapter 3 Funding

This chapter details current disability service funding arrangements through Ageing, Disability and Home Care (ADHC) and other major funding streams such as the National Disability Agreement (NDA) and the Home and Community Care program (HACC). This includes a discussion of the adequacy and the difficulties of measuring unmet and ‘undermet’ demand. ADHC's procurement of services provided by other agencies and non-government organisations is also discussed in this chapter, along with possible alternative models of funding.

ADHC funding

- 3.1** The role of ADHC is to promote social inclusion by providing services to older people and people with disability, to assist them to live independently and participate in the community.¹²⁵ ADHC was incorporated into the newly created Department of Human Services in 2009.
- 3.2** Chapter 2 provides background to disability service system funding in NSW, including state and commonwealth funding contributions.
- 3.3** In 2010-11, ADHC's budget totals \$2.5 billion.¹²⁶ This figure includes both specialist disability and HACC funding. HACC provides services for both the ageing and people with disability. Mr Jim Moore, Chief Executive, ADHC, described ADHC's role in assisting people with disability and their families:

We as an agency are predominantly, in terms of size, overseeing dollar size, about \$1.9 billion that we spend on disability services, about \$550 million that we spend on home community care services and a small number of millions of dollars – to the tune of \$10 million to \$15 million – we spend on various services for what we would refer to the well-aged things ranging from Seniors' Week events and seniors concerts, Seniors Card and those sorts of things and a small amount of ageing grants. But our business is predominantly about assisting about 50,000 families and people with a disability with specialist disability services, and about 250,000 generally frail older people but there are some people with a disability who get home and community care services.¹²⁷

- 3.4** As noted in Chapter 2, ADHC provides a range of specialist services for people with disability, including community access programs, learning and life skills development, respite and accommodation services. Employment and income support programs for people with disability are provided by the Commonwealth government.

The adequacy of funding and unmet need for disability services

- 3.5** There was widespread acknowledgement among Inquiry participants that increased expenditure, particularly through Stronger Together, has improved the availability of services for people with disability in recent years. For example, Mr Douglas Herd, Executive Officer,

¹²⁵ Submission 31, ADHC, p 6

¹²⁶ Submission 31, p 6

¹²⁷ Mr Jim Moore, Chief Executive, ADHC, Evidence, 9 August 2010, p 2

Disability Council of NSW, observed that Stronger Together funding had made a significant difference to people with disability:

It is true to say, without wishing to be seen to be using hyperbole, that the atmosphere before the Stronger Together policy was put in place in the sector, as it likes to describe itself – the relationship between people with disability and the department, between people with disability and government, between non-government advocacy organisations and government and sometimes with non-government service providers – was hostile and difficult at times. My personal opinion that that was because gross levels of unmet need meant that people with disability were not getting access to services and that family members were doing enormously difficult jobs under huge stresses to look after and care for both themselves and family members who ought to have been receiving services. The \$1.4 billion that we subsequently got [through Stronger Together] ...has made a very significant difference. There is no doubt about that at all.¹²⁸

- 3.6** Some Inquiry participants felt that funding for disability services is inadequate.¹²⁹ The Physical Disability Council of NSW and the Council on the Ageing NSW, for example, believe that "demand greatly exceeds the supply of funding."¹³⁰ Similarly, Ms Jennifer Rollo expressed the view that inadequate funding meant that the system was unable to respond to need when it reached crisis level:

In NSW, the disability support system clearly does not have enough money to adequately meet the needs of people with disability ... resulting in a system of crisis intervention only.¹³¹

- 3.7** Many participants acknowledged that funding for disability services had increased in recent years, particularly since Stronger Together, but felt that "... while Stronger Together has improved the adequacy of the disability support system since 2006 ... it has been a good first step only."¹³² For instance, Professor Ron McCallum, Interim Chair of the Disability Council of NSW, expressed the view that there is still a long way to go. He said that:

... we need more money in the disability sector ... the Committee heard from Mr Moore how the sector is growing, how funding is growing faster than the all-consuming health budget. Yet we know our sisters and brothers with non-English speaking backgrounds still require more services and are underrepresented. Similarly, although splendid work is being done with indigenous Australians in NSW, we know that there is a long way to go.¹³³

- 3.8** Ms Christine Regan, Senior Policy Officer, Council of Social Service NSW (NCOSS), noted that the increase in funding for disability services – including that provided through Stronger Together – did not result in an adequate increase in services:

¹²⁸ Mr Dougie Herd, Executive Officer, Disability Council of NSW, Evidence, 9 August 2010, p 28

¹²⁹ See for example, Submissions 23, 30, 39 and 91

¹³⁰ Submission 51, Physical Disability Council of NSW and Council on the Ageing NSW, p 4

¹³¹ Submission 38, Ms Jennifer Rollo OAM, p 2

¹³² Ms Samantha Edmonds, Deputy Director Policy and Communications, NCOSS, Evidence, 9 August 2010, p 56

¹³³ Professor Ron McCallum, Interim Chair, Disability Council of NSW, Evidence, 9 August 2010, p 28

There has been money streaming into disability services in the past 15 years or so but the number of new services bought for that has been very small. For example, for a doubling of the DADHC budget in disability we got less than a 19 per cent increase in the number of people using disability supported accommodation. So really it was more about bringing the services and standards up to date rather than increasing the number of people who could use them.¹³⁴

- 3.9** The view that funding for disability services remains inadequate is based on an unmet need for services. However, the definition and measurement of unmet need in the context of disability services can be complex. Mr Moore explained ADHC's understanding of unmet need and the problems in trying to quantify it:

The definition we work with is the level of need for support that needs to be met by government intervention but is not being met. A person with a disability may need assistance with getting out of bed. That does not require government intervention in all circumstances for that to happen. So you have this very difficult issue to determine, which is not just whether there is an objective need but how best for that need to be met, government intervention or not. To answer how we define unmet need, it has to come down to quite a technical one of need required to be met by government intervention and not being met by government intervention.¹³⁵

- 3.10** The existence of unmet need for disability services was widely acknowledged by participants in the Inquiry and is examined in more detail in Chapter 6. For example, National Disability Services (NDS) wrote that, "[i]t is an undeniable reality that there remain people with disability, families and carers in need of services and supports."¹³⁶ Similarly, People With Disability (PWD) wrote of considerable unmet need:

PWD is aware of considerable unmet need for disability services in NSW. We regularly assist people with disability and their families who have been waiting for long periods of time for services, who are in crisis due to lack of services or failures in the service system, who cannot control the supports they need, who fall between service system gaps or who cannot obtain a service unless they are in crisis.¹³⁷

- 3.11** Ms Regan felt that the degree of unmet need in the community was significant and provided an example of the crises that unmet need can generate for people with disability and their families:

We would say that there is a crisis looming and there is such a degree of unmet need at the moment that we hear some really tragic stories...I know of one woman who could not get equipment into her house in order to have her son, who had very high support needs, seated and into bed. This was only about three years ago. She used to put a sleeping bag on the floor and she fed him on the floor until her own shoulders gave out and she had to go into hospital. Only at that point was she offered supported accommodation for her son, when she had completely broken down. These stories just happen over and over. It is shameful.¹³⁸

¹³⁴ Ms Christine Regan, Senior Policy Officer, NCOSS, Evidence, 9 August 2010, p 58

¹³⁵ Mr Moore, Evidence, 9 August 2010, p 7

¹³⁶ Submission 32, Ms Emily Caska, NDS NSW, p 10

¹³⁷ Submission 91, p 6

¹³⁸ Ms Regan, Evidence, 9 August 2010, p 62

- 3.12** Some Inquiry participants referred to the concept of undermet need as well as unmet need, which refers to a need which is only partially met by an available service. For example, Mr Patrick Maher, Chief Operating Officer and State Manager of NDS, explained the difference between the two terms:

We are dealing with an environment where you have a department [ADHC] that has a finite budget to meet a need that is far in excess of that which they can fund. So without significant additional funding being brought into the sector we are going to have unmet need. There is a capacity to identify some of that unmet need. I think undermet need is probably best explained in some of the active ageing type programs that Ageing, Disability and Home Care has out there where people may have been funded to receive one, two or three days support a week when in reality their needs are for four or five days or their family's or carer's needs are for four or five days. So there is a need being met but it is not the full need.¹³⁹

- 3.13** The concept of undermet need further complicates attempts to measure unmet need, as data in relation to service provision may actually serve to mask undermet need. NCOSS provided the following example to illustrate this issue:

A family might accept the offer of respite for their loved one with very high support needs as a temporary measure, when they actually desperately require appropriate supported living/accommodation ... ADHC can correctly indicate that services were provided to meet the specified need but those very people and families would indicate undermet need rather than needs met.¹⁴⁰

- 3.14** Mr Moore acknowledged that there is unmet need for disability services in NSW.¹⁴¹ However, he emphasised that measuring the level of unmet need is a complex task:

Understanding the numbers of people, and understanding how many of those people are getting services, is the easy bit. Being able to then extrapolate from that as to what is the right level of intervention is required, how much need is not being met, how much need needs to be met by government intervention, and what sort of government intervention – in respect of those things there is a real paucity of data.¹⁴²

- 3.15** The lack of reliable data to accurately measure unmet need was noted by several participants in the Inquiry.¹⁴³ This makes it difficult to assess what kind of services are most in demand or where the demand lies. The difficulty in measuring need is further complicated by regional variations, as the Committee was advised by Carers NSW, who said that, "The adequacy of funding and the extent of unmet need for services in NSW varies."¹⁴⁴

- 3.16** However, NCOSS disputed the view that data about unmet need is not available, instead pointing out that much data collected by ADHC is not analysed:

¹³⁹ Mr Patrick Maher, Chief Operating Officer and State Manager, NDS, Evidence, 9 August 2010, p 38

¹⁴⁰ Submission 30, p 7

¹⁴¹ Mr Moore, Evidence, 9 August 2010, p 6

¹⁴² Mr Moore, Evidence, 9 August 2010, p 9

¹⁴³ Submission 39, p 10; Submission 32, p 10

¹⁴⁴ Submission 33, Carers NSW, p 2

There is plenty of information provided to and collected by ADHC that is not analysed for indicators of unmet need. Much of this information is provided under a compliance requirement for each funded service and when received, ADHC officers store it against that organisation's information deposit.¹⁴⁵

Committee Comment

- 3.17** The Committee recognises that, despite increases in funding and available services in recent years primarily as a result of Stronger Together, there is still significant unmet need for ageing and disability services in NSW. However, attempts to quantify the level of unmet need for various services is currently hampered by a lack of quality data, data analysis, collection and management.
- 3.18** The Committee notes that additional examination of issues regarding disability services data are examined in Chapter 9.
- 3.19** The Committee acknowledges that measuring unmet need is a complex task. However, the Committee considers that an accurate assessment of unmet need is crucial to the future planning of disability services in NSW. The Committee therefore believes that ADHC should commission further work to assess unmet need in services provided by the agency and to make this information publicly available.
- 3.20** The Committee notes that issues regarding unmet need are examined in detail in Chapter 6, including analysis of specific service types that were identified as experiencing significant unmet need.

Recommendation 1

That the Minister for Disability Services audit the existing data that is collected by ADHC and data that is available to ADHC, identify any additional data that is required to accurately assess unmet and under-met need for ageing and disability services in NSW.

That the NSW Government amend the *Disability Services Act 1993* to require the Minister for Disability Services to table a biannual report into unmet and under-met need for ageing and disability services in NSW.

Recommendation 2

That ADHC prioritise the attainment of its targets for supported accommodation places, as identified in the first phase of Stronger Together.

¹⁴⁵ Answers to questions taken on notice during evidence, 9 August 2010, NCOSS, p 9

Stronger Together II

- 3.21** Several Inquiry participants discussed unmet need in relation to phase two of Stronger Together. Stronger Together is a ten year strategy with the first five year phase due to be completed in 2011.
- 3.22** The Hon Peter Primrose, Minister for Disability Services, told Parliament that consultation to inform the next five years of Stronger Together commenced in June 2010:

As we approach the halfway mark of Stronger Together, the NSW Government's 10-year plan for disability services, we have taken the opportunity to conduct an extensive consultation program to inform the next five years of the plan. We were strongly committed to ensuring that the consultations took into account a diversity of views to help shape the future of disability services in NSW.

...

Over 300 people attended these consultations ... We received 420 written submissions following the consultation paper from people with a disability, their families and carers, as well as a broad spectrum of service providers and advocates. As with the first stage of Stronger Together, stakeholder consultations will be critical in making sure we get the next five years right for people with a disability in NSW. I note, for example, that one of the key messages to come out of the consultation process is that people want more choice and control over how the funding currently allocated to them is used. We have heard that message from the community, and the NSW Labor Government will, as part of the next five-year phase of Stronger Together, deliver personalised funding arrangements for people with a disability as part of our person-centred approach.¹⁴⁶

- 3.23** During the Ageing, Disability Services, Volunteering and Youth Budget Estimates hearing in September 2010, the Minister for Disability Services advised General Purpose Standing Committee 2 that "[w]e will be making an announcement about Stronger Together II towards the end of this calendar year."¹⁴⁷
- 3.24** The views of Inquiry participants about funding and unmet need frequently converged around the priorities and planning for the second phase of Stronger Together. Mr Moore reflected on the history and current situation of disability services in NSW in the following terms:

Most of the responses in the disability stage had been of the ilk of reacting to pressure at the moment. With Stronger Together we acquired a more systemic response. The Government set some longer objectives that we were required to manage against ... In the early years of Stronger Together the implementation was about getting the resources out the door. The choice that we made in rolling out the \$1.3 billion, that was part of Stronger Together, in the first five years was to get capacity on the ground, to do some of the major policy things ... As we are now heading towards the

¹⁴⁶ NSWPD (*Legislative Council*), 1 September 2010, p 24953

¹⁴⁷ General Purpose Standing Committee 2, Inquiry into Budget Estimates 2010/11, Hon Peter Primrose MLC, Minister for Disability Services, Evidence, 13 September 2010, p 29

second five years, we are doing a lot of policy refinement and tidying up and moving ourselves to being able to administer the system more systematically.¹⁴⁸

- 3.25** Some participants in the Inquiry also expressed views about the level of funding which is required for the second phase in order to meet the objectives of Stronger Together. For example, Mr Herd suggested that \$2 billion of new funding is required:

[W]hen we talk about Stronger Together II, I have yet to meet a human being on the planet who is prepared to say in public that they think Stronger Together II should be funded for anything less than \$2 billion worth of new money. That takes it up to \$5 billion in five years' time.¹⁴⁹

- 3.26** Mr Maher expressed a similar view in regard to costing the second phase. He said that:

I am happy to go on record as saying that needs to be well in excess of \$2 billion for the second five years, to maintain the identified growth that is needed ... It is \$2 billion over five years. I am saying \$2.5 billion over five years additional funding to complement what was to be \$1.3 billion over the first five years of Stronger Together.¹⁵⁰

- 3.27** The Government has not yet announced its proposed direction in terms of funding for the second phase of Stronger Together. The Committee's Inquiry has highlighted the level of interest and concern in the disability sector about funding for Stronger Together II. For example, Mr Herd commented that, "Premier Keneally has indicated that her Government will give a statement on perhaps the number by the end of the year ... We are all waiting with bated breath for that number."¹⁵¹

Committee comment

- 3.28** The funding and policy priorities of Stronger Together II have the potential to address many of the issues identified through this Inquiry, including the significant level of unmet need in some service types and a clear implementation of person-centred planning. The Committee agrees that funding of the second phase of Stronger Together will require the commitment of a significant amount of funding, given the increase in population and the number of issues in the disability service system that require immediate attention.
- 3.29** The Committee agrees with Mr Maher and Mr Herd that funding for Stronger Together II should be well in excess of \$2 billion, and recommends that the Government commit at least \$2.5 billion for phase two. This funding should be provided in addition to the \$1.3 billion that was committed for the first five years.
- 3.30** The Committee is aware of the growing anticipation felt by the disability sector regarding the important announcement of the second phase of Stronger Together. The Committee recommends that the Government announce the funding available for Stronger Together II by the end of November 2010.

¹⁴⁸ Mr Moore, Evidence, 9 August 2010, p 6

¹⁴⁹ Mr Herd, Evidence, 9 August 2010, p 32

¹⁵⁰ Mr Maher, Evidence, 9 August 2010, p 38

¹⁵¹ Mr Herd, Evidence, 9 August 2010, p 32

Recommendation 3

That the NSW Government commit at least \$2.5 billion to deliver phase two of Stronger Together. That phase two funding is provided in addition to the \$1.3 billion in funding that was provided during phase one and is announced by the end of December 2010.

Recommendation 4

That the Minister for Disability Services table an annual report to Parliament on the implementation of, and expenditure on, Stronger Together II.

Procurement of services funded by ADHC

- 3.31** As identified previously, ADHC funds a large number of organisations - including other government agencies - to provide various services for people who are ageing, people with disability and their carers. Service provider and advocacy organisations that participated in the Inquiry identified a range of problems with ADHC's funding of organisations, not only in terms of the level of funding to provide services (which was seen by some participants as insufficient to meet service users' needs) but also the process of tendering for available funds and meeting funding obligations.
- 3.32** ADHC routinely allocates funding through competitive tendering processes. Some participants noted that over time competitive tendering had led to a significant increase in the number of service providers in NSW.¹⁵² However, competition for funding between services did not necessarily result in increased choices for service consumers. NCOSS, for example, expressed the view that, "[i]n reality, the weight of unmet demand usually dictates that the service user gets to choose only whether to accept the service as offered not to freely choose from among a number of service providers."¹⁵³
- 3.33** NCOSS also noted that competition between service providers had led to unintended negative effects, as services were less inclined to share information and cooperate with each other.¹⁵⁴
- 3.34** Several participants expressed concerns about the burden that the tendering process placed on service providers. Tendering for funds requires the provision of detailed planning and other information. Because organisations may be required to tender for funding repeatedly, the process of tendering itself can create a significant management and administrative burden. For example, Anglicare described this burden:

The process of tender application is unnecessarily costly and time consuming. Even where a relationship already exists with a department such as ADHC, Not-for-Profits are required to pour the same extensive resources into fresh tender processes.¹⁵⁵

¹⁵² Answers to questions taken on notice during evidence, 9 August 2010, NCOSS, p 11

¹⁵³ Answers to questions taken on notice during evidence, 9 August 2010, NCOSS, p 11

¹⁵⁴ Answers to questions taken on notice during evidence, 9 August 2010, NCOSS, p 12

¹⁵⁵ Submission 66, Anglicare, Diocese of Sydney, p 6

- 3.35** Mr Barrie Styles explained that although the number of people who receive services from his organisation has doubled since 1999, his service has received no additional funding from ADHC. He has observed a larger funded organisation receiving new funding in his local area, rather than his service which was already well established to provide these services.¹⁵⁶
- 3.36** Some participants were also concerned that the requirements of competitive tendering inherently favoured large organisations which have more resources to direct towards tendering processes.¹⁵⁷ Further, some participants felt that while competitive tendering may lead to better tender applications, it does not necessarily produce better services. For example, Ms Elena Katrakis, Chief Executive Officer, Carers NSW, observed that:
- Just because people might write a better tender does not mean they cannot deliver the service, but you have larger non-government organisations able to outsource the development of a tender – even a professional writer – all those kinds of things that are so far removed from the actual service on the ground. But they can tick all the boxes in a way that maybe a smaller non-government organisation cannot. It is not an even playing field.¹⁵⁸
- 3.37** Some participants expressed concerns that over the long term competitive tendering may lead to loss of small locally-based service providers.¹⁵⁹ Ms Emily Caska, State Policy Coordinator, NDS, suggested that preference for larger services over smaller ones may be a deliberate strategy on the part of ADHC:
- There are concerns by some of our member organisations around preferential procurement of services, particularly in the western and the northern region. There is some fear of small providers being taken over by large statewide providers, and that was very clear in our consultations with the sector.¹⁶⁰
- 3.38** The Committee was advised by NCOSS that the NSW HACC Issues Forum suggested that introduction of ‘approved provider’ status may reduce the burden on services, particularly smaller services.¹⁶¹ NDS suggested moving towards mutual recognition of quality assurance frameworks of different jurisdictions.¹⁶²
- 3.39** Mr Mark Trevaskis, Executive Director, Best Buddies Australia, recommended that funding be awarded for three year periods to provide improved security and enable funded organisations to effectively forward plan.¹⁶³

¹⁵⁶ Mr Barrie Styles, Public Forum, 30 September 2010, p 26

¹⁵⁷ Answers to questions taken on notice during evidence, 9 August 2010, NCOSS, p 12

¹⁵⁸ Ms Elena Katrakis, Chief Executive Officer, Carers NSW, Evidence, 9 August 2010, p 49

¹⁵⁹ For example Ms Kerry Stubbs, Chief Executive Officer, Northcott Disability Services, Evidence, 26 August 2010, p 56

¹⁶⁰ Ms Emily Caska, State Policy Coordinator, NDS, Evidence, 9 August 2010, p 40

¹⁶¹ Answers to questions taken on notice during evidence, NCOSS, 9 August 2010, p 12

¹⁶² Submission 32, p 23

¹⁶³ Submission 76, Mr Mark Trevaskis, Executive Director, Best Buddies Australia, p 4

- 3.40** The Shepherd Centre submission recommended that ADHC implement improved transparency and consistency regarding the amount of funding that is allocated to organisations.¹⁶⁴

Compliance requirements

- 3.41** Service providers expressed concerns about the burden of complying with accountability requirements for services funded by ADHC. Ms Carol Berry, Executive Director, NSW Council for Intellectual Disability, stated

People constantly report – both service users and service providers – that they are frustrated by a lack of transparency in the department, a lack of clear information, that there is too much red tape, paperwork, activities and process that rather than enhancing services and enabling people actually frustrates them.¹⁶⁵

- 3.42** The burden of reporting is increased by the need to comply with different requirements of different funding bodies (such as Commonwealth agencies) as well as different projects funded by one agency such as ADHC. The Disability Trust provided the following example of its reporting requirements:

The Disability Services sector can be highly regulated with mandatory external and internal accountability demanded by various jurisdictions. In addition to the general corporate regulations, IR, taxation, OH&S, Privacy Act provisions, charitable fundraising compliance, and financial audit requirements, there are a range of specific standards and accreditation processes that may be required by providers in the sector. Some that are pertinent to the Trust include; NSW Disability Service Standards, measureable in previous years through the Integrated Monitoring Framework; Commonwealth Disability standards; Attendant Care Industry accreditation, also externally measured; Office of the Children's Guardian registration; and Statutory Out of Home Care compliance. Accountability is further demonstrated through regular quarterly data returns, external scrutiny through a community visitors' scheme and end of year financial acquittals. Additionally the Expression of Interest process for new funding requires evidence of an organisation's capacity to deliver the quality and outputs of services that are subject to tendering.

These overlaying accountabilities can divert energy and resources from the most important part of the care system, that is, interface with clients.¹⁶⁶

- 3.43** This view that meeting compliance requirements diverted resources away from service delivery was shared by NDS, who felt that reducing the burden of compliance with reporting requirements would increase resources available for service users:

By reducing requirements on non-government providers in the tendering process and in monitoring of performance, the 'burden' on providers can be reduced – freeing resources for service delivery and achieving outcomes for people with disability.¹⁶⁷

¹⁶⁴ Submission 80, The Shepherd Centre, p 6

¹⁶⁵ Ms Carol Berry, Executive Director, NSW Council for Intellectual Disability, Evidence, 26 August 2010, p 11

¹⁶⁶ Submission 107, The Disability Trust, p 6

¹⁶⁷ Submission 32, p 11

- 3.44 Several participants in the Inquiry referred to the work already undertaken by the Department of Human Services in its NGO Red Tape Reduction report,¹⁶⁸ which is to be jointly implemented by the Department of Human Services and NSW Health.¹⁶⁹

Committee Comment

- 3.45 The Committee recognises the burden that multiple accountability requirements can create for non-government organisations, particularly small organisations and those that provide services funded from multiple sources.
- 3.46 The Committee commends the Government on its NGO Red Tape Reduction report. However, the Committee notes that ADHC has yet to report publicly on implementation of the recommendations from this report.

Recommendation 5

That the Minister for Disability Services report publicly on ADHC's implementation of the recommendations of the NGO Red Tape Reduction report by November 2011 including the level of third party outsourcing by ADHC NGO-contracted service providers.

Funding and procurement inconsistencies

- 3.47 Service providers also expressed frustrations about inconsistencies or inequities in funding and in ADHC's decision-making processes in relation to funding. Participants in the Inquiry raised a number of issues in this regard and these are briefly canvassed below.
- 3.48 Some participants expressed concerns about ADHC's position as both a purchaser/funder of services and a provider. "One of the long-held concerns in the sector," observed Mr Maher, "is the concept of the funder being a competitor, in being the policeman."¹⁷⁰ This potential conflict of interest is examined in more detail in Chapter 9.
- 3.49 Northcott Disability Services identified that non-government organisations may be funded at a lower rate than ADHC for the delivery of the same service:

In the disability system, ADHC is both the funding body and a provider of some direct services, for example: centre based respite, case management, therapy. However, non-government organisations (NGOs) are often funded at a lower rate than ADHC services for providing the same service. As a result of this, staff working in NGOs received lower rates of pay than those working in ADHC services. This can serve as a barrier to attracting skilled staff to the NGO sector.¹⁷¹

¹⁶⁸ Ms Stacey Sheppard-Smith, Executive Officer, NSW Home Modification and Maintenance Services State Council, Evidence, 3 September 2010, p 12; Submission 32, p 72

¹⁶⁹ NSW Department of Premier and Cabinet, *Non-Government Organisation Red Tape Reduction Report*, November 2009

¹⁷⁰ Mr Maher, Evidence, 9 August 2010, p 41

¹⁷¹ Submission 70, Northcott Disability Services, p 5

- 3.50** Workforce issues were identified as a significant issue by numerous service providers, and these are discussed in detail in Chapter 11. For example, indexation of funding was seen as inadequate to cover full increases in costs, while ADHC's own services were not subject to the same constraints.¹⁷²

Funding inequities between regions

- 3.51** The Physical Disability Council of NSW and the Council on the Ageing also pointed out that there are inequities between different areas of the state, simply because of variations in the cost of delivering services. The difficulty and expense of delivering services in rural and remote areas was raised by a number of participants:

Rural and remote communities struggle with minimising and controlling costs. Costs in these communities are considerably higher than metropolitan areas. Whilst rent may be cheaper in the country than in the city; other costs can be extremely prohibitive such as fuel, food and water ... Simply put, it costs more in the country to deliver services.¹⁷³

- 3.52** However, some participants noted that inequities between regions can also arise as a result of administrative decisions.¹⁷⁴ Because ADHC often makes funding decisions on a regional basis, inconsistencies between ADHC regions can produce inequities or inconsistencies for both service providers and, ultimately, service users. For example, People with Disability noted that "different ADHC regions can vary in the way services are delivered depending on the availability of service types and the interpretation of service and funding guidelines."¹⁷⁵

- 3.53** Such inconsistencies in the administration of funding were a source of considerable frustration for service providers, particularly those which delivered services on a statewide basis. NDS commented that:

[T]here are some slight inconsistencies that we continue to work with ADHC on. The main ones are inconsistency and the application and interpretation of policies. The policies of our providers who work with different regions can be implemented completely differently, depending on which level of middle management is implementing the policy.¹⁷⁶

Individualised funding

- 3.54** 'Individualised' or 'self-directed' models of funding were widely supported by participants in the Inquiry. These models were seen as consistent with the aim of person-centred approaches to service provision, which are discussed in more detail in Chapters 4 and 5. The key advantage of individualised funding is that it offers service users a greater level of control and choice over the services they receive. This was highlighted by Ms Jo-Anne Hewitt, Chairperson of the Futures Alliance:

¹⁷² Submission 66, p 4

¹⁷³ Submission 51, p 10

¹⁷⁴ See for example, Submission 32 and 91

¹⁷⁵ Submission 91, p 10

¹⁷⁶ Ms Caska, Evidence, 9 August 2010, p 36

I think that the move towards individualised funding and even self-managed funding is a very important step. Certainly I think it addresses the need for people with a disability to be in control of their own lives.¹⁷⁷

3.55 Mr Greg Killeen, Senior Policy Officer, Spinal Cord Injuries Australia, echoed this view:

[W]e are all individuals who would like to have a good life which may only be achieved with access to, and support from, a choice of appropriately funded and coordinated disability specific or community services and programs, and the option of individualised funding to enable us to have some autonomy and control over the services we require.¹⁷⁸

3.56 Some Inquiry participants also felt that individualised funding has the potential to allocate funding efficiently, as the relationship between the consumer and provider of a service is more direct. Ms Regan identified a disconnect in current funding models:

Right now there is a disconnect in the market when we use market theory. The people who are actually purchasing the service are not the people using it. So the satisfaction and degree of quality can be quite different, and the way it is measured can be quite different. When a person with a disability and their family become the purchaser suddenly the services we all know need to lift their game.¹⁷⁹

3.57 The Committee heard that individualised funding models had the potential to provide greater flexibility in the delivery of services. Lack of flexibility in guidelines and eligibility for ADHC services is a major frustration for service providers, for example, NCOSS:

[I]n previous years during the NCOSS regional visits to regional and country centres, disability providers consistently complain of the lack of flexibility in guidelines and contracts to meet the needs of their service users with disability. This complaint is second only to inadequate resources.¹⁸⁰

3.58 The inflexibility of funding guidelines can also have serious effects for service users whose needs are not met. For example, Ms Regan reported that "... we have the ludicrous situation of a family on the north coast who cannot get enough continence aids but is offered a holiday."¹⁸¹

3.59 Despite their potential, individualised funding is not widely used in NSW at present. People with Disability, which strongly supports the development of individualised funding mechanisms, commented on the lack of options available to consumers:

Currently, individualised funding and self-directed supports are not widely available for people with disability in NSW. There are some programs that provide individualised funding with varying levels of control by the person receiving the funding, but generally, people with disability are reliant on what the service system provides, what support they are eligible for, and the type of support that is available.¹⁸²

¹⁷⁷ Ms Jo-Anne Hewitt, Chairperson, Futures Alliance, Evidence, 3 September 2010, p 47

¹⁷⁸ Mr Killeen, Evidence, 30 September 2010, p 17

¹⁷⁹ Ms Regan, Evidence, 9 August 2010, p 60

¹⁸⁰ Submission 30, p 12

¹⁸¹ Ms Regan, Evidence, 9 August 2010, p 62

¹⁸² Submission 91, p 12

3.60 Mr Moore acknowledged that individualised funding mechanisms are not yet widely used in NSW. He expressed concerns about the workforce implications of this model:

[I]n the NSW context we have chosen not to move rapidly down the path of individualised funding. We have quite a bit in little places but it has not become a whole scale system setting because we need to solve the issue of where the workforce is going to come from...¹⁸³

3.61 Mr Moore also noted that self-directed funding options were not always popular with service users. For example, the Direct Funded Model implemented in ADHC's Attendant Care Program, which provides personal care assistance for people with physical disabilities, was not widely adopted by service users.¹⁸⁴ Mr Moore reflected on the possible reasons for this:

[O]ne important point of this space is that with individual funding models, even where there has been a lot of flexibility made in the English circumstance, you see a relatively small proportion of people take it up. We have one experience where in recent years our attendant care program, which provides fairly intensive generally in-home support for a person, we now say if you want it you can have the money direct into your bank account – the ultimate flexibility in a way. Of the just over 700 people that we have, 18 have elected to take up the arrangement, and that is a reflection that people need a lot of help and support.¹⁸⁵

3.62 Mr Gordon Duff, State Manager, Policy and Projects, NDS, felt that there is a lack of clarity about exactly what is meant by terms such as 'individualised' and 'self-directed' funding:

This is an area in which there is a certain lack of clarity of language in describing personalised approaches in disability services. A lot of people describe individualised funding and they think they mean the same thing when someone else talks about it.¹⁸⁶

3.63 Mr Duff emphasised that terms such as 'individualised funding' or 'self-directed funding' can refer actually to a number of different models of providing funding. All of these models aim to provide service users with a greater level of control over the services they receive:

[T]here needs to be a continuum of different offerings to people with a disability. One of those, right at the extreme end, is the direct payments model...that can move right along to a looser allocation for a place in a day centre or supported accommodation. There is a range of different models that we say can enable choice and voice and control, and they do not always need to be the passporting over of money to the service recipient.¹⁸⁷

3.64 Ms Hewitt also expressed the view that different models of individualised funding may be necessary, as different service users may have varying levels of capacity – or importantly, desire – to manage service funding:

¹⁸³ Mr Moore, Evidence, 9 August 2010, p 4

¹⁸⁴ Submission 31, p 72

¹⁸⁵ Mr Moore, Evidence, 9 August 2010, p 4

¹⁸⁶ Mr Gordon Duff, State Manager Policy and Projects, NDS, Evidence, 9 August 2010, p 40

¹⁸⁷ Mr Duff, Evidence, 9 August 2010, p 40

As you say, though, that can look different for different people. There are some people and some families who can make those decisions, and who wish to, and others who may require immense support and may in fact also require, or want, an organisation to take some control of that.¹⁸⁸

- 3.65** Some Inquiry participants acknowledged concerns about the risks involved in moving to individualised funding.¹⁸⁹ For example, Carers NSW acknowledged concerns and explained that it was working to develop individualised funding models which minimised probity risks:

It can be difficult and there is a lot of evidence from the United Kingdom around problems within those sorts of consumer-directed care packages in that way where they employ family members. The model we have and what we are working on works because we defer that risk to the employment agency. Yes, there is a small risk that comes off the package for the family, but we think it is worth it.¹⁹⁰

- 3.66** However, it was also noted that on a large scale, the implementation of individualised funding could be complex. Further, not all services can be provided in an individualised way. This potential for complexity was raised by Ms Margaret Bowen, Chief Executive Officer of The Disability Trust:

In the old days, funded services just opened their doors and said, "This is what you will receive". The management of those sorts of systems is not complex. Delivering flexible service systems is incredibly complex. Other issues include sustaining infrastructure around individual funding. It is all very well to say individualised funding, but people have to have the option of having the infrastructure there to access and sometimes that does not work very easily within an individual funding model.¹⁹¹

- 3.67** Carers NSW pointed to the *My Plan My Choice* pilot project, which is currently being trialled in the northern region.¹⁹² This project provides funds to an intermediary service which works with older carers to identify appropriate supports and manage funding. Ms Elena Katrakis of Carers NSW, expressed the view that it ... seems to be making a real difference to people's lives.¹⁹³

- 3.68** The Minister for Disability Services identified that phase one of Stronger Together provided greater funding flexibility in disability service provision. The Family Assistance Fund is an example that provides families with increased flexibility in accessing services and equipment:

... [F]amilies who are caring for children with a disability now have greater flexibility through programs such as the Family Assistance Fund because they are able to purchase services and equipment that are not available to other programs or other funding sources. Since June 2007 almost 5,000 families have accessed the fund. The

¹⁸⁸ Ms Hewitt, Evidence, 3 September 2010, p 47

¹⁸⁹ Ms Regan, Evidence, 9 August 2010, p 63; Ms Diana Qian, Executive Director, Multicultural Disability Advocacy Association, Evidence, 26 August 2010, p 50

¹⁹⁰ Ms Katrakis, Evidence, 9 August 2010, p 54

¹⁹¹ Ms Margaret Bowen, Chief Executive Officer, The Disability Trust, Evidence, 3 September 2010, p 54

¹⁹² Submission 31, p 132

¹⁹³ Ms Katrakis, Evidence, 9 August 2010, p 47

Extended Family Support Program provides up to \$50,000 in flexible funding to families who require significant levels of support to be able to continue to care for their child with a disability who is under 18 years of age. The Flexible Respite Program and individual accommodation support packages are other important examples of the new options that the Keneally Government is developing to provide more individualised support.¹⁹⁴

- 3.69** The NSW Government has committed to providing personalised funding as part of the second phase of Stronger Together. The Minister for Disability Services told Parliament that the NSW Government will "... as part of the next five-year phase of Stronger Together, deliver personalised funding arrangements for people with a disability as part of our person-centred approach."¹⁹⁵
- 3.70** The Minister has also stated that the Government is moving away from "... a one-size-fits-all service system, where people will take up places that may be available, to one in which people receive truly individualised, natural and creative support."¹⁹⁶

Committee comment

- 3.71** The Committee acknowledges that individualised funding packages offer people who are ageing, people with a disability and their carers the potential for greater flexibility and control of the services that support them.
- 3.72** The Committee recognises that there are a range of possible models of individualised funding that may enhance autonomy for consumers and recognise that self-directed funding may not be desirable or appropriate for all service users.
- 3.73** The Committee acknowledges the commitment from the Minister for Disability Services to deliver personalised funding options for people with disability and commends ADHC for its work in developing individualised approaches to funding to date. The Committee believes that further work to identify effective models is needed and that the result of this work should be made public.
- 3.74** The Committee believes that ADHC should work towards increasing the availability of individualised funding options across all service types. The Committee believes that the next phase of Stronger Together should include development of a comprehensive strategy to implement individualised funding models for people who are ageing, people with disability and their carers in NSW.

Recommendation 6

That the phase two of Stronger Together include development of a comprehensive strategy to make individualised funding models available for all people who receive services from ADHC, who wish to utilise them.

¹⁹⁴ NSWPD (*Legislative Council*), 26 October 2010, p 26

¹⁹⁵ NSWPD (*Legislative Council*), 1 September 2010, p 24953

¹⁹⁶ NSWPD (*Legislative Council*), 26 October 2010, p 26

Chapter 4 Planning for future service needs

This chapter examines issues regarding the planning of disability services for service users, carers and their families in the NSW. The move towards a person-centred planning approach is examined, including the ability to plan for services at key transition points and barriers that may prevent effective planning from taking place. This chapter also examines issues in planning and service provision that result from variation in processes used to share sensitive client information between Ageing, Disability and Home Care (ADHC) and NSW Health.

The issues identified and experienced by carers are wide ranging and are examined in all chapters, with reference to specific carer issues being provided in Chapter 10. Recommendations in response to planning issues are included in this chapter.

Service planning experiences

- 4.1 The disability service planning experience of ADHC, service users, carers, their family and funded organisations is examined in this section. Opportunities to improve the way that planning currently takes place are also identified.
- 4.2 Planning for an ageing population and carers is examined in Chapter 4 and Chapter 10 and the role of individualised funding in planning for disability services is examined in Chapter 3.

ADHC service planning

- 4.3 Many Inquiry participants expressed concern regarding the lack of planning that takes place when service users attempt to access disability services such as accommodation, case management and programs provided by non-government organisations.¹⁹⁷ Others, however, complimented ADHC on committing to a person-centred planning approach, which is believed to be a significant improvement in the provision of disability services in NSW.¹⁹⁸
- 4.4 ADHC has committed to adopting a person-centred approach for disability service planning, which is a policy approach that is supported by Inquiry participants. However, there are differing opinions regarding the level of person-centred planning that is currently implemented.
- 4.5 Mr Jim Moore, Chief Executive, ADHC, explained that the recently completed *NSW Disability Services Sector Directions for Industry Development* report puts people with disability at the centre of the service system, rather than the services being at the centre.¹⁹⁹ The report identifies a person-centred approach as one of the founding principles of the structure of the disability services system. The report includes the following principle:

Enhancing the voice, choice and control of people with disability: the structure of the disability services system will support contemporary evidence-based practice founded

¹⁹⁷ See for example, Submissions 5, 14, 15, 21, 25, 41, 58 and 98

¹⁹⁸ See for example, Submissions 55 and 70

¹⁹⁹ Submission 31, Mr Jim Moore, Chief Executive, ADHC, p 93

on person-centred approaches to facilitate greater choice, voice and control for people with disability in the context of an equitable service system.²⁰⁰

- 4.6** As part of the NSW Government's commitment to the first five years of Stronger Together, ADHC's submission acknowledged that "... services needed to be designed around the needs and circumstances of individuals and families, instead of a 'one size fits all' approach."²⁰¹
- 4.7** Mr Moore outlined some of ADHC's achievements resulting from the first five years of Stronger Together, including that "[m]ore flexible approaches to service planning have been implemented to ensure families receive the most appropriate supports at the right time."²⁰²
- 4.8** ADHC was praised by Northcott Disability Services, who stated that "ADHC's support for person-centred planning, and local ADHC initiatives to implement this [strength based and family focused] approach in practice, are a welcomed development in the move towards personalisation in disability services."²⁰³
- 4.9** Northcott Disability Services also expressed that ADHC's support for person-centred planning is a "... clear demonstration of ADHC's commitment to ... client focused services."²⁰⁴
- 4.10** The author of Submission 55 commends ADHC on the consistency of service delivery and planning, in comparison to a non-government sector that is perceived to be providing less satisfactory services.²⁰⁵
- 4.11** However, many service users and organisations did not support the view that ADHC undertakes adequate planning.²⁰⁶ For example, Ms Roz Armstrong, an Official Community Visitor in northern NSW, stated "[a]s a group of people, Official Community Visitors have yet to see any really good examples of person-centred planning in the sector. Certainly it is not apparent in ADHC."²⁰⁷
- 4.12** Ms Armstrong also believes that " individual planning goals are more about meeting service objectives rather than focusing on individual support needs. This occurs in both ADHC funded and ADHC provided services although it is more prevalent in ADHC Large Residential Centres."²⁰⁸

²⁰⁰ Department of Human Services and NDS, *NSW Disability Services Sector Directions for Industry Development Final report*, June 2010, p 10

²⁰¹ Submission 31, p 33

²⁰² Submission 31, p 40

²⁰³ Submission 70, Northcott Disability Services, p 2

²⁰⁴ Submission 70, p 10

²⁰⁵ Submission 55, Name suppressed, p 1

²⁰⁶ See for example, Submissions 4, 13, 14, 15, 39, 41, 94, 105 and 110

²⁰⁷ Ms Roz Armstrong, Official Community Visitor, Evidence, 27 September 2010, p 53

²⁰⁸ Submission 41, Ms Roz Armstrong, Official Community Visitor, p 4

Service users' experience

4.13 Many carers and direct service users expressed frustration at the inability to plan disability services such as personal care support, supported accommodation and for transition at key life stages.²⁰⁹

4.14 Ms Carolyn Mason, the mother and primary carer of Amy, believes that poor planning practices extend to ADHC funded organisations. She described that a funded organisation who was providing care to her daughter focused on "... expanding their business empire ..." at the expense of person-centred planning:

It should never be accepted practice to physically and/or chemically restrain as a substitute for professional care and treatment or to simply make the job easier for poorly trained, inexperienced or unprofessional staff or in the absence of quality care and service provision and person centred planning.²¹⁰

4.15 The author of Submission 12 also expressed concern about an ADHC funded organisation. This service user has received personal care services one day a week from an ADHC funded organisation for over three years, however, is unable to receive this help at his requested time of 8.00 am. Even with two days full notice he is only able to get help after 10.00 am, which affects his attendance at work and meetings.²¹¹

4.16 Ms Janice Marshall is the mother and carer to her son Daniel aged 22 years, who "... has autism, suffers from extreme anxiety, has bizarre behaviours, is very destructive and has an intellectual disability." Ms Marshall identified issues regarding a lack of planning for accommodation services. She described the stress caused by the gap in future accommodation planning, expressing that "[u]nless you have walked in the shoes of our families you cannot possibly know the anguish and stress under which we all live every day, where there is no hope and no planning for the future."²¹²

4.17 Ms Marshall explained that "ADHC has no future planning process or transition strategy to help relieve the pressure from families hanging on by their finger tips." Ms Marshall stated that:

Parents have to die, be seriously ill or abandon their loved one to even get into the system. This crisis driven scheme causes widespread mental and physical illness within the families and often leads to family breakdowns, which ends up costing the State and ADHC even more money than if they actually funded the accommodation in the first place.²¹³

4.18 This view was supported by Ms Estelle Shields:

It is only the people with a disability whose parents have died, whose support arrangements have totally broken down and who are homeless and destitute that are considered to be of sufficient priority to gain a supported accommodation placement

²⁰⁹ See for example, Submissions 10, 12, 13, 14 and 15

²¹⁰ Submission 14, Ms Carolyn Mason, p 23

²¹¹ Submission 12, Name suppressed, p 1

²¹² Ms Janice Marshall, Public Forum, 30 September 2010, p 21

²¹³ Ms Marshall, Public Forum, 30 September 2010, p 21

... There remains no way we can plan for the futures of our sons and daughters, no way we can see them gradually transitioned into a new residential setting, no way we can avert the tragedy and trauma that will befall them when they will lose, in one fell swoop, the primary carer, the only home ever known and the local community.²¹⁴

4.19 Ms Carol Berry, Executive Director of the NSW Council for Intellectual Disability, also identified that the disability service system is crisis-drive. She stated, at that the "... the system seems to be driven by crisis. It is crisis responsive and this immediately places everybody on the back foot."²¹⁵

4.20 Ms Bernadette Moloney, the mother and carer of Charley aged 17 years, expressed that Charley will soon require supported accommodation. She described her concerns for Charley's future:

... there does not seem to be any forward planning or any idea of seeing a need and trying to prevent a crisis. I have heard that most of ADHC's money is pooled in the Crisis Response Fund, which I think says a lot.²¹⁶

4.21 Further examination of issues regarding the delivery of supported accommodation services is provided in Chapter 6 and Chapter 10, from the perspective of service delivery and carers' experience.

Disability sector organisations' experience

4.22 Ms Berry reported that many members and callers to the Council report systemic complaints about ADHC, including "[a] lack of planning and management services (including case management)."²¹⁷

4.23 The NSW Association of Doctors in Developmental Disability (ADIDD) also identified issues regarding poor planning practices implemented by ADHC. Specifically, it was identified that accommodation is generally arranged in response to "... an emergency rather than as a planned process."²¹⁸

4.24 Poor planning resulting in emergency or crisis driven accommodation services was a key issue raised by many Inquiry participants and are examined further in Chapter 5.

4.25 In its submission, the ADIDD also expressed concern that that there is minimal planning for the future accommodation and respite needs of infants with complex medical problems.²¹⁹

4.26 Ms Armstrong identified that the Official Community Visitor Scheme made 2,301 visits to disability services over the year to 30 June 2009²²⁰ and stated that many of the issues raised related to planning:

²¹⁴ Submission 15, Ms Estelle Shields, p 2

²¹⁵ Ms Carol Berry, Executive Director, NSW Council for Intellectual Disability, Evidence, p 11

²¹⁶ Ms Bernadette Moloney, Public Forum, 30 September 2010, p 18

²¹⁷ Submission 39, NSW Council for Intellectual Disability, p 16

²¹⁸ Submission 94, ADIDD, p 17

²¹⁹ Submission 94, p 7

Out of these visits Official Community visitors identified 3,362 issues of which 55% were resolved. The majority of these issues were about individual planning, environment, facilities, nutrition and health ... there are visitable services out there that are not meeting the requirements under the Act."²²¹

4.27 Furthermore, Ms Armstrong noted that some service users do not get any individualised planning in long-term respite placements:

The much more difficult ones are like the young man who has been in a blocked respite bed for 2½ years and never had any individual planning. It is said, "He is in a respite centre; we don't do individual planning." This young man is a permanent resident of a respite centre until such time as we find him other accommodation, and therefore he should be delivered the same sort of service. There should be planning for this service."²²²

4.28 Ms Sarah Fogg, Policy Manager at the Benevolent Society, explained that planning for community care services is generally based around existing service types and configurations which prevent unmet need from being addressed in "... different and perhaps cheaper ways."²²³

What can be done to improve planning of disability services?

4.29 Ms Emily Caska, State Policy Coordinator, National Disability Services (NDS), suggested that the development of a comprehensive service planning framework could achieve more robust planning outcomes for people with disability. She stated that the framework should utilise the Industry Development Fund (IDF) and build upon the "... population-based planning framework which is already in place". The IDF is described in Chapter 2.

4.30 Ms Caska believes that a comprehensive service planning framework should have the following features:

- take a long-term view of 5 to 10 years
- integrate planning at a state-wide, regional, local and organisational level
- be underpinned by robust data, evidence and comprehensive analysis of data and evidence
- provide tools and support to strengthen planning at an organisational level."²²⁴

4.31 To improve the coordination of planning at a local level, Ms Caska also recommended "... joint oversight and governance of planning ... involving both government and NGO representatives."²²⁵

²²⁰ Submission 41, p 1

²²¹ Ms Armstrong, Evidence, 27 September 2010, p 48

²²² Ms Armstrong, Evidence, 27 September 2010, p 48

²²³ Submission 98, Benevolent Society, p 5

²²⁴ Submission 32, NDS, p 13

²²⁵ Submission 32, p 13

- 4.32** Ms Berry suggested that the provision of "... better information would help people with disability (including their families and carers) to access services that will best meet their needs."²²⁶ Mrs Diana Palmer from IDEAS NSW, also highlighted the importance of good access to information.²²⁷
- 4.33** Mr Graham Opie, Chief Executive Officer, Motor Neurone Disease Association of NSW recommended that timely and client focussed service delivery is required.²²⁸
- 4.34** In relation to improving disability service planning for Aboriginal people with disability, Mr Damian Griffis, Executive Officer of the Aboriginal Disability Network (ADN), explained that planning appropriately for Aboriginal people "... needs to involve a concerted outreach approach."²²⁹
- 4.35** In his submission, Mr Griffis explained what an outreach approach involves:
- The ADN often encounters situations where brochures are developed by various agencies and they may even have Aboriginal motifs on them to make them feel more culturally accessible, however the ADN argues strongly that they are rendered meaningless without a concerted outreach approach to support them. That is, resources and effort must be made on the part of agencies to go to the people instead of continuing to expect Aboriginal people with disabilities and their families to come to them. This is a simple but major barrier for many Aboriginal people with disabilities and their families.²³⁰
- 4.36** The effectiveness of Stronger Together to address issues such as future planning was questioned by Ms Marshall who stated, "Stronger Together One failed to address the issue of lack of future planning for supported accommodation and the total crisis and misery of families."²³¹
- 4.37** Mr Moore acknowledged that ADHC face difficulties in planning for the disability service system. He explained that discussion is currently underway "... about how we will be dealing with the second five years of the 10-year plan of Stronger Together. We built our modelling on the 2003 ABS data collection to do the initial five years of funding. We are having to build plans around the second five years on exactly the same 2003 data."²³²
- 4.38** In addition, Mr Moore explained that issues such as infrequent data collection, reactive research and a limited evidence base "... limit the ability to review past experience and to plan strategically for the future needs of people with disabilities."²³³
- 4.39** Further examination of issues regarding disability services data is provided in Chapter 9.

²²⁶ Submission 39, p 16

²²⁷ Submission 52, Mrs Diana Palmer, IDEAS NSW, p 5

²²⁸ Submission 54, Mr Graham Opie, Chief Executive Officer, Motor Neurone Disease Association of NSW, p 2

²²⁹ Mr Damian Griffis, Chief Executive, ADN, Evidence, 27 September 2010, p 39

²³⁰ Submission 97, Mr Damian Griffis, Chief Executive, ADN, p 4

²³¹ Ms Marshall, Public Forum, 30 September 2010, p 21

²³² Mr Moore, Evidence, 26 August 2010, p 4

²³³ Submission 31, p 61

Committee comment

- 4.40** The Committee notes the difficulties faced by many carers, families and service users when attempting to plan to use disability services. The impact that poor planning has had on many carers, families and services users and the stress that this continues to cause is unacceptable.
- 4.41** The Committee acknowledges the ongoing fear and frustration experienced by many carers who are not supported to plan for the future accommodation needs of their children. A service system that requires carers to reach breaking point before it provides appropriate services and support is not sustainable for the families or the system and may act to increase pressure on the system in future years.
- 4.42** The Committee notes that recommendations in Chapter 6 address the shortage of supported accommodation placements and recommend the provision of improved supports to people who register their need for an accommodation placement.
- 4.43** The Committee notes with concern that individualised planning is not required to occur for people who reside in long-term respite placements. This example suggests that the support and planning received by service users is linked to *service types* rather than *individual need*.
- 4.44** The Committee believes that this is not in accordance with the person-centred approach the Government has committed to and may result in some service users missing out on receiving appropriate planning and supports if they are not linked with the 'right' service type. The Committee recommends that *all* service users who are in, or are likely to remain in, long-term placements receive individualised planning.

Recommendation 7

That the Minister for Disability Services ensure that all service users who are in, or are likely to remain in, long-term placements have access to individualised planning.

That this is achieved through:

- conducting a review of service users who have been in, or are likely to remain in, placements long-term and have not received individualised planning
- completing individualised planning for these service users as a matter of priority
- ensuring that individualised planning is provided for all accommodation placements that are, or are likely to be, long-term.

- 4.45** The Committee agrees with Mr Griffis, that an outreach approach should be implemented by ADHC to ensure that disability services for Aboriginal people are planned in the most appropriate way and recommends the Minister develop and implements such a program. The Committee notes that further issues associated with the provision of appropriate services to Aboriginal people are examined in Chapter 5.

Recommendation 8

That the Minister for Disability Services develop and implement an outreach approach for the planning of disability services for Aboriginal and Torres Strait Islander communities.

- 4.46** The Committee believes that service planning needs to move away from a crisis response if it is going to meet the needs of carers, service users and their families. The Committee agrees with Ms Caska, who identified that a comprehensive service planning framework is required to achieve more robust planning outcomes, and recommends that the Minister develop such a framework.
-

Recommendation 9

That the Minister for Disability Services convene a Working Group made up of government Departments, NGO service providers, representatives of the Disability Council of NSW and other stakeholders, to develop and implement a comprehensive service planning framework, in consultation with disability service stakeholders, to identify how the disability service system will develop over the next five years.

That the framework:

- identifies how and when policy priorities, including person-centred planning, will be incorporated into service provision
 - integrates planning at a state, regional, local and organisational level and provides tools to strengthen planning at an organisational level
 - demonstrates how data and research will be used to inform development of the disability service system over time
 - is published on ADHC's website.
-

- 4.47** The Committee acknowledges the many challenges faced by ADHC in attempting to plan for the disability service system, including poor access to robust data and evidence. The Committee also acknowledges improvements in the disability service system that have been achieved by ADHC, including moving away from a one-size-fits-all approach towards a more person-centred planning approach.

- 4.48** The Committee agrees that although ADHC has committed to person-centred planning, there are few examples of where this has been implemented. Additional planning is required to outline how this approach will be rolled-out across all funding programs and service types. The Committee recommends that development and implementation of a person-centred approach for all funding programs takes place during phase two of Stronger Together.
-

Recommendation 10

That the Minister for Disability Services work in collaboration with the non-government sector and other relevant stakeholders to develop and implement a person-centred approach for *all* funding programs and service types during phase two of Stronger Together.

Planning for transition

4.49 Many Inquiry participants stated that they encountered challenges when trying to plan and access disability services during periods of transition in their lives, such as when leaving hospital or transitioning from high school.²³⁴

4.50 Northcott Disability Services explained that service users can experience variation in the services available, waiting list times and the quality of services provided as they move through different life-stages:

Many carers and families of a person with a disability find the transition from childhood into young adulthood, and the change in the system and level and type of services, as an anxious time and the process difficult to navigate. When people should be exiting services due to age limits, they often have no-where to go to receive the support they need - for example, some families still access children's respite services because the adult support available is insufficient to meet the family's needs.²³⁵

4.51 In addition, Northcott Disability Services identified that transition points are usually the times when things go wrong, with Ms Kerry Stubbs, Chief Executive Officer, stating, "I think a lot more thinking around specialist services at the right transition points would probably assist in some way before we get to the nirvana of a national disability insurance scheme, which is where we would all like to be."²³⁶

Increased flexibility around exiting services, better transition planning and increased capacity in the system would assist with this. Specialist services that support the transitions between 'life change' points (and systems) would also improve outcomes for people with a disability and help facilitate communication between services and systems.²³⁷

4.52 In his submission Mr Moore acknowledged that the disability service system needed to be "... more flexible and responsive to people's changing needs as they move through their life stages."²³⁸

Education

4.53 Mr Michael Coutts-Trotter, Director-General of the Department of Education and Training, acknowledged that "[t]he transition from school to adult life is a significant time for young people, including school leavers with a disability and their parents and carers."²³⁹ He stated:

Transition planning commences well before a student leaves school. To maximise the post school opportunities for students with a significant disability, including

²³⁴ See for example, Submissions 39, 67, 94, 100a and 105

²³⁵ Submission 70, p 8

²³⁶ Ms Kerry Stubbs, Chief Executive Officer, Northcott Disability Services, Evidence, 26 August 2010, p 57

²³⁷ Submission 70, p 8

²³⁸ Submission 31, p 33

²³⁹ Submission 64, Mr Michael Coutts-Trotter, Director-General, Department of Education and Training, p 8

intellectual disability, schools focus on planning for this period with students and their families as early as possible. The Department of Education and Training and ADHC have processes in place for transitioning students with a moderate to severe disability into specialist ADHC provided or funded Community Participation and Transition to Work programs that provide a sound basis for commencing transition planning early in high school.²⁴⁰

- 4.54** Mr Moore also recognised the importance of planning appropriately for transition points such as from school to post-school programs:

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.²⁴¹

- 4.55** In addition, Mr Moore identified that improvement in programs such as Transition to Work sit within the framework of Stronger Together:

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, 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.²⁴²

- 4.56** Ms Mason identified that transition planning for people with disability who are leaving high school does not take place for all students, and provided her daughter's experience as an example. She stated that there was a "... failure to put into place a transition plan for Amy when she left school and was entering tertiary programmes."²⁴³

- 4.57** Dr Robert Leitner, Chairperson of ADIDD, identified issues regarding planning for the transition of people into school. He stated that "[i]n many ADHC areas, there is a distinct lack of high quality transition services from early intervention to school age and then onto to adult services." Specific areas of concern about ADHC's Transition to School program include:

- There is a lack of flexibility in transition to school programs
- Transition should be seamless
- It needs clarity of purpose and is well done in some rural areas (such as Nowra)
- Families may not be aware of ADHC service that is being provided to the child at school
- ADHC feedback to other services is minimal

²⁴⁰ Submission 64, p 8

²⁴¹ Submission 31, p 76

²⁴² Submission 31, pp 22-23

²⁴³ Submission 14, p 9

- ADHC often close cases even if the child and family have ongoing needs
- There is a limited focus on working with the family in a holistic manner
- The provision of intervention is not co-ordinated between therapists
- Case management is not routinely offered or provided to families following transition.²⁴⁴

4.58 The NSW Ombudsman, Mr Bruce Barbour, stated that between June and August 2010 consultations were undertaken with families of children with disability regarding their experience of using the disability service system in NSW. Mr Barbour stated that parents "... communicated that they find choosing a school suited to their child's needs a daunting task, often undertaken without professional guidance."

4.59 Mr Barbour also stated that, when accessed, " people praised transition to school programs run by government agencies or by early childhood intervention services. However, many families were not aware of these programs, had not accessed them, or had been unable to gain a place for their child."²⁴⁵

4.60 Dr Leitner provided an example of an issue in the Transition to School program regarding the use of a funded organisation to provide the program:

In some areas, transition to school programs have been 'out sourced' to the Spastic Centre. The service provided may be the child's only ADHC-funded intervention. The Spastic Centre's core business is not intellectual disability, so therapists do not necessarily have expertise in this area. The Spastic Centre's premises may not be suitable for mobile children with developmental disabilities; for example, a child may access car park onto main road at the press of a button. There may be no toys to occupy an active child not confined to a wheelchair.²⁴⁶

4.61 Dr Leitner recommended that "[t]he intake process via ADHC for the Transition to School Therapy Program run by NGOs should be simplified. There is a need for better collaboration with Children's Diagnostic and Assessment Teams and ADHC intake processes for transition to school therapy programs."²⁴⁷

4.62 Mr Barbour explained that "[f]amilies also told us that transition of children with disabilities from primary to high school can be difficult, and is often complicated by delayed transition planning, and the length of time it can take to organise appropriate support."²⁴⁸

4.63 Ms Berry conveyed that many NSW Council for Intellectual Disability members are also concerned about transition into and out of school:

... the impact of the education system on children with a disability, in particular transitional issues into school and out of school that results in access to less services (for example, a significant drop in access to disability services provided by ADHC and

²⁴⁴ Submission 94, p 14

²⁴⁵ Submission 100a, Mr Bruce Barbour, NSW Ombudsman, p 6

²⁴⁶ Submission 94, p 14

²⁴⁷ Submission 94, p 14

²⁴⁸ Submission 100a, p 6

within the education system) in the time immediately after a person with disability leaves school.²⁴⁹

- 4.64** Ms Diana Qian, Executive Director, Multicultural Disability Advocacy Association, identified that transition from high school can also present difficulties for service users from non-English speaking backgrounds:

There are students from NESB (non-English speaking backgrounds) with disability going through the school system and when they finish school they fall off the face of the earth, they drop off. Because in post school programs from AHDC we often find a very low utilisation of post school programs, which means school leavers from NESB with disability are not being transitioned to either vocational training, employment support or community motivation.²⁵⁰

Committee comment

- 4.65** The Committee sympathises with the challenges faced by many service users and carers when transitioning into and out of the education system, including delays in transition planning, some families receiving no transition planning at all, difficulties navigating the system, receiving less disability support services when entering education and facing a complicated intake process.
- 4.66** The Committee notes that both ADHC and the Department of Education acknowledge the importance of good transition planning. The Committee further notes the success achieved in the Transition to Work program.
- 4.67** The Committee is concerned by the apparent discrepancy between the statement that 'transition planning commences well before students leave school' and service users' experiences of delay in transition planning or not receiving planning at all. The Committee agrees that it is important for transition planning to take place as early as possible for *all* people with disability leaving school.
- 4.68** The Committee acknowledges that the Transition to School program works well when accessed, but there are barriers to people accessing this service, including issues regarding intake and awareness of the program.
- 4.69** The Committee notes that there are fewer services available from ADHC when service users enter school. The Committee believes that people with disability need to be well supported to access education and that ADHC should ensure that adverse consequences do not result when service users transition to school.
- 4.70** The Committee notes with concern the low utilisation rates of post-school programs by people with disability from non-English speaking backgrounds. The Committee believes that improved transition support and planning should be provided to people with disability from non-English speaking backgrounds who are leaving school. The Committee notes that access to services for people with disability from non-English speaking backgrounds are also examined in Chapter 5.

²⁴⁹ Submission 39, p 9

²⁵⁰ Ms Diana Qian, Executive Director, Multicultural Disability Advocacy Association, Evidence, 26 August 2010, p 44

- 4.71** The Committee acknowledges the success achieved by ADHC and the Department of Education and Training in increasing the number of people with disability who are successfully transitioning to work.
- 4.72** The Committee acknowledges the importance of transitioning people with disability into and out of school, and recommends that transition planning policies are reviewed and amended to improve awareness about relevant programs and ensure that early transition planning takes place.
- 4.73** The Committee also recommends that improved support is provided for people from non-English speaking backgrounds, clear transition planning resources are available for service users, carers and their families and that people with disability receive appropriate support upon entering the education system.

Recommendation 11

That the Minister for Disability Services, in consultation with the Department of Education and Training, review and amend transition planning policies as part of phase two of Stronger Together.

That the review:

- is conducted in consultation with relevant stakeholders including services users, carers and their families
- increases awareness of the Transition to School program
- ensures that all people with disability leaving school are able to access transition planning as early as possible
- improves transition support and planning provided to people with disability from non-English speaking backgrounds who are leaving school
- provides clear resources for service users, carers and their families who are seeking information on how to access transition planning services
- ensures that people with disability receive appropriate support upon entering the education system and that access to education does not result in adverse consequences such as a reduction in necessary services or supports.

That the review and actions resulting from the review are published on ADHC's website.

From hospital to home

- 4.74** Many Inquiry participants identified concerns regarding the services, supports and planning that are available to service users when transitioning from hospital to home, such as after a spinal cord injury.²⁵¹

²⁵¹ See for example, see Submissions 67, 88 and 98

- 4.75** The author of Submission 88 questioned why there were no support services provided to her husband upon leaving hospital after an injury that rendered him quadriplegic:

I can't believe that once a patient is discharged from the spinal unit in hospital, that there is no further support offered. Since leaving hospital my husband has not had any physiotherapy, which I find astounding - and we can't afford to pay for it, and there are very few services offered to us up here in northern NSW. If there are services - how are we supposed to access them, find out about them etc?²⁵²

- 4.76** Mr Lomas described the experience of a lady who needed to be in hospital for six months due to a spinal cord injury, however, remained in a Sydney hospital for a total of two years due to poor transition planning and support. The "sheer stress of having to wait to be discharged from the hospital ..." resulted in a nervous breakdown. This "... put her into a particularly bad place and they were unable to discharge her because they were afraid that she would be at risk to herself."²⁵³

- 4.77** Mr Lomas told the Committee that the process and support available when this lady was meant to transition from hospital to her home would have been significantly improved if she was able to access the Lifetime Care and Support Scheme:

... that person would have been transitioned into temporary accommodation which would have been sourced through a case manager and the whole thing sorted out. They would have got by in that instance and they would have at least been out of the hospital setting.²⁵⁴

- 4.78** Ms Jackie Dufty also experienced issues associated with poor discharge planning when her husband, who is quadriplegic, was leaving hospital. She was informed that her husband would have to wait in an aged care facility after leaving hospital until ADHC allocated funds for his home modification.²⁵⁵

- 4.79** Ms Dufty stated that putting her husband into a long-term aged care facility "... would not constitute a proper mental wellbeing. It would actually regress the situation, since he has been out of hospital since 1 April 2009."²⁵⁶ Additional information on Ms Dufty and her husband's experience is provided in case study 13 in Chapter 10.

- 4.80** Spinal Cord Injuries Australia identified that it is often up to the initiative of hospital social workers to navigate the services available when people transition from hospital:

Our organisation deals primarily with people with a spinal cord injury and this means providing appropriate levels of support to individuals both in the hospital setting and the community. Where we are seeing gaps opening up in the provision of ADHC directly delivered services is in the transition between hospital and home. At present Hospital Social workers are tasked with navigating the bureaucracy of applications for services and then often, through their own, initiative cobbling together a package that

²⁵² Submission 88, Name suppressed, p 3

²⁵³ Mr Lomas, Evidence, 26 August 2010, p 27

²⁵⁴ Mr Lomas, Evidence, 26 August 2010, p 27

²⁵⁵ Ms Jackie Dufty, Public Forum, 30 September 2010, p 24

²⁵⁶ Ms Dufty, Public Forum, 30 September 2010, p 24

will at least and in some part, satisfy the needs of that individual being exited to the community.²⁵⁷

- 4.81** The Benevolent Society described how assumptions made during hospital discharge can result in a lack of support for people transitioning home:

A woman from Victoria flew to Sydney to be with her elderly father while he was in hospital. He was discharged from hospital without the personal care service he would require (short-term) during his recovery period in order to transition back to living independently at home. He was discharged without any community support being arranged as it was assumed that his daughter was his 'carer' and would take care of this need.²⁵⁸

- 4.82** In order to resolve issues regarding transition from hospital, the Benevolent Society believes that ADHC should take a 'lead role' in cross-agency coordination and discharge planning for people with disability:

ADHC should take a lead role in developing appropriate agreements and protocols with NSW Health to address long standing problems such as poor or inadequate discharge planning by hospitals, failure to organise short term post-acute care community assistance through NSW ComPacks and wrong assumptions made about caring relationships and responsibilities.²⁵⁹

- 4.83** Case study 1 illustrates the poor transition planning and post-hospital support that was provided to an older lady and her husband. The case study also highlights the impact that poor transition planning can have on carers and family.

Case study 1 – Name suppressed²⁶⁰

My 80 year old husband discharged from hospital after a fall November 2008. He was very confused and hospital said they would contact Commonwealth Carers for help. Two young girls visited us, but as it was close to Christmas they had no hours for me. ACAT [Aged Care Assessment Team] also phoned, no help there. I struggled as he was a big man, so confused and up and wandering around all night. I have no family to assist. Without the help of a neighbour, older than me, I did not know how I would shop.

He collapsed and died January 2008. Three months after he passed away, Commonwealth Carers phoned, as did ACAT. I also cancelled a doctor appointment, as they could not see him when alive. This was very upsetting for me. I wonder what use the big office Commonwealth Carers has, all the advertising they do, had a leaflet in the mail recently.

When a person needs help, there is none there. He collapsed and died here at home early January 2008.

- 4.84** Ms Adeline Hodgkinson, the Director and Chair of the NSW Agency for Clinical Innovation, Brain Injury Rehabilitation Directorate, stated that "[a]ccess to ADHC case management needs to be available as a continuation of discharge planning for adults, young people and

²⁵⁷ Submission 67, Spinal Cord Injuries Australia, p 5

²⁵⁸ Submission 98, p 10

²⁵⁹ Submission 98, p 10

²⁶⁰ Submission 4, Name suppressed, p 1

children with newly acquired brain injuries and needs to be more proactive to ensure transition of care from hospital to community."²⁶¹

- 4.85** The Committee was informed of two successful transition programs in NSW and Queensland. Professor James Middleton, Director and Chair State Spinal Cord Injury Service, identified a successful initiative in Queensland that provides recurrent funding for service providers to respond to the needs of people transitioning from hospital with spinal cord injuries:

In addition, a research report commissioned by Disability Services Queensland was released in June 2008, after evaluation by Griffith University of effectiveness of an initiative called the Spinal Cord Injuries Response (SCIR) which followed allocation in 2005/06 of \$1.5 million in recurrent funding to enable service providers to respond to the needs of people with SCI [spinal cord injury] transitioning from hospital to the community. SCIR demonstrated positive outcomes in three main areas, namely client outcomes, service delivery methods and inter-agency integration. Shorter lengths of hospital stay with safe and efficient transitions were achieved through establishing improved processes with clearly defined roles and lines of responsibility, standardised procedures, written protocols and effective communication strategies allowing better information-sharing, collaborative problem-solving and resolving conflicts between agencies. For clients discharged in the 2006/07 financial year a net saving of \$681,786 was estimated.²⁶²

- 4.86** The ADIDD identified the South East Sydney Illawarra Area Health Service (SESIAHS) Agency for Clinical Innovation (ACI) Transition Model as a successful model that supports adolescents with complex needs to transition between different services provided by different government departments:

The multidisciplinary health team based at Kogarah in conjunction with the ACI Transition Network ... supports adolescents with complex needs in their transitions between health, disability and educational services. Many clinics are provided in collaboration with ADHC and DET [Department of Education and Training] and are conducted off-site, often in special schools such as Cairnsfoot.²⁶³

- 4.87** The SESIAHS ACI Transition Model includes regular interagency meetings to "... support clients with complex needs and their families during transition." The ADIDD submission outlined the aims of the transition team to include:

- Improve access to quality health care for adolescents with developmental disabilities during the transition period from paediatric to adult services.
- Reduce preventable presentations to ED [Emergency Department] and decrease prolonged hospital admissions for non-medical reasons. The significant cost savings that result from these reductions can be then be used to assist funding of preventative programs.
- Develop and establish policies and protocols for (a) access to hospital, (b) specialist multidisciplinary health services and (c) for Disability Action Plans.
- Facilitate the development of networks between teams and individual clinicians from the paediatric and adult health facilities. Such networks will assist in

²⁶¹ Submission 101, NSW Agency for Clinical Innovation, Brain Injury Rehabilitation Directorate, p 4

²⁶² Submission 78, State Spinal Cord Injury Service, p 2

²⁶³ Submission 94, p 26

development of transition pathways for clients and families/ carers, in accordance with the 'Framework for Policy and Planning of Services for Children and Young People in NSW' (2008).

- Promote collocation / conjoint clinics between paediatric and adult services for young people in transition.
- Ensure interagency collaboration between ADHC, DET, Mental Health, Community Health, shared care with GPs, NGOs, Carers NSW, Police Department and Justice Health.
- Develop and establish ongoing programs for staff education and promote development of KPI's quality assurance projects and outcome based research activities.²⁶⁴

Committee comment

- 4.88** The Committee notes the concerns expressed by Inquiry participants regarding the lack of services, supports and planning available to service users when transitioning from hospital to home. The Committee believes that transitioning out of hospital is often a stressful time for service users and that it is essential that appropriate support is available.
- 4.89** The Committee acknowledges the importance of providing well-planned transitional support when people leave hospital. The Committee believes that people leaving hospital with inadequate support is an area of unmet need that is important to address. The Committee further notes that current responsibility to complete transition planning rests with hospital social workers which limits ADHC's ability to respond to particular needs of people with disability.
- 4.90** Assumptions made by hospital staff regarding the care that is available to people when they leave hospital can result in no support being provided. The Committee believes that a system should be developed that ensures *all* people with disability have access to relevant support upon leaving from hospital.
- 4.91** The Committee notes the recommendation that ADHC case management should be available as part of discharge planning and that ADHC needs to be more proactive in ensuring transitional care is provided. The Committee agrees that improved allocation of responsibility needs to be identified to ensure that all people with disability have appropriate support upon transition from hospital.
- 4.92** The Committee believes that a coordinated approach to transition planning is required across relevant Government agencies. The innovative model implemented in the SESIAHS in conjunction with the ACI is a good example. The Committee supports the expansion of this Transition Model to be applied in other Area Health Services, as a means to improve transition planning for people with disability who access multiple government services.

²⁶⁴ Submission 94, p 26

Recommendation 12

That the NSW Government review and amend transition policy and processes for people with disability who transition from hospital to home.

That the outcome of the review ensures that people have appropriate, accessible and well-coordinated support available prior to transitioning out of hospital and during the period of readjustment to their home. The review should consider existing successful programs and models, such as the South East Sydney Illawarra Area Health Service Agency for Clinical Innovation Transition Model.

Recommendation 13

That the NSW Government review and clarify current staff responsibilities in transition planning, including reviewing whether hospital social workers are the most appropriate role to conduct this planning and whether there is a greater coordinating role for ADHC caseworkers.

That the review identifies clear staff roles responsible for providing support to service users while they complete transition planning in hospital and as they re-settle in their home. That the outcomes of the review are communicated to all relevant staff.

That the review identifies safeguards to prevent people with disability from being discharged from hospital with inadequate support.

Recommendation 14

That the Minister for Disability Services provide ADHC case management to all ADHC service users who are being discharged from hospital.

Recommendation 15

That the NSW Government consider the Spinal Cord Injuries Response initiative for relevance to the NSW disability service sector.

Into accommodation placements

- 4.93** Transition planning for service users moving into and between accommodation placements was identified as an issue by some Inquiry participants.²⁶⁵ This includes issues regarding the creation of a transition plan, following appropriate policy when new residents transition into an established group home and the conduct of ADHC staff when transitioning service users.

²⁶⁵ See for example, see Submissions 14, 47, 49 and 50

- 4.94** ADHC's Allocation of Places in Supported Accommodation policy was identified by the author of Submission 47. The policy states:

A transition plan will be developed for each person who accepts an offer of supported accommodation to facilitate a move that meets the persons' needs. At the beginning of the transition, residents residing in the accommodation service and their families and carer will be informed that a new person will be moving into the service. During the transition there will be opportunities for all residents and families to meet each other.²⁶⁶

- 4.95** The author of Submission 47 believes that this policy was not followed during the transition of a new client into the group home that his brother resided in, as the placement resulted in "... violations of personal space, protested physical contacted, bedroom and bathroom entries while in use." He also stated that ADHC staff bullied the funded organisation's staff during the transition period:

The transition period was continued even though this contravened ADHC's own documented standard for service entry which states: page 1.1.2 "An agency has a procedure to involve existing residents of a group home in deciding overall compatibility and in selecting new residents". In this case the service provider, and the current three residents all objected to the placement, but ADHC proceeded with the placement. It is, at best, poor practice to insist that a provider accepts a new resident whom they clearly believe is unsuitable in this particular household.²⁶⁷

- 4.96** Issues raised by Inquiry participants regarding ADHC staff are examined in Chapter 11.

- 4.97** The author of Submission 14 explained that inappropriate transition planning took place when a new resident entered the group home that her daughter Amy lived in, stating "[t]he house was too small to accommodate all residents and ... no transition plan had been developed for the new resident." She also stated:

Amy stayed back home with her mother for five months while a slow gradual transition could take place. As per planning meeting, recommendations of [name suppressed] and Amy's teachers. Whilst Amy was at home with her mother, DADHC moved another resident into the house overnight without any transition or compatibility assessment and without any consultation or involvement with Amy or her parents, as recommended by [name suppressed] and Amy's teachers.²⁶⁸

- 4.98** Ms Moloney expressed fear at the prospect of transitioning her 17 year old child from Kingsdene special school into the ADHC service system once he turns 18 years of age, as she has "... not seen any progress or forward planning, or proactive or preventive planning. That terrifies the living daylights out of me because when Charley turns 18 we will be left with no service option other than the ADHC services."²⁶⁹

- 4.99** Ms Armstrong told the Committee that people with disability commonly move between accommodation services, in both ADHC funded and provided services:

²⁶⁶ Submission 47, Name suppressed, p 2

²⁶⁷ Submission 47, p 2

²⁶⁸ Submission 14, pp 10 and 12

²⁶⁹ Ms Moloney, Public Forum, Evidence, p 18

The view of Official Community Visitors is that this activity is mostly focused on the needs of the service provider rather than the person with a disability. People with a disability are often moved across or within services to meet funding and resource needs and the policies and procedures that guide this process are either non-existent, vague and/or poorly implemented.²⁷⁰

- 4.100** The author of Submission 50 suggested that the compatibility of residential care needs to be closely monitored and managed:

Judgements need to be responsibly and professionally conducted to ensure suitable placement of residents and staff to ensure the care is consistent with special needs of all parties concerned. Collaborative work with other relevant agencies and departments needs to be developed and enhanced to ensure that people with disabilities, special and additional needs are being met as full members of the community and society.²⁷¹

- 4.101** Case study 2 provides an example of ADHC's transition policy not being followed when a new resident was being moved into an established group home. It illustrates the impact this has on existing residents and their families, and the significant disruption and stress that poor planning causes.

Case study 2 – Ms Valerie Noone²⁷²

I would like to give you a brief overview of my dealings with the Department of Ageing, Disability and Home Care. These have been in regard to my younger sister, a 51 year-old Down syndrome lady. She has been in the care of the current service provider for nine years and we have always been very happy with the service she has received from them. The service provider is funded by ADHC. The death of one of the female household members created a vacancy in the home. The remaining household members included my sister and two males in their 40s and 50s, both of whom have Down syndrome and are quiet and gentle.

ADHC has some wonderful policies and guidelines regarding the placement of a new resident into a group, which would include the involvement of the existing residents in the choice of the replacement as the resident has the right to feel safe and have their privacy and dignity respected. My sister requested a female resident. ADHC decided to ignore all its policies and practices and act upon a

provision that allowed it to direct the placement as it sees fit. What it saw fit was the placement of a 28-year-old fully autistic male, who is nearly half the age of the other household members and with an extremely different disability.

A long transitioning process of a directed placement began. It was late in this process that my family and I became involved with ADHC. Over the transitioning period of the new resident into the home, our sister, who was quite small, became fearful of the new resident and some of his obsessive behaviours ... By this time we were becoming quite alarmed for our sister's safety. We requested ADHC to reconsider its choice of resident as we thought it was unsuitable. The other residents objected to him

²⁷⁰ Submission 41, p 6

²⁷¹ Submission 50, Name suppressed, p 2

²⁷² Ms Valerie Noone, Public Forum, 30 September 2010, p 13

and the service provider also raised a number of concerns, all of which were ignored. So, insisting that the placement go ahead, the needs of the other three residents were completely disregarded.

Last December the transitioning of the new resident was completed and he moved in permanently. After this, over a period of months, the unacceptable incidents between my sister and the new resident escalated ... At this point, even ADHC agreed that it could no longer guarantee my sister's safety.

Committee comment

- 4.102** The Committee sympathises with the frustration experienced by many Inquiry participants in relation to inappropriate transition planning and the transition of inappropriate service users into group homes. The stress placed on families as a result of inappropriate transition planning has resulted in the displacement of service users in well established accommodation options and represents an area of the service system that requires improvement.
- 4.103** The Committee notes with concern that some funded services may not prioritise person-centred planning for service users. While transition policies have been developed by ADHC, the Committee was told that it appeared that some staff are unaware of the policies or do not understand them.
- 4.104** The Committee acknowledges that many of the concerns regarding accommodation transition were often not adequately handled by ADHC or funded organisations. The Committee recommends that current policy regarding transition planning in accommodation services is understood and implemented by *all* relevant staff
- 4.105** Recommendations regarding the handling of complaints and grievances are provided in Chapter 9.

Recommendation 16

That the Minister for Disability services ensure that current policy regarding transition planning in accommodation services is understood and implemented by all relevant staff, to ensure that a person-centred approach is implemented, for both the person who is transitioning into accommodation options and existing residents.

Cross-agency service planning

- 4.106** The ADIDD identified barriers in the sharing of service user information between government agencies for service users who access services and supports from more than one government agency. It was stated that this reduces the ability for all agencies to plan appropriately and impacts on the quality of care provided.

- 4.107** Professor Julian Trollor, ADIDD, identified that disability service records for individuals are inaccessible. He stated:

If you come in to our A & E [Accident and Emergency] service here, you might have a community mental health file, you might have a hospital mental health file, you might have an A & E file, a hospital medical record and then you have disability sector which is entirely inaccessible. So the information cannot be integrated in any meaningful way. I think it really is an artificial separation.²⁷³

- 4.108** Professor Trollor explained that inaccessible information reduces the ability for professionals such as hospital staff to provide 'whole of care' services to people and reduces the quality of care that is provided:

If you are looking at the whole of care for somebody, social services need to talk to health, the speech therapist needs to talk to the physician, the accommodations manager needs to be able to talk to the general practitioner. So you need all of these parts of the puzzle essentially in one room, or at least with one frame of reference and the ability to refer to the same set of documents. We simply do not have that. It is an artificial separation which certainly in our view diminishes the quality of care, in particular mental health, but I think the whole of health.²⁷⁴

- 4.109** Dr Helen Somerville, also from the ADIDD, stated "[t]here is a lot of confusion about the term confidentiality and sharing records." Dr Somerville identified that sometimes very serious meetings take place, that the ADIDD contribute to through making health recommendations, and that these meetings can result in recommendations such as guardianship changes. Dr Somerville is concerned that her organisation is unable to get any record of what has happened and the reasons for this relate to confusion of what confidentiality means in this context.²⁷⁵

- 4.110** In regard to confidentiality, Dr Richard Matthews, Deputy Director General, Strategic Development, NSW Health, explained that "... confidentiality and the exchange of this information is not an issue, if you have consented" and that "... it is a matter of putting instructions out about it."²⁷⁶

- 4.111** Dr Matthews also identified an example of where a good system has been put in place that allows for the sharing of confidential information:

What we have managed to achieve in another area around Keep Them Safe for kids who are at risk is a really outstanding example of how agencies can get together and put in place an information system that enables, in that case, approximately seven or eight agencies to appropriately share information. It can be an issue, but in this particular case where you really do have a patient or person for whom you are trying to put together some structures to assist them, as I say if you cannot get consent from

²⁷³ A/Prof Julian Trollor, Member, ADIDD, Evidence, 27 September 2010, p 3

²⁷⁴ A/Prof Trollor, Evidence, 27 September 2010, p 3

²⁷⁵ Dr Helen Somerville, Member, ADIDD, Evidence, 27 September 2010, p 4

²⁷⁶ Dr Richard Matthews, Deputy Director General, Strategic Development, NSW Health, Evidence, 27 September 2010, p 31

the patient, the parent or guardian, then there is something wrong with you as a practitioner, in my view.²⁷⁷

4.112 Professor Trollor explained there are pockets where collaboration takes place between ADHC and NSW Health and information is shared well. He also identified that these pockets work "... very well by nature of the personalities involved, but for the vast majority it does not work."²⁷⁸

4.113 Dr Somerville noted that "... where the sharing works, it works beautifully. In rural areas ... it is fantastic because you all have to get on because you all live in the same town so sharing between Health and ADHC is often much better in smaller communities."²⁷⁹

4.114 Dr Somerville stated that she experiences "great collaboration" with ADHC because she has a nurse that is funded, albeit insecurely, by ADHC:

It has taken us a long time to build that up. The fact that you have two departments sharing patients means that you share information. I do not know where it has come from but over the years we have tried to make them understand what confidentiality means and that the sharing of information is what is best for patient-client care, and there is a very difficult understanding of that.²⁸⁰

4.115 Professor Trollor told the Committee that a Memorandum of Understanding (MOU) has been developed between Mental Health and ADHC, which may provide "... a philosophical agreement to work together in a certain way and framework."²⁸¹ However, Professor Trollor does not believe that the MOU will be very effective:

... unless you have a fundamental change in the system whereby there is designated funding that is handed down and administered by people who are not bound by the Ageing, Disability and Home Care-Health - the us and them - boundary, it will not get very far.²⁸²

4.116 Dr Matthews advised the Committee that the MOU has almost been completed, however, has not been finalised by the Directors General.²⁸³

4.117 Mr Moore identified that ADHC is working with NSW Health around how the health system can cater better for the special needs of people with disability. Mr Moore noted, "[w]e have been providing some resources in Stronger Together to try to get within the medical processes a better sensitivity to disability issues, but it is difficult."²⁸⁴

²⁷⁷ Dr Matthews, Evidence, 27 September 2010, p 31

²⁷⁸ A/Prof Trollor, Evidence, 27 August 2010, p 4

²⁷⁹ Dr Somerville, Evidence, 27 September 2010, p 4

²⁸⁰ Dr Somerville, Evidence, 27 September 2010, p 4

²⁸¹ A/Prof Trollor, Evidence, 27 August 2010, p 4

²⁸² A/Prof Trollor, Evidence, 27 August 2010, p 4

²⁸³ Dr Matthews, Evidence, 27 September 2010, p 27

²⁸⁴ Mr Moore, Evidence, 27 September 2010, p 11

- 4.118** Mr Moore stated that the "[t]he number of times people with a disability and their families have to go through health systems to satisfy us that we have got the right health care plans in place is excessive." He identified:

The number of times that GPs need to provide us a statement that a person with a disability has a disability in order to complete the right forms for going to various respite providers is absurd. That is something that we need to tackle. We have tried to streamline some things but it is quite clear that we have not gone near far enough. There must be ways in which we can have a much less repetitive requirement placed on people as to how they engage with the health system.

- 4.119** Ms Lauren Murray, Deputy Director General, ADHC, described some of the work that is taking place between ADHC and NSW Health to improve medical health outcomes for people with intellectual disability:

In terms of what we are doing with NSW Health, NSW Health has just put together a framework for looking at improving medical health outcomes for people with intellectual disability. There has been a significant injection of funds to look at a pilot around clinical nurse specialists in terms of looking at triage and building relationships across the health sector. They are the types of services being piloted. In a sense, we do not know a great deal about what are the particular types of things that would assist people with intellectual disability to get better health outcomes. This is a way of trying to assess that.²⁸⁵

- 4.120** Ms Cathrine Lynch, Director, Primary Health and Community Partnerships, NSW Health also reflected on some of the work that is taking place between ADHC and NSW Health to improve outcomes for people with intellectual disability:

We are working on a lot of things with Ageing, Disability and Home Care, but another one is the hospitalisation of people with an intellectual disability as well. We ensure that when those people come to hospital their communication needs, or the way in which they are looked after, are accounted for in hospital. In addition, we are working with ADHC to have carers present—whether it be a carer from ADHC or a member of a person's own family—to support him or her in the hospital environment and to work with and communicate with staff about supporting that person at the same level—or probably a little less to tell you the truth because hospital staff are there all the time. But if people need some support in the home to do everyday activities they might need that support also in hospital. For instance, some people need help with feeding themselves and that kind of thing.²⁸⁶

Committee comment

- 4.121** The Committee recognises the importance of effective collaboration between agencies such as the NSW Health and ADHC in providing quality support to people who access services from more than one agency. The Committee acknowledges the positive contribution that good collaboration and information sharing make in improving service planning and the quality of care that is provided to service users who access services from multiple agencies.

²⁸⁵ Ms Lauren Murray, Deputy Director General, ADHC, Evidence, 27 September 2010, p 12

²⁸⁶ Ms Cathrine, Lynch, Director, Primary Health and Community Partnerships, NSW Health, Evidence, 27 September 2010, p 28

- 4.122** The Committee believes that good collaboration between government agencies should not depend on the nature of the personalities involved. The Committee believes that there should be systems in place to ensure consistent and quality collaboration between ADHC and NSW Health across all of NSW.
- 4.123** The Committee notes the lack of consistency in sharing information between ADHC and the NSW Health and that there are different understandings regarding the meaning and application of confidentiality requirements. The Committee further notes that a conflicting understanding of the application of confidentiality requirements for client information may result in decreased quality of service provision.
- 4.124** The Committee believes that work is required to be undertaken by both of these agencies to clarify what confidentiality means in the context of health and disability service provision. The Committee further believes that a consistent understanding and implementation of confidentiality requirements could improve the quality of care provided to people with disability.
- 4.125** The Committee recognises the achievements in Keep Them Safe regarding the sharing of confidential information between agencies for children who are at risk. The Committee believes that lessons from this should be applied to the sharing of sensitive client information between ADHC and NSW Health.
- 4.126** The Committee acknowledges the work that is being completed by ADHC and NSW Health to improve the health outcomes of people with disability, including the Mental Health and ADHC MOU. The Committee further notes that no evidence was received from ADHC regarding the sharing of sensitive client information with NSW Health.
- 4.127** The Committee notes that people with disability face unnecessary challenges when navigating between the disability and health system, including being required to obtain multiple statements from their GP in order to complete ADHC forms to access services. The Committee recognises that ADHC has attempted to streamline this process and is aware that further work is required to improve the process.
- 4.128** The Committee recommends that the process by which ADHC and NSW Health share sensitive information about service users who access both agencies is reviewed to improve the quality of care that is provided.
- 4.129** The Committee believes that the requirement for people with long-term disability to obtain multiple statements from General Practitioners to confirm their disability when accessing ADHC services is unnecessary and creates an obstacle for people to access services. The Committee recommends that this requirement be amended to allow the General Practitioners statement to be valid for varying time periods that are relevant to the disability and needs of the individual.

Recommendation 17

That the NSW Government review and amend the process by which ADHC and NSW Health share sensitive information about service users who access both agencies.

That the review:

- develops and applies a common understanding of the meaning of 'confidential information' in the context of health and disability service user information sharing
- identifies how confidential information can be shared between agencies to improve the quality of services provided, including considering issues of consent
- learns from the successful models of information sharing between ADHC and NSW Health that exist in some regions
- learns from the achievements of information sharing in Keep Them Safe and applies them as appropriate.

That the report resulting from the review and ADHC response to recommendations are published on the website.

Recommendation 18

That the NSW Government amend the requirement for people with disability to obtain multiple statements from General Practitioners to confirm their disability when accessing ADHC services, to allow the General Practitioners statement to be valid for varying periods of time that are relevant to the disability and needs of the individual.

Chapter 5 Service availability

The previous chapter examined issues regarding the planning of disability services, considering the role of person-centred planning and barriers to effective planning. This chapter examines the delivery of services, focusing on the availability of different service types across NSW and access to these services. Issues regarding intake and assessment, vacancy management processes and service eligibility are examined, as is the role of waiting lists in the provision of disability services. This chapter also examines access to and availability of culturally appropriate services to people with disability. Chapter 6 examines the level of unmet need in specific service types and provides additional examination of issues regarding availability and access to these service types.

Accessing services

5.1 Access to services is a key issue in people with disabilities relationship with ADHC. It was raised repeatedly throughout the Inquiry and has been addressed in many chapters in the Committee's report. This section examines issues regarding availability and access to disability services by service users, carers and their families.

5.2 Ms Amelia Starr, Senior Policy Officer, Disability Council of NSW, summarised issues that are faced by some service users when attempting to access disability services:

I sat in on most of the consultations [for Stronger Together Two] that were recently held. It is still very alarming and very hard to hear parents saying, "I have an extraordinary son or daughter with a disability. I know I am a good parent but I am extraordinarily exhausted with the system." Whether it is getting into the system, whether it is servicing the system, whether it is getting the right services, whether it is about being able to navigate linking to another system, there still seems to be a level of overlay that parents and people caring for people with disabilities find just too hard to get through.²⁸⁷

5.3 Dr Robert Leitner, Chairperson of the NSW Association of Doctors in Developmental Disability (ADIDD), stated that the current system has a lack of focus on the needs of service users' families and there is a perception that the system has barriers that limit access to services.²⁸⁸

5.4 Mr Greg Killeen, a service user and Policy and Advocacy Officer of Spinal Cord Injuries Australia, also identified barriers to accessing disability services. Mr Killeen stated that there is inequality in the current financial means testing of people with disability which exclude assessment of expenses:

As many government services are means tested against income and assets, the application forms always seek details of applicant's income but never seek information about the applicant's expenses. The majority of people with disability have extra unavoidable costs associated with having a disability that the general society does not have including higher costs including: wheelchair accessible taxis (even with applying the NSW Government's Taxi Transport Subsidy Scheme it is still relatively expensive

²⁸⁷ Ms Amelia Starr, Senior Policy Officer, Disability Council of NSW, Evidence, 9 August 2010, p 29

²⁸⁸ Submission 94, ADIDD, p 17

for people with disability to travel when the wheelchair accessible taxis are there only accessible transport option) extra water as it takes longer to have a shower, extra gas and electricity due to people with neurological conditions such as multiple sclerosis and spinal cord injury not been able to regulate body temperature and having heating and cooling appliances running for longer periods of the day for longer periods of the year equipment, aids and appliances as well as assistive technology personal care support services and respite.²⁸⁹

5.5 Mr Killeen recommended that this "... inequality of eligibility criteria and unregulated copayment or fee-for-service for all government provided or funded services" needs to be addressed by the NSW Government "... to understand the financial impact on people with disability that require multiple services and programs."²⁹⁰

5.6 Ms Diana Qian, Executive Director, Multicultural Disability Advocacy Association, identified barriers faced by people with disability from non-English speaking backgrounds when attempting to access services:

... it is a maze - it is not easy to navigate - and if English is not their first language you can imagine the frustration. We hear a lot of real experiences of people trying to make contact. Unfortunately a lot of people after the first phone call if they do not get through they give up. We identified a trend where the service users from NESB with disability tend to be in the high-end age group and they tend to be in crisis.²⁹¹

5.7 The provision of culturally appropriate services is examined in detail from section 5.123.

5.8 Ms Elena Katrakis, Chief Executive Officer, Carers NSW, conveyed that "[c]arers complain that it is they who must meet the requirements of the service and not the other way around. Carers who cannot fit around rigid program guidelines do not receive the services they need."²⁹²

5.9 Mr Killeen identified issues associated with people accessing multiple services, including inconsistency in administration, eligibility and funding:

Often people with disability require multiple disability and/or community support services and programs to remain living at home in the community. The different government and non-government disability and/or community services and programs often have separate administration, eligibility, funding etc, that can have a negative impact on service users that require multiple services or programs and whereby the same services and programs are co-dependent where one cannot (or will not) be delivered without the other. Or there is a threat by one service provider to withdraw the service unless the other essential service is provided. e.g. NSW Home Care (ADHC) providing personal care support to a client, and the client's condition deteriorates and needs a lifting hoist and sling, but there is a waiting list for the client to be provided with the equipment by EnableNSW (NSW Department of Health (NSW Health)).²⁹³

²⁸⁹ Submission 42a, Mr Greg Killeen, p 3

²⁹⁰ Submission 42a, p 3

²⁹¹ Ms Diana Qian, Executive Director, Multicultural Disability Advocacy Association, Evidence, 26 August 2010, p 44

²⁹² Submission 33, Carers NSW, p 5

²⁹³ Submission 42a, p 3

- 5.10 Mr Killeen recommended that a whole of government approach is required to be implemented by the NSW Government, including developing a 'one-stop-shop' to "... minimise and simplify the administration and related operational cost of providing services and programs for people with disability."²⁹⁴

Committee comment

- 5.11 The Committee recognises the barriers identified by Inquiry participants regarding access to disability services, including financial assessment, eligibility and administration. The Committee notes that issues such as eligibility are examined in more detail from paragraph 5.15.
- 5.12 The Committee sympathises with the challenges faced by people who access multiple government provided or funded services, which results from the separate application, eligibility and administration processes. The Committee notes that some services are only able to be accessed when other essential services are provided, which are not within the control of the client.
- 5.13 The Committee acknowledges that current means testing does not include assessment of the expenses incurred by people with disability who access multiple services, and agrees with Mr Killeen, that the inclusion of assessment of expenses in means tests would provide a more comprehensive picture of people with disability's financial position and ensure that these people are not further disadvantaged by this process. The Committee recommends that ADHC's means testing policy be reviewed for people with disability, to include assessment of expenses. This will provide a more complete picture of their financial position.
- 5.14 The Committee also notes the challenges that people with disability from non-English speaking backgrounds face in accessing services, and that access to services by people from non-English speaking backgrounds is examined in more detail later in this chapter.

Recommendation 19

That the NSW Government review and amend means testing policy for people with disability attempting to access services, to include assessment of expenses, so that people with disability are not disadvantaged through being required to provide an incomplete picture of their financial position.

That the amended policy is communicated to ADHC staff, funded organisations and disability service users.

Recommendation 20

That the Minister for Disability Services introduce standardised income/means testing forms across all ADHC provided and funded programs and ensures forms are available in multiple languages and formats.

²⁹⁴ Submission 42a, p 3

Intake and assessment

5.15 Many Inquiry participants identified barriers to accessing disability services resulting from the intake and assessment processes that take place before a service can be received.²⁹⁵ Concern was expressed regarding a lack of information, unspecific intake rules, poor referral administration processes and inconsistent processes across regions.

5.16 Ms Carol Berry, Executive Director of the NSW Council for Intellectual Disability, described that intake and assessment processes determine eligibility and the services required within the available budget:

Prior to people with disability receiving services, an intake and assessment process together with case management services are used to determine the eligibility of individuals for specific formal services and to identify the appropriate mix of services required to meet the needs of a person with disability. These two mechanisms are also used to balance the needs of people with disability within budgetary limitations.²⁹⁶

5.17 Ms Berry also conveyed a 'key systemic complaint' that is communicated by members of the Council regarding intake and assessment processes, namely that they do not know the amount of funding that is available to them:

A lack of a client focussed approach, for example, the current intake and assessment process does not allow for people with disability to know the funding level that is set aside for them individually, or to be communicated in a way that they can easily understand (such as service hours, where appropriate). Many clients of ADHC have reported that they find working with the Department extremely frustrating, there appear to be some systemic issues within the organisation that need to be addressed as a matter of urgency, particularly in regard to internal communication, and communication with the client base.²⁹⁷

5.18 Ms Jenny Barron from the Attendant Care Industry Association of NSW Inc, identified that there is "... currently no consistent or integrated National approach or method of assessing the need for community based care and support."²⁹⁸

5.19 Dr Helen Somerville, a member of the ADIDD, also expressed concern about intake processes for disability services, telling the Committee that poorly communicated intake rules make it difficult for doctors, families and service users to find out how to access services:

How can we advocate, compliment or complain when we do not even know what the rules are? We do not know what the intake rules are. We do not know how the decisions are made about getting a service ... If we do not know what the rules are - there is no written information and it appears to us that that is deliberate - and if we do not have information how can a family or a person find out and ask questions? They do not even have a tracking system for when the referrals come in.²⁹⁹

²⁹⁵ See for example, Submissions 32, 39, 62 and 94

²⁹⁶ Submission 39, Ms Carol Berry, Executive Director, NSW Council fo Intellectual Disability, p 8

²⁹⁷ Submission 39, p 16

²⁹⁸ Submission 46, Ms Jenny Barron, Attendant Care Industry Association of NSW Inc, p 4

²⁹⁹ Dr Helen Somerville, ADIDD, Evidence, 27 September 2010, p 2

- 5.20** Dr Vivian Bayl, also from the ADIDD believes that a big (negative) change to the intake process has been a move away from clinician-based intake. He stated that previously, extensive assessments were completed for service users which were used by ADHC to determine the level of need and services required.³⁰⁰
- 5.21** Dr Bayl outlined changes to the intake process that have resulted in delays for people accessing services. Delays have been caused by the requirement for a needs assessment to be completed before any service type can be accessed, in addition to when an assessment has been completed by another professional:
- Now every person, no matter what they want to access, whether it is case management, behaviour management, respite, therapy services, all have to go through a needs assessment. We just feel it is a huge waste of resources ... No matter what service is being requested by the parent, the carer or another professional with parents' permission, whether it is respite, behaviour management, other accommodation issues, therapy services, all those things require, first of all, for a needs assessment to be done. So that the intake, a clerical person takes a call, they record the call in some way - we have problems even making sure that when a call has been made they actually match it up with a detailed eight-page report we send for our multidisciplinary assessment. They then wait three months to have a needs assessment. For the needs assessment someone goes out to the home, spends an hour in someone's living room, as parents tell us, and then they wait another 12 months before they get a service. This is for a three-year-old who desperately needs a service.³⁰¹
- 5.22** The submission from the ADIDD recommended that an ADHC needs assessment should not be required "... when the referring agent such a Diagnosis and Assessment Team has provided a comprehensive multidisciplinary assessment and report of both child and families needs,"³⁰² referring to needs assessments as a waste of resources and time:
- Needs assessments are often reported by families as a waste of resources and of clinicians' time. They can add confusion at times as families assume that the needs they have reported will be acknowledged and met. Often, the needs assessment leads to a lengthy wait on a list which renders the data collected out of date. Needs assessments should be briefer and completed upon initial intake or re-referral.³⁰³
- 5.23** The Committee invited Mr Moore to respond to the issue of multiple needs assessments being required by ADHC. He advised that the assessment completed by ADHC relates "... much more about a person and their life rather than health-related issues ... the focus of what we are trying to do is on a person's whole of life and getting them a good life."³⁰⁴
- 5.24** Mrs Jo-Anne Hewitt, Chairperson of the Futures Alliance, identified that barriers to the receipt of services can also result from the complexity associated with assessing "... the ageing

³⁰⁰ Dr Vivian Bayle, Member, ADIDD, Evidence, 27 September 2010, p 2

³⁰¹ Dr Bayle, Evidence, 27 September 2010, p 2

³⁰² Submission 94, p 12

³⁰³ Answers to questions taken on notice during evidence, 27 September 2010, ADIDD, p 3

³⁰⁴ Mr Moore, Chief Executive, ADHC, Evidence, 27 September 2010, p 4

needs of a person with a lifelong disability." Mrs Hewitt stated that "[t]his can act as a barrier to people with a disability being considered eligible to access an Ageing specific service."³⁰⁵

5.25 The ADIDD submission identified that intake processes vary across ADHC regions, for example "... some regions are happy to email an intake form to the referring agent to complete. Other ADHC regions want to speak to the referring agent."³⁰⁶

5.26 The ADIDD stated that the intake process "... is extraordinarily complex and often has to be done repeatedly for any one client" and the capacity of the intake system "... falls far short of meeting the needs of client families and referring professionals." Additional issues regarding the intake process identified by the ADIDD include:

- The current ADHC intake system disadvantages families from a CALD [Culturally and Linguistically Diverse] background.
- Delays in processing the referral by the allocation panel as they do not act on referral until the detailed reports/scores are sent.
- There is excessive reassessment, time wasted, duplication, loss of information, lack of co-operative partnerships and confusion which essentially results in the attrition of needy families.³⁰⁷

5.27 Ms Berry recommended that improvement of client intake, assessment and eligibility process be a priority in phase two of Stronger Together:

The Department undertook some work to improve their client intake, assessment and eligibility processes but as far as we are aware this work has stalled. If the Department is genuinely committed to becoming a more client-focussed body in the delivery of the second phase of Stronger Together, this must become a matter of priority.³⁰⁸

5.28 Improved intake and assessment processes for specialised disability services are prioritised in the *NSW Disability Services Sector Directions for Industry Development* report (Industry Development report). The report describes features of a 'leading edge' intake, assessment and referral process:

Intake, assessment and referral processes that support access to the full range of informal and community supports, mainstream and specialist services are consistent with contemporary leading edge practice in Australia and internationally. Such approaches move away from program-driven service responses to a system based on assisting people with disability to obtain information about and access the range of supports that fit their needs and aspirations. This requires:

- well-defined, clear entry points into the service system;
- consistent and streamlined intake and assessment processes which are person centred;
- a service system which is easy to navigate, where people with disability and their families and carers are provided with clear information about community,

³⁰⁵ Submission 62, Futures Alliance, pp 4-5

³⁰⁶ Submission, 94, p 12

³⁰⁷ Submission 94, p 12

³⁰⁸ Submission 39, p 8

mainstream and specialist service options, and know where to go to get support when needed;

- clear referral pathways to both mainstream and specialist services; and
- an understanding of system capacity and a resource planning process linked to need.³⁰⁹

5.29 The ADIDD recommended that a different intake model is required that does not discharge clients, rather clients can be reactivated. The intake model should reduce the current complexity and enable client families to remain with the same case manager where possible.³¹⁰

5.30 In answers to questions on notice the ADIDD suggested two options to improve the provision of ADHC clinical services, including intake and assessment. Option 1 is a restructure of ADHC clinical services and Option 2 is the transfer of ADHC clinical services to NSW Health.³¹¹

5.31 ADHC has committed to creating a consistent and streamlined intake and assessment process for accessing specialist disability services through the Industry Development report, actions 2G and 2H:

2G Review the existing evidence base to examine different models of intake to both ADHC and NGO provided services, as well as the intake processes of other agencies (such as Health, Aged Care) e.g. the centralised intake and assessment model with either a single entry point or multiple entry points.

2H Review current approaches to priority of access for specialist services and explore the potential for introducing a single set of priority of access criteria which are consistently applied.³¹²

5.32 Ms Emily Caska, State Policy Coordinator of NDS, also suggested features that an intake and eligibility processes should include. They are:

- a single, visible point of access
- a standard approach to entry screening regardless of disability
- immediate notification of eligibility and entitlement for ADHC funded services
- a reduction in the need for repetitive provision of information
- ease of transition to other Departments for those who are not eligible for ADHC funded or provided services and support
- fast, efficient referrals to providers, with all relevant information shared
- access based on the level of functional need in the context of a person's environment, regardless of disability type
- appropriate case management mechanisms and options for families that are long term, consistent and well resourced.³¹³

³⁰⁹ Industry Development report, June 2010, pp 21-22

³¹⁰ Submission 94, p 12

³¹¹ Answers to questions taken on notice during evidence, 27 September 2010, ADIDD, p 3

³¹² Industry Development report, June 2010, p 44

³¹³ Submission 32, NDS, p 34

- 5.33** Ms Caska described the benefits that are resulting from a program that is trialling the use of a single entry point:

A single entry point for Home and Community Care (HACC) services is also currently being trialled in the Hunter region. This access point means that clients who need HACC services contact a single point, have their needs assessed, and be referred to one or a number of services. Clients are able to contact one place rather than potentially multiple service providers and give their personal information once only (with information stored and transferred electronically). The single access point has enabled more consistent assessment of needs and eligibility, and aims to ensure that clients reach the services that are most appropriate for their needs. Wider roll-out of the access point model is currently being examined.³¹⁴

- 5.34** The National Disability Agreement (NDA), described in Chapter 2, also addresses issues relating to assessment. The NDA commits states and territories to developing a nationally consistent assessment process by the end of 2011.³¹⁵ As part of this assessment process, a single access point is recommended to enable "... more consistent assessment of needs and eligibility, and aims to ensure that clients reach the services that are most appropriate for their needs."³¹⁶

- 5.35** Mr Martin Lavery, Chairman of the Board, Lorna Hodgkinson Sunshine Home, recommended that an advisory group is established for needs assessment, stating:

A needs assessment advisory group be established to be chaired by the ADHC Director General and comprising equal numbers of ADHC staff, service provider representatives, and independent community members with terms of reference to assess on a rolling basis unmet need within every region at least once every four years with the purpose of making recommendations on how current and future unmet need can best be addressed.³¹⁷

Committee comment

- 5.36** The Committee acknowledges the issues identified by Inquiry participants regarding ADHC's intake and assessment processes and the challenges these create in accessing disability services. The Committee notes that ADHC complete duplicate needs assessments, there is a lack of consistency across and within regions, unclear intake rules, poor communication with service users and within ADHC and there is no tracking system for referrals.
- 5.37** Inquiry participants made many suggestions for how to improve intake and assessment processes, and the Committee urges the Government to consider these. The Committee agrees with the recommendation from National Disability Services and the NSW Disability Services Sector Directions for Industry Development report that intake and assessment in the disability service system requires well-defined and clear entry points.

³¹⁴ Submission 32, p 25

³¹⁵ National Disability Agreement (accessed 13 October 2010) <www.coag.gov.au/intergov_agreements/federal_financial_relations/docs/IGA_FFR_ScheduleF_National_Disability_Agreement.pdf>

³¹⁶ Industry Development report, June 2010, p 25

³¹⁷ Submission 61, The Lorna Hodgkinson Sunshine Home, p 3

- 5.38** The Committee notes that ADHC completes a needs assessment, even when a comprehensive one has been completed by a professional and it accompanies the referral to ADHC. The Committee acknowledges that ADHC may sometimes require an additional assessment, however, some flexibility is required within the system to prevent unnecessary duplication occurring which results in lengthy delays in accessing services and a waste of scarce resources.
- 5.39** The Committee further notes the poor communication that service users and referring professionals experience during intake and assessment processes. Poor internal communication within ADHC has also been observed by people using the intake and assessment system.
- 5.40** The Committee believes that people with disability face many challenges and that a well functioning intake and assessment process is required to adequately support, rather than provide challenge, to the lives of these people.
- 5.41** The Committee acknowledges that ADHC has committed to creating a consistent and streamlined intake and assessment process for accessing specialist disability services through the Industry Development report, specifically committing to reviewing different intake models, the number of entry points and developing a single set of priority of access criteria. The Committee believes that this review could significantly improve the intake and assessment process and that it should be expedited.
- 5.42** The Committee recommends that the review of the intake and assessment process for disability services is expedited to address entry to the system, prevent duplicate needs assessments being completed where possible, improve notification of eligibility and entitlements to services, improve consistency in intake and assessment processes and improve navigation of the system.

Recommendation 21

That the Minister for Disability Services expedite the review of the intake and assessment process for disability services to:

- develop a single, well-defined and clear entry point into the service system
- prevent duplicate needs assessments being completed, through not requiring ADHC to complete an assessment when one has been completed by the referring professional
- provide immediate notification of eligibility and entitlement for ADHC provided and funded services
- develop and implement a consistent intake and assessment policy across regions
- improve navigation of intake and assessment, including the provision of clear information about service options, eligibility and support
- review the eligibility criteria for the Attendant Care Program.

That the outcomes of the review, recommendations and ADHC's response to the recommendations are published on ADHC's website.

Vacancy management

5.43 Some Inquiry participants identified issues regarding the use of ADHC's vacancy management system in accessing supported accommodation services, including that system is biased towards certain disability types, increases the difficulty in accessing accommodation, involves a complicated application process, can result in people being placed a long way from their families and communities and limits service users' choice of where to live, who to live with and who supports them.³¹⁸

5.44 Ms Estelle Shields, a mother and carer, provided some background to ADHC's vacancy management system:

Seven or eight years ago ADHC introduced its vacancy management system. Hailing it as transparent and equitable, ADHC was responding to the overwhelming demand for supported accommodation. Prior to this, when a vacancy occurred, NGO's had been able to select a client who was known to be compatible with existing clients from within the community of families known to it. ADHC's rationale was that since it was funding all the places, it should be able to select the most needy person in the state to fill the vacancy.³¹⁹

5.45 Mr Max Bosotti, Chief Executive Officer of the Paraplegic and Quadriplegic Association of NSW (ParaQuad), expressed concern about the bias of ADHC's Supported Accommodation Policy towards people with intellectual disability. Mr Bosotti stated that ADHC agrees that this bias takes place, but "... there remains a disconnect between client needs and the policy framework."³²⁰

5.46 The submission from ParaQuad provided an example of the difficulties encountered in using ADHC's supported accommodation vacancy management system for a service user aged in her fifties:

- There was a clear lack of understanding of the needs of our client group, or an understanding of the purpose of Ferguson Lodge [a residential centre]. The Social Worker was advised to contact ACAT [Commonwealth Aged Care and Assessment Team] to find suitable residential placement despite the client being in her 50's.
- Advice was given that every client that applies through the program required an appointed case manager (difficult to obtain case management when they have capacity to manage their own affairs and goals)
- The applicant found the process confusing as to complete the client profile and risk profile, the information requested is targeted at intellectual disability and not relevant for people with high level physical disability and high level cognitive functioning. This creates challenges in trying to complete the documentation as accurately as possible when questions are not relevant to their circumstances.
- The applicant was attempting to get immediate placement, not a placement in the future, so was told that I need to demonstrate that all other options

³¹⁸ See for example, Submissions 15, 21, 23, 38 and 70

³¹⁹ Submission 15, Ms Estelle Shields, p 4

³²⁰ Submission 21, ParaQuad, p 8

(including ACAT) were exhausted before being accepted for immediate placement. Unable to understand if there are no other clients awaiting placement at this facility why the client has to wait to be placed?

- The only other option for this client now is to go to a Nursing Home at the age of 50, this seems incredulous.³²¹

5.47 Ms Belinda Epstein-Frisch from Family Advocacy stated that the vacancy management process used to manage supported accommodation limits peoples' choice "... to choose where the person lives, who the person lives with or who supports them and how. People are often housed far away from their family or community." Ms Epstein-Frisch explained how the system works:

Supported accommodation provided by government and non government providers is managed as one system through a vacancy management process. Vacancies in existing houses and services are offered to the person in most critical need that matches the vacancy.³²²

5.48 Ms Shields also stated that ADHC's vacancy system results in people being placed a long way from their original community "... when a crisis occurs and immediate accommodation must be found."³²³

5.49 Ms Jennifer Rollo OAM, a mother and carer to her son, also believes that the supported accommodation vacancy management system results in people being places a long way from their family and community. She stated:

The person who DOES get that vacancy has been taken away from everything and everyone THEY know. People are shuttled around every morning and afternoon in taxis and vans to their workplaces or day programs, or perhaps worse, are so far away they are no longer able to access their programs and friends. We are made to accept these situations and to feel grateful for any accommodation crumbs that come our way. This policy makes it impossible to plan any future for our sons and daughters. It means that parents can no longer invest their time and efforts into a local service provider who should one day provide accommodation services for their own child.³²⁴

5.50 An impact of the vacancy management system is a change in the way that communities support local accommodation providers, with local funded organisations no longer being able to choose who they accommodate. This was explained by Ms Shields:

In the past years, I have witnessed a total breakdown of sense of community within families with a disabled member. These are the families who need each other so greatly. They, together with their friends and extended family, used to gather around a local provider, supporting it and raising funds, forming a close-knit community and hoping one day to receive a placement for their person within that circle. The provider, in turn, came to know the families and the people with disability, often through work, day, respite or recreational programs that it ran. It became familiar with the circumstances of each family and the care needs and personality of their person.

³²¹ Submission 21, pp 8-9

³²² Submission 23, Family Advocacy, p 5

³²³ Submission 15, p 5

³²⁴ Submission 38, Ms Jennifer Rollo OAM, pp 1-2

All this vanished with the Vacancy Management System. Over-stressed families have little incentive to support an NGO who will not be able to accommodate their family member in the future. NGO's are forced to take people from far away whom they have never seen before and who may or may not be compatible with existing clients.³²⁵

- 5.51** The concern expressed by Ms Shields was echoed by Ms Rollo, that supported accommodation providers lose the support of local communities as a result of ADHC's vacancy management system:

ADHC's Vacancy Management Policy has had a devastating effect on families. Service providers lose the support of their local community in fundraising and personal involvement when they are no longer seen as providing services to the children and adults of their neighbours and friends. PWD ... are no longer finding supported accommodation in their area – IF AT ALL – because the department deems someone from out of the area most needy at that time.

- 5.52** Ms Judy Brosas, sister to a lady with Down Syndrome, believes that ADHC's use of inappropriate vacancy management processes has contravened the Convention on the Rights of Persons with Disabilities:

ADHC has contravened the Human Rights Convention on the Rights of Persons with Disabilities ratified by Australia in 2008 in Articles 4, 6, 10, 13, 16 and 19 ... ADHC have acted in the most discriminatory way, sacrificing the safety and wellbeing of the original three residents for the convenience of housing one. The money thrown into this situation is obscene, especially when you know so many are waiting for accommodation. The stress ADHC has imposed on the residents and staff of this group home is criminal, not only for the original three members but for the autistic man as well.³²⁶

- 5.53** The submission from Northcott Disability Services recommended the redevelopment of ADHC's vacancy management system, to "... ensure that accommodation vacancy management processes place decision-making power with people with a disability needing accommodation support (and their families and carers), any residents currently living in the proposed accommodation placement, and the services that support these people."³²⁷

Committee comment

- 5.54** The Committee acknowledges there are significant issues with ADHC's vacancy management system and that it does not currently meet the needs of many service users. The Committee sympathises with the challenges experienced by many service users, carers and their families in using ADHC's vacancy management system.
- 5.55** The Committee notes with concern that the vacancy management system makes it difficult for service users to access supported accommodation and is biased towards specific disabilities. It is also a concern that the vacancy management system can result in people being placed a long way from their family and community and limits people's choice of where to live, who to live

³²⁵ Submission 15, p 5

³²⁶ Ms Judy Brosas, Public Forum, 30 September 2010, p 15

³²⁷ Submission 70, Northcott Disability Services, p 11

with and who supports them. The Committee believes the Government should manage vacancies in a person-centred manner, in line with their commitment to deliver person-centred services.

- 5.56** The Committee agrees with the recommendation from Northcott Disability Services, that vacancy management processes should place decision making power with the people who need the disability support, their families and carers, existing residents and the support services.
- 5.57** The Committee is concerned that the current vacancy management system may not comply with the Convention on the Rights of Persons with Disabilities, through reducing the choice of service users and jeopardising their safety through inappropriate placement matching.
- 5.58** The Committee also questions whether ADHC's vacancy management policy is in-line with many of the NSW Disability Service Standards and recommends that vacancy management policy is reviewed and amended to bring this important process in-line with the NSW Standards and person-centred policy, and to address the issues identified above.
- 5.59** Additional issues regarding supported accommodation are examined in Chapter 6 and Chapter 10.

Recommendation 22

That the Minister for Disability Services review and amend ADHC's vacancy management system for supported accommodation in consultation with stakeholders. That the review considers:

- person-centred policy
- access to supported accommodation based on need rather than disability type
- complexity of the application process
- the distance that service users are placed from their family and community
- the compatibility of people placed together in supported accommodation
- the level of choice that service users have regarding where they live, who they live with and who supports them
- compliance with the NSW Disability Service Standards and the United Nations Convention on the Rights of Persons with Disabilities
- provision for information sharing and co-ordination of data exchange between ADHC and NGO service providers.

That the outcomes of the review, recommendations and actions are published on ADHC's website.

Disability service information

- 5.60** This section examines issues regarding access to appropriate disability service information by service users, carers and their families. Some Inquiry participants identified there are difficulties accessing information from and providing information to the disability service

system.³²⁸ Difficulties include the complexity of the system, language barriers and a lack of information about specific services. The stress resulting from having to repeat difficult information and experiences in order to access ADHC services was also conveyed to the Committee.

5.61 Additional issues regarding disability service information are addressed in other chapters and sections, including access to culturally appropriate information from section 5.120, access to information regarding the eligibility for disability services from section 5.15, access to information to enable planning for disability services in Chapter 4 and access to disability services statistical information is provided in Chapter 3 and Chapter 9.

5.62 The Industry Development report identifies the importance of providing information in the disability service system:

Across Australia, the provision of information is a pivotal part of an effective disability service system. It supports and empowers people with disability, their families and carers to make choices about their supports and to live as independently as possible. It is also an important mechanism for raising awareness and influencing attitudes and behaviours within the broader community in order to increase the social and economic inclusion of people with disability in society.³²⁹

5.63 Ms Caska also told the Committee that appropriate information provision and support for navigation of the system "... is critical to empowering and strengthening families."³³⁰ Ms Katrakis identified that carers face barriers to accessing information through "... an overly complex and fragmented service system, limited time of carers, language and unawareness of rights to services and the lack of availability of information in specific service setting."³³¹

5.64 Barriers to accessing information for people living with a print disability were also identified by Ms Sue Crane, Advocacy and Research Officer from Vision Australia, who stated that "[l]ess than 5 percent of the information available to sighted people" can be accessed by these people. Ms Crane continued, "... for this group, lack of access to information is the single biggest barrier to employment and effective participation in the community."³³²

5.65 Ms Berry conveyed that her organisation receives complaints about the quality of information that is provided by ADHC:

NSW CID regularly receives complaints about the fact that information coming out of the Department about services that are available is quite unclear, and that accessing services or funding that is available can be a complex and onerous process. For example, at present, many people complain that there is a lack of information regarding eligibility for services and service capacity in different areas. This lack of clarity in regard to clients accessing ADHC services is a major problem, and a great source of frustration for clients.³³³

³²⁸ See for example, Submissions 33, 39 and 60

³²⁹ Industry Development report, June 2010, p 23

³³⁰ Submission 32, p 34

³³¹ Submission 33, p 8

³³² Submission 60, Vision Australia, p 3

³³³ Submission 39, p 8

5.66 A key focus area of the Industry Development report is that "[p]eople with disability have access to the information and range of supports they need to live the lives they choose."³³⁴ ADHC has committed to "[i]mproving navigation of the service system for people with disability and their families and carers particularly at key transition points" through the Industry Development report, including action 2E, which states:

Improving access to information through exploring the potential for online information —hub(s) or portal(s) to provide information for people with disability, disability services, mainstream services, families, and community members. Information should emphasise life choices, and may include:

- links to information about resources, supports and services
- positive stories about the experiences of people with disability and families
- potential pathways across all life stages highlighting supports available
- links to local community information (geographical, cultural etc)
- services and capacity
- referral, assessment, and intake processes.³³⁵

5.67 Ms Debbie Robertson is the mother and carer of Brett, who has fragile legs and a severe intellectual disability. Ms Robertson described another issue concerning disability services information, regarding the frustration and sometimes trauma experienced by carers that are required to constantly repeat information and relive difficult experiences in order to access ADHC services. She stated:

In relation to paperwork and constant repetitive questions that need to be answered in order to access ADHC's services, that has caused us and, I am sure, many others great frustration and stress. I spoke to another mother recently who said that she felt traumatised by having to relive difficult experiences over and over again. There absolutely needs to be an acknowledgement of how much burden is placed onto already exhausted carers by asking them to repeat the same processes over and over.³³⁶

Committee comment

5.68 The Committee acknowledges the importance of ensuring appropriate access to information for service users, carers and their families in the disability service system. The Committee agrees that good access to information empowers service users to make appropriate decisions and is vital for people to live as independently as possible.

5.69 The Committee understands that people with disability depend on quality information to be able to make informed decisions about the services they receive and the way they live their lives. Barriers to accessing information include the complexity and fragmentation of the service system, limited resources of carers, information that is not provided in appropriate languages and a lack of available information for eligibility into specific services.

³³⁴ Industry Development report, June 2010, p 14

³³⁵ Industry Development report, June 2010, p 44

³³⁶ Ms Debbie Robertson, Public Forum, 30 September 2010, p 23

- 5.70** The significant impact that poor access to information has on people with print disability is was highlighted to the Committee. The Committee believes that all people with disability should have access to information that enables them to be able to choose to access employment and participate effectively in the community.
- 5.71** The Committee acknowledges that information about services available from ADHC is sometimes unclear, which can increase difficulties accessing these services. The Committee believes that improved clarity is required so that people who require services from ADHC or funded organisations are aware of the eligibility requirements, location and availability of services.
- 5.72** The Committee strongly supports the key focus area in the Industry Development report that relates to people with disability being able to access the information and range of supports they require.
- 5.73** The Committee sympathises with the carers who are required to repeat traumatic information many times in order to receive ADHC services. The Committee believes that Recommendation 21 will improve ADHC intake and assessment processes for carers, through reducing duplicate collection of information.
- 5.74** The Committee recommends that access to disability service information is improved for all service types, programs and supports that are available to service users, carers and their families, including for people with print disability.
-

Recommendation 23

That the Minister for Disability Services improve access to disability service information for all service types, programs and supports. That this is achieved through:

- ensuring information is available and easily accessible on all ADHC provided and funded services, including locations where the services are provided, eligibility criteria and how to access the service
 - providing information in a variety of formats, including Easy Access, non-English languages, electronically and in hard copy
 - providing references to other reputable sources of information, such as websites and organisations, that can provide support and general information to service users, carers and their families.
-

Recommendation 24

That the Minister for Disability Services improve the availability of information to people who are deaf or those with vision disability through making available disability service information in relevant formats.

Service eligibility

- 5.75** Many Inquiry participants stated that they experienced confusion when attempting to understand whether they were eligible to receive disability services.³³⁷ Issues regarding eligibility of disability services were identified as resulting from inconsistent information, separate and sometimes inconsistent program guidelines, varying administration processes, eligibility requirements that change frequently and narrow eligibility criteria that results in some disabilities not receiving services.
- 5.76** The National Council of Social Services, NSW (NCOSS), submission identified that services provided by ADHC generally have differing eligibility criteria, "[t]hese are largely provided in silos, with separate (and sometime conflicting) program guidelines, differing eligibility criteria, varying service mechanisms and differing uncoordinated fee structures."³³⁸
- 5.77** Confusion about eligibility criteria extends to both clinicians and ADHC staff, according to Dr Leitner:
- Applied Behavioural Intervention (ABI) is a quality Autism therapy, with only limited places. There is confusion with clinicians and ADHC themselves about availability, eligibility, priorities. Some regions were not aware that children only needed an Autism diagnosis for referral in spite of the referral needing to go through ADHC intake.³³⁹
- 5.78** The Disability Trust submission identified that "... it is hard to stay up to date with the various eligibility requirements in terms of geography, service type and levels of care available from each provider."³⁴⁰
- 5.79** Service users who require more than one type of service face additional complications, according to NCOSS who told the Committee that "[s]ervice users requiring more than one type of support must demonstrate eligibility for each separate program, and then learn the requirements, obligations and expectations of each provider before receiving services and providing consents along the way."³⁴¹
- 5.80** Mr Stephen Nicholson, Manager, Consumer and Community Services, Deaf Society of NSW and Ms Janne Bidenko identified that current eligibility arrangements make it difficult for

³³⁷ See for example, Submissions 30, 90, 93, 94 and 107

³³⁸ Submission 30, p 12

³³⁹ Submission 94, p 11

³⁴⁰ Submission 107, Disability Trust, p13

³⁴¹ Submission 30, p 12

people who are deaf and blind to access services.³⁴² Ms Bidenko stated "[w]hile working in the Intellectual Disability field I realised that Deafblind people did not get any funding unless deemed intellectually disabled."³⁴³

5.81 Mr Nicholson stated that people who are deaf and blind have applied for services through the attendant care and home care program in the past, however, "... have been unsuccessful because they do not meet the specific [eligibility] criteria for one or the other."³⁴⁴ In absence of a funded service being available, the Deaf Society has assisted people who are deaf and blind without receiving funding from ADHC:

They have ended up becoming reliant on our organisation again. That is an unfunded service, but we need to provide that quality of service. If that is not there, there is nothing.... I have raised the issue of people who have not met the criteria. The response has been that I should get in touch with Home and Community Care. When we have done that, Home and Community Care has said they do not meet its criteria and that we should go back to the other service. There is a catch 22.

5.82 Eligibility barriers for deaf and blind people were also discussed by Mr Colin Allen, the Director of Services at the Deaf Society, who recommended that "[t]he attendant care program criteria need to incorporate people who are deaf and blind as eligible to receive that service."³⁴⁵

5.83 Vision Australia also identified the lack of services and funding available for people who are deaf and blind:

The key issue for Vision Australia is that, predominately due to lack of funding, we are not able to provide services to the number of people in NSW who are blind, have low vision or are deafblind.³⁴⁶

5.84 Ms Bidenko identified that other countries fund and train interpreters and guides for people who are deaf and blind, and that this service is "... urgently needed in Australia and must be part of any new national disability and support scheme."³⁴⁷

5.85 Ms Sondra Wibberley from the Association for Blind Citizens of NSW Inc also identified that there is unmet need in the provision of services to people who are blind. She stated that a lack of funding to her organisation impacts on the quality, effectiveness and delivery of services to people who are blind or vision impaired.³⁴⁸

5.86 Case study 3 provides an example of restrictive eligibility criteria that have wrongly deemed a service user as independent and not eligible for ADHC support. The impact of this on the service user's elderly parents is also described.

³⁴² Mr Stephen Nicholson, Manager, Consumer and Community Services, Deaf Society of NSW, Evidence, 27 September 2010, p 58 and Submission 93, Ms Janne Bidenko, p 1

³⁴³ Submission 93, p 1

³⁴⁴ Mr Nicholson, Evidence, 27 September 2010, p 58

³⁴⁵ Mr Collin Allen, Director of Services, Deaf Society of NSW, Evidence, 27 September 2010, p 58

³⁴⁶ Submission 60, p 6

³⁴⁷ Submission 93, p 1

³⁴⁸ Submission 45, Ms Sondra Wibberley, p 3

Case study 3 – Name suppressed³⁴⁹

Our daughter lived with us in a Retirement Village unit until September 2009. She then moved into a 'self care' unit of her own in a similar Retirement Village. At this point was deemed to be independent and, as such, no longer eligible for any ADHC services. At present she needs daily assistance with the many aspects of living independently. We, her aged parents (aged 77 and 79) have to help her with shopping, medical, dental and money matters. She purchases some of the other necessary services at rates of \$27 per hour weekdays and up to \$53.60 per hour at weekends. Such a situation is plainly not sustainable. To date, our plans for our daughter's independent future have been blocked due to our inability to obtain an appropriate care package for. We therefore request that the eligibility guidelines for such care packages be reviewed along with funding availability for the older disabled.

- 5.87** An impact of current eligibility criteria as identified by Ms Berry is that some people who could "substantially benefit from Government support" not being eligible for ADHC assistance.³⁵⁰ Ms Berry noted that "[t]his is a substantial area of unmet need which is extremely difficult to quantify. Many families who, from the outset, would seemingly definitely qualify for some form of Government assistance, simply do not."
- 5.88** The submission from NDS also provided a recommendation to improve disability services eligibility policy, suggesting that "[p]eople are screened for eligibility only once using a common screening tool, though their needs are reassessed at key life stages or as their needs change." NDS also recommended that people are immediately notified "... of eligibility and entitlement for ADHC funded services."³⁵¹
- 5.89** The NSW Ombudsman conveyed that people need "... access to comprehensive and timely information about existing services for children with disabilities and their families ... This includes information about what types of services and supports are available; the eligibility criteria; and how to access services."³⁵²
- 5.90** A recommendation to improve eligibility policy was put to the Committee by Ms Therese Sands, Executive Director, People With Disability:

ADHC review eligibility and assessment for services so that procedures are based on a robust, internationally valid framework, such as the World Health Organisation's (WHO) International Classification of Disability Functioning and Health (ICF), which determines eligibility and assesses need according to a sophisticated classification that takes account of the functional limitations of a person, and their level of disadvantage relative to the social, economic and environmental context in which they live.³⁵³

³⁴⁹ Submission 7, Name suppressed, p 1

³⁵⁰ Submission 39, pp 9-10

³⁵¹ Submission 32, p 23

³⁵² Submission 100, Mr Bruce Barbour, NSW Ombudsman, p 3

³⁵³ Submission 91, People With Disability, p 10

- 5.91** Ms Caska believes that "[a] particular focus should be improving current approaches to establishing eligibility, and consideration should be given to agreeing its purpose and when it occurs so as to reduce the need for re-establishing eligibility at multiple points in a person's life or when accessing more than one service."³⁵⁴ Ms Caska also recommended that access to services is based on a persons' *need* rather than disability type.³⁵⁵
- 5.92** Ms Louise Bannerman, Disability Development Officer, Warringah Council, stated that "[p]eople who don't quite fall into a specific diagnosis for example someone that has a rare genetic disorder which causes a disability struggle within the inflexibility of eligibility criteria for services."³⁵⁶ Ms Bannerman recommended that greater flexibility is required in eligibility requirements "... to ensure easier process for the carer and to prevent people in need of falling between the gaps."
- 5.93** The Committee was told that people who don't fall within a clear category of disability may be disadvantaged by current eligibility criteria. Mr Noel Baum, Director, Local Government and Shires Association of NSW, provided the example of people who may have a rare genetic illness:
- Eligibility requirements currently appear to negatively impact people with a disability who are not able to be categorised with a specific disability, such as those who have a rare genetic illness. They often struggle to gain eligibility for much needed services and funding. The Associations suggest that a classification system that is based on impacts on health and lifestyle as opposed to the 'type' of disability may ensure fairer support for all people with a disability and better funding to the sector. This would also ensure that people with a mental health issue and those that do not easily fit into 'a' diagnosis' are not marginalised.³⁵⁷
- 5.94** Consistent with Mr Baum's concerns, Northcott Disability Services recommended that the "[e]ligibility for ADHC services should be expanded to people with any disability (as defined under the *Disability Services Act*)."³⁵⁸

Committee comment

- 5.95** The Committee sympathises with the concern expressed by Inquiry participants regarding ADHC eligibility policy, and the impact this has on people attempting to access services and notes the confusion experienced by service users and clinicians when attempting to determine eligibility for different programs.
- 5.96** The Committee acknowledges how difficult it is for service users to navigate the eligibility policy of disability services to try and ascertain whether they qualify for services, when both clinicians and ADHC also find some policy confusing. Current eligibility criteria varies between geographical location, service type, levels of care and service provider. The Committee believes that development and consistent implementation of revised eligibility policy would improve the provision of disability services.

³⁵⁴ Submission 32, p 27

³⁵⁵ Submission 32, p 34

³⁵⁶ Submission 108, Warringah Council, p 3

³⁵⁷ Submission 72, Mr Noel Baum, Director, Local Government and Shires Association of NSW, p 5

³⁵⁸ Submission 70, p 6

- 5.97** The Committee agrees with Ms Sands that review of eligibility criteria for services should be based on a robust, internationally valid framework, such as the WHO's International Classification of Disability Functioning and Health, and that greater flexibility is required in eligibility requirements, including a revision of eligibility criteria to determine eligibility based on need rather than disability.
- 5.98** The Committee also agrees with Ms Caska, that service users' experience in accessing disability services would be significantly improved through the use of a common eligibility screening tool. The Committee also agrees that service users' should be immediately notified of their eligibility and entitlement to ADHC funded and provided services.
- 5.99** The Committee notes with concern the challenges faced by people who are deaf and blind in accessing support and services, due to limited and inadequate eligibility criteria. Trained interpreters and guides should be available for people who are deaf and blind. The Committee recommends that eligibility criteria in the attendant care program are amended as a matter of urgency to include people who are deaf and blind.
- 5.100** The Committee also recommends eligibility policy is developed and consistently implemented for all funded and provided service, including the development of a common eligibility screening tool. This includes a review of eligibility criteria for all disability services.
- 5.101** Implementation of Recommendation 21 could address many of the issues identified in this section.

Recommendation 25

That the Minister for Disability Services convene a Working Group made up of government departments, NGO service providers, representatives from the Disability Council of NSW and other stakeholders, to complete a review of eligibility criteria for all services, based on an internationally valid framework such as the WHO's International Classification of Disability Functioning and Health. That revised eligibility criteria determine service eligibility based on need rather than disability.

That the Working Group undertakes consultation with a range of ADHC service users and ensure eligibility criteria are consistent with the UN Convention on the Rights of Persons with Disabilities.

That the outcomes of the review, recommendations and actions are published on ADHC's website.

Recommendation 26

That the Minister for Disability Services develop (or revise as appropriate) and consistently implement eligibility policy for all funded and provided service, including the development and implementation of a common eligibility screening tool, and that the policy ensures that service users' are immediately notified of their eligibility and entitlement to ADHC funded and provided services.

Recommendation 27

That the Minister for Disability Services amend the eligibility criteria of the attendant care program as a matter of urgency to include people who are deaf and blind.

Recommendation 28

That the Minister for Disability Services ensure that appropriate services are available for people who are deaf blind, through funding and training interpreters and guides for deaf and blind service users.

Waiting lists

5.102 The lack of waiting lists used by ADHC was identified as a concern by many Inquiry participants.³⁵⁹ Inquiry participants told the Committee that waiting lists are not used consistently across service types or programs, there is confusion about what they are and whether they should be used in all programs.

5.103 Issues regarding the use of waiting lists to manage access to supported accommodation services are examined in Chapter 6.

5.104 Mr Moore told the Committee that an assessment is always completed when a service is requested and the wait that follows to access services depends on the level of need:

... when children or people with a disability and their families make a request for services, there is always an assessment of the requirement for immediate response or not. It is quite likely that the people who are waiting longest have other services or their need is considered not as high as other people's. There is a definite assessment to determine how quickly people should respond and be given priority.³⁶⁰

5.105 The author of Submission 1 explained that there are many issues with waiting lists for disability services, including their length, transparency of the process and repetition of paperwork:

Waiting lists are long. Priorities are not transparent. Paperwork is intrusive and repetitive. Currently we have been on the waiting list for over two years for Occupational Therapy and recently my son finally got back on the case load for Speech Therapy after two years on the waiting list. I have chosen to seek therapy through Royal Far West Children's Health (RFW) because I cannot trust ADHC to provide service. I travel to Sydney to access RFW every 6 months to bi-annually. It provides a one stop shop that ADHC does not.³⁶¹

³⁵⁹ See for example, Submissions 1, 30, 66 and 73

³⁶⁰ Mr Moore, Evidence, 9 August 2010, p 15

³⁶¹ Submission 1, Mrs Vicki Happ, pp 1-2

5.106 Ms Janice Marshall, mother and carer, stated that "ADHC has kept no waiting list to gauge unmet need, although a register of future need has recently been introduced after much lobbying. This is, however, not well publicised hence the data is probably not very useful."³⁶²

5.107 The NCOSS submission explained that there are no waiting lists used by the ADHC home care service. Instead, if the service is full people may be asked to call back at another time, which may reduce access to this service:

The Home Care Service of NSW maintains no waiting lists, despite the recommendation of the 2005-6 NSW Public Accounts Committee Inquiry into Home and Community Care Program and Services. While talking to the regions, NCOSS hears constant frustrations from people and providers who try to access support services from Home Care Service. If capacity is full on the day, the caller is asked to call another time and/or given other phone numbers. Ordinary people may interpret this as being rejected by the entire HACC system and may not call again. There has been some improvement in recent times but regional variations still occur, despite the centralised system.³⁶³

5.108 The Committee heard from Mr Sean Lomas, Policy and Advocacy Manager, Spinal Cord Injuries Australia, that ADHC waiting lists are the source of jokes in the disability services sector. He stated:

Jokingly we have heard it is bandied around in quite wide circles that ADHC just do not want to keep waiting lists, it is not necessary for them to keep them; it kind of clogs the issue and clouds everything up. So, hey, some people out there need some support. That is how everyone jokes about it.³⁶⁴

5.109 Ms Katrakis described issues regarding poor communication and unrealistic expectations that result from the use of waiting lists. She stated that "[f]amilies think that they have got their names on a waiting list and then find out years down the track that it does not exist, or something that may have existed five or ten years ago no longer exists today." Ms Katrakis also stated that families:

... put their name on that list thinking that their problems will be solved down the track and that that will address their concerns. Whether the list exists is always a matter for debate but it is about expectation about communication.³⁶⁵

5.110 It appears that there is no agreement across service providers about what a waiting list is.³⁶⁶ The Committee was advised by Ms Sharryn Llewellyn, Regional Manager, the Benevolent Society, that this lack of agreement results in some service providers keeping comprehensive waiting lists and others keeping no record.

5.111 Ms Llewellyn explained why there may be inconsistent use of waiting lists. She stated that "... there can be a culture in some providers around unmet need or waiting lists being seen to

³⁶² Ms Janice Marshall, Public Forum, 30 September 2010, p 21

³⁶³ Submission 30, p 8

³⁶⁴ Mr Sean Lomas, Policy and Advocacy Manager, Spinal Cord Injuries Australia, Evidence, 26 August 2010, p 42

³⁶⁵ Ms Elena Katrakis, Chief Executive Officer, Carers NSW, Evidence, 9 August 2010, p 47

³⁶⁶ Ms Sharryn Llewellyn, Regional Manager, the Benevolent Society, Evidence, 26 August 2010, p 24

be a negative about their program so they want to be seen to be full because their output funded is based on being full and providing that number of hours continuously."³⁶⁷

5.112 The Committee understands the use of waiting lists by ADHC and funded organisations is required to improve so that there is a common understanding of when and how they are used. Ms Llewellyn observed that "... we do not have a level of sophistication in the system around what to do with waiting lists or the data that we collect because we cannot agree on whether to collect it, and then when we do, how to leverage that or use that to better service the clients."³⁶⁸

5.113 Mr Peter Kell, Chief Executive Officer of Anglicare, Archdiocese of Sydney, explained that long waiting lists for services can result in people remaining in services that are no longer needed, for fear of not being able to access the services later if required:

HACC funded services focus on providing person-centred care. However clients can be afraid to temporarily leave a service because it places them at risk of having to wait until another vacancy becomes available. Some HACC services have long waiting lists; therefore it is an incentive for the client to stay on regardless of whether they need help with the activities of daily living.³⁶⁹

Committee comment

5.114 The Committee believes the variety of issues identified by Inquiry participants suggests that waiting lists are a very complex issue. For example, the Committee notes that waiting lists can be useful in gauging demand for a service and letting service users know how long a wait for a service may be, however, long waiting lists can also compel people to remain in services that may not be appropriate for fear of not receiving any other service. The many resulting issues faced by service users, carers and their families regarding disability service waiting lists, include confusion about what they are, whether they should be used in all programs and a lack of use in some programs.

5.115 The views expressed regarding a lack of transparency and repetitive paperwork involved in the use of ADHC waiting lists are of concern to the Committee, as it may reduce people's trust in the disability service system and influence the number of people who attempt to access services.

5.116 It is also of great concern to the Committee that some people have placed their name on a waiting list, trusted that they would one day receive a service then found out many years later that the waiting list no longer exists. The Committee strongly believes that service users who are placed on a waiting list by ADHC or a funded organisation deserve good communication so that they are aware of how long they may have to wait for a service and can then choose whether to wait or explore other options.

5.117 The Committee sympathises with service users who attempt to access ADHC's home care services who, instead of being provided with a service or being put on a waiting list, are told to call back another day. The Committee believes that this response is unacceptable and may

³⁶⁷ Ms Llewellyn, Evidence, 26 August 2010, p 24

³⁶⁸ Ms Llewellyn, Evidence, 26 August 2010, p 24

³⁶⁹ Submission 66, Anglicare, Archdiocese of Sydney, p 8

leave people without essential services, as many people do not have any option other than to use this service.

- 5.118** The confusion within the disability service sector regarding the use of waiting lists indicates to the Committee that services are not provided in a planned manner, which was also identified by Inquiry participants in Chapter 4. The Committee believes that a policy needs to be developed that provides for the consistent understanding and use of waiting lists by ADHC and funded organisations. The Committee believes that it is important for service users to be aware if and when they may be able to access services.
- 5.119** The Committee notes the belief held by some service providers that waiting lists may be perceived as a negative about their program and that this perception influences whether waiting lists are kept.
- 5.120** The Committee recommends that ADHC addresses this perception with funded organisations so that there is a clear and consistent understanding across the sector about the use of waiting lists. Clarity will also ensure that service users are not adversely affected as a result of service providers' misunderstanding the impact of waiting lists on their relationship with their funder.
- 5.121** The Committee also recommends that ADHC develop policy regarding the use of waiting lists in ADHC provided and funded disability services to improve transparency and understanding of waiting lists in the sector.
- 5.122** The Committee notes that waiting lists and registers of service requests are an important mechanism to track and measure unmet and under-met need. Waiting lists or registers of service requests may also be used to log communication history with ADHC service users.

Recommendation 29

That the Minister for Disability Services develop a policy regarding the use of waiting lists in ADHC provided and funded services, to improve transparency and understanding of waiting list through:

- providing clear direction on when waiting lists will be kept by ADHC and funded organisations
- providing direction on how waiting lists will be maintained
- identifying when, how and the frequency that service users will be communicated with regarding their position on the waiting list
- reducing the amount of red tape in accessing waiting lists
- communicating that waiting lists will not negatively impact funded organisations' relationship with ADHC
- being circulated to service providers, ADHC staff and peak organisations so there is a common understanding across the sector.

Culturally appropriate services

5.123 Many Inquiry participants identified issues regarding the provision of culturally appropriate services to people from non-English speaking backgrounds. Issues include the under-representation of people with disability from non-English speaking backgrounds in accessing services, cultural differences in the use of the word 'disability', lack of culturally appropriate information and trained staff, policy gaps and a narrowly focused service provision.

5.124 Mr Damian Griffis, Executive Officer, Aboriginal Disability Network (ADN), identified that Aboriginal and Torres Strait Islander people with disability are some of the most disadvantaged Australians:

They often face multiple barriers to their meaningful participation within their own communities and the wider community. The vast majority of Aboriginal and Torres Strait Islander people with disabilities are at the periphery of all aspects of the disability services sector. In accessing individual advocacy services this is particularly acute, despite the fact that in many ways Aboriginal and Torres Strait Islander people with disabilities are the group within the Australian community who are most in need of individual advocacy support.³⁷⁰

5.125 Ms Diana Qian is the Executive Director of the Multicultural Disability Advocacy Association (MDAA), which is the "... only systemic advocacy organisation in the State that focuses on issues for people from a NESB with a disability."³⁷¹

5.126 Ms Qian told the Committee that awareness of the need to include people from a non-English speaking background with a disability in service delivery is increasing, "... but very little has been translated into real action and therefore a very limited outcome has been achieved."³⁷² She stated:

The experience of MDAA in working with ADHC we have found that individual staff from ADHC are quite responsive and there seems to be a commitment from ADHC to improve service access for people from NESB but that commitment has not been translated into broad, systemic action.³⁷³

5.127 Mr Dougie Herd, Executive Officer of the Disability Council of NSW, identified that ADHC has a cultural competency strategy that it is attempting to put into practice. He also stated:

I believe it has been more successful now than it used to be in the past, but the numbers are pretty clear: 25 per cent of the population of people with a disability come from a non-English-speaking background; fewer than 10 per cent of clients come from a non-English-speaking background.³⁷⁴

5.128 Ms Qian agrees that there is a disproportionate number of people with disability from non-English speaking backgrounds accessing ADHC services (about 5 per cent), when compared to the number of people from these communities that have disability (about 36 per cent):

³⁷⁰ Submission 97, ADN, p 1

³⁷¹ Ms Qian, Evidence, 26 August 2010, p 42

³⁷² Ms Qian, Evidence, 26 August 2010, p 42

³⁷³ Ms Qian, Evidence, 26 August 2010, p 44

³⁷⁴ Mr Dougie Herd, Executive Officer, Disability Council of NSW, Evidence, 9 August 2010, p 35

People from NESB make up ... about 36 per cent of the State's population. So we are demographically in NSW increasingly diverse. That proportion would be equivalent in the disability community, so more than a quarter of the disability population are either born in a non-English-speaking country or are second generation NESB. We do not see that proportion in the people who access disability services. We see about 5 per cent of ADHC service users from NESB - that is according to our estimate.³⁷⁵

- 5.129** Many Inquiry participants identified some of the barriers that prevent people from non-English speaking backgrounds with disability from accessing disability services.³⁷⁶ Mr Herd explained that there is a lack of access to information for these people. He also stated:

Language differences are important. A number of people tell us—it is true also in the Aboriginal communities—that in some communities, some languages, there is no word for disability. So if you organise a disability services system you may not even know that there are support systems around for you to get access to. There may be cultural values in accessing the kinds of services that we organise but the responsibility is on the system to develop cultural competency, to develop culturally appropriate services.³⁷⁷

- 5.130** The Early Childhood Intervention Australia submission identified that there is an under-representation of families from culturally and linguistically diverse (CALD) communities "... and Aboriginal backgrounds in most services."³⁷⁸

- 5.131** Ms Qian stated that disability services are underutilised due to a "... lack of access to culturally appropriate information." She continued:

If you do not know the service is there then you would not be able to inquire about it, you would not be able to get yourself onto a waiting list and you would not be able to get access to it. So the vast majority of people from NESB with a disability cope with their needs within the family context and they are very isolated.³⁷⁹

- 5.132** Ms Elena Katrakis, Chief Executive Officer of Carers NSW, stated that having relevant information available in different languages is only part of the answer to improving the cultural appropriateness of disability services:

... it is about getting into the communities and really working with those communities. A lot of culturally and linguistically diverse communities do not even have a word for "carer"; it is a different concept. It is about looking at what that service mix might be. Sometimes a brochure or an Aboriginal-looking brochure about how to get services is not enough; it needs to be more at the coalface and to have appropriately trained and responsive services on the ground.³⁸⁰

- 5.133** Mr Griffis also stated that brochures with Aboriginal designs on them are not enough to meet outcomes for Aboriginal people with disability:

³⁷⁵ Ms Qian, Evidence, 26 August 2010, p 42

³⁷⁶ See for example, Submission 33, 84 and 97

³⁷⁷ Mr Herd, Evidence, 9 August 2010, p 34

³⁷⁸ Submission 84, Early Childhood Intervention Australia (NSW Chapter) Inc., p 3

³⁷⁹ Ms Qian, Evidence, 26 August 2010, p 43

³⁸⁰ Ms Katrakis, Evidence, 9 August 2010, pp 52-53

I see a lot of great brochures that have nice Aboriginal motifs on them are sitting in the waiting rooms of health services or whatever, and that has been a bit of a trend, in some ways. But it requires sitting down and having a yarn with people...Organisations go out and have a conversation with people. It is just whether they go back and whether they are prepared to hear that they will cop it a little bit and have to swallow their pride. Something we do a lot of is partner with existing disability rights organisations and go out into the community and introduce them to communities. So, the planning side of stuff needs to involve outreach basically.³⁸¹

- 5.134** During debate in Parliament, the Hon Peter Primrose MLC, Minister for Disability Services, noted that the Government faced a number of obstacles when delivering services to Aboriginal communities:

The Department of Ageing, Disability and Home Care recognises the challenges of ensuring older Aboriginal people are supported to live independently in their own homes and be connected with their communities. The Department of Ageing, Disability and Home Care also recognises the challenges of ensuring that Aboriginal people with a disability have every opportunity to reach their potential, and at the same time supporting and sustaining the unique community responses that are an integral part of Aboriginal culture. The agency acknowledges that true engagement with Aboriginal families and communities in service planning and development is essential to encourage access to services and to foster skills and independence so that the health and wellbeing of Aboriginal families and communities are maximised.³⁸²

- 5.135** Ms Ethel McAlpine, Deputy Director General, ADHC, acknowledged the frustration that people living in Aboriginal communities may feel towards governments regarding the lack of flexibility provided to meet their needs:

I think if you were living in an Aboriginal community you would have a fair degree of frustration with all governments in that you have articulated your needs a number of times and things have not happened to increase flexibility. I would hope that we are starting to see the change in that.³⁸³

- 5.136** Ms Qian believes that there are issues regarding the responsiveness of disability services meeting the needs of individual people, including "... their linguistic needs, their religious needs, or it could be their cultural needs."³⁸⁴ Ms Qian stated that the disability service sector "... still very much focus on managing disability and not supporting people who happen to have disability." She believes this is "[v]ery single dimensional; very narrow."

- 5.137** Ms Qian told the Committee that ADHC does not have a broader policy framework that addresses "... the needs of disadvantaged groups."³⁸⁵ This includes gaps regarding the way that contracts and funded services are managed and:

[the use of data] about indigenous access and NESB access. We do not know what ADHC does with the data. We do not know whether the organisation is being held

³⁸¹ Mr Damian Griffis, Executive Officer, ADN, Evidence, 27 September 2010, p 39

³⁸² *NSWPD, Legislative Council*, 20 October 2010, p 17

³⁸³ Ms Ethel McAlpine, Deputy Director General, ADHC, Evidence, 9 August 2010, p 25

³⁸⁴ Ms Qian, Evidence, 26 August 2010, p 44

³⁸⁵ Ms Qian, Evidence, 26 August 2010, p 44

accountable if they really have no clients in their service that are actually from those backgrounds."³⁸⁶

- 5.138** Mr Herd gave an example of cultural barriers that are faced by some people when accessing community transport. He told the Committee that the rules of some community transport organisations prevent people with disability from travelling with their family, which restricts some people from being able to carry out their family role:

If you happen to be a client with a disability, a grandmother, who is also part of an extended family, either because you come from India or from Coffs Harbour, if part of your extended family role is to look after your daughter's four-year-old kid but the community transport organisation will not allow you as the client to take the four-year-old kid with you, you need to rethink how you organise community transport.³⁸⁷

- 5.139** A/Professor Eileen Baldry, School of Social Sciences and International Studies, University of NSW, explained the importance of enabling Indigenous workers to work in a culturally competent way "... rather than trying to enforce them into working in a pattern which works for middle-class Sydney."³⁸⁸

Supporting and training indigenous workers would go a huge way ... That is not a huge amount of more money. It means, and what we are saying, we need to focus on ensuring that we support more indigenous workers. Equally importantly, training non-indigenous workers who work with indigenous people because indigenous people want everybody to be able to work with them.³⁸⁹

- 5.140** Ms Qian told the Committee that she phoned a number of ADHC intake phone lines and spoke in Chinese "... to see how responsive the system might be."³⁹⁰ Unfortunately, the staff responded by speaking "... louder and louder."

How can disability services better meet the needs of people from NESB with disability?

- 5.141** Minister Primrose told Parliament that ADHC is attempting to increase the number of Aboriginal staff members as a means to provide more culturally appropriate services. Minister Primrose explained the initiatives:

[T]he Government ... resources the Department of Ageing, Disability and Home Care to develop and implement structural reforms and target employment of Aboriginal people to increase its capacity to deliver culturally responsive services to Aboriginal communities. The Department of Ageing, Disability and Home Care currently funds eight programs that target Aboriginal communities specifically. The flagship program is the Aboriginal Home Care Service, which is the largest provider of community care services to Aboriginal people in NSW.

³⁸⁶ Ms Qian, Evidence, 26 August 2010, p 44

³⁸⁷ Mr Herd, Evidence, 9 August 2010, p 35

³⁸⁸ A/Professor Eileen Baldry, School of Social Sciences and International Studies, University of NSW, Evidence, 26 August 2010, p 6

³⁸⁹ A/Professor Baldry, Evidence, 26 August 2010, p 6

³⁹⁰ Ms Qian, Evidence, 26 August 2010, p 43

- 5.142** Mr Moore expanded on the agency's projects concerning the employment of Aboriginal people. He told the Committee that this could "... build our capabilities as an organisation to be able to hear what is being said, and translate that into action ..." He also stated:

To some extent we, as an organisation, need to have a much greater prevalence of Aboriginal staff within our operation. For the past two years we have been running a program of recruiting Aboriginal people to positions which are training level positions and then setting them up to see if they can compete for mainstream jobs at the end. We are committed to bringing in around 90 staff a year into that program within our group home network. We are also doing a similar thing within Aboriginal Home Care.³⁹¹

- 5.143** Minister Primrose also identified other ADHC services specifically catering to the needs of Aboriginal people:

In addition, the Department of Ageing, Disability and Home Care has a range of Aboriginal specific services and programs that target Aboriginal people. Examples of these include Department of Ageing, Disability and Home Care early intervention services and intensive family support services for families with young children, community participation programs for school leavers as well as programs for carers and older carers. The Department of Ageing, Disability and Home Care has also established the Aboriginal Service Development Delivery Directorate to provide leadership, coordination and support across the agency to bring about systemic structural reforms to improve ageing and disability services for Aboriginal people now and into the future.

- 5.144** Ms McAlpine acknowledged the challenges associated with making "... our services individualised enough and culturally appropriate enough" to ensure that Aboriginal communities receive the "... best benefit".³⁹² Ms McAlpine identified that this is a process the Department is still working through:

We have been running some flexible accommodation packages in the northern region, to support Aboriginal people to remain within their communities. It does not look like any other accommodation service, and it is completely individualised to meet their needs. That is the direction we are trying to head in.³⁹³

- 5.145** In relation to improving the provision of disability services to Aboriginal people, Mr Griffis suggested that "... there is a real opportunity to do some training, and I mean more than about bush tucker and BBQ stuff." He stated:

I am talking about meaningful engagement about disability and the different way it is talked about in Aboriginal communities. People might go into a community with a brochure saying they are a disability service provider. Many Aboriginal communities will not understand what that means and will be nervous about what might happen if they engage with the provider. Even the notion of service is - for want of a better word - foreign in many ways. Many people do not understand the idea of going outside community to get support.³⁹⁴

³⁹¹ Mr Moore, Evidence, 9 August 2010, p 26

³⁹² Ms McAlpine, Evidence, 9 August 2010, p 25

³⁹³ Ms McAlpine, Evidence, 9 August 2010, p 25

³⁹⁴ Mr Griffis, Evidence, 27 September 2010, p 37

- 5.146** Ms Regan recommended that ADHC should implement "... different and innovative approaches to ensure that Aboriginal people and those from culturally and linguistically diverse backgrounds are able to access appropriate services, both specialist and mainstream."³⁹⁵
- 5.147** Mr Griffis identified a local area coordinator model of service delivery as a model that is working well in some Aboriginal communities. It is used by the Western Australian Disability Services Commission and "... involves a person located in community who effectively acts as an advocate. They do not really have restrictions on their role. They become conduits and linkages for people to access services."³⁹⁶
- 5.148** Ms McAlpine identified that changes to the Aboriginal Home Care Service have resulted in more people from Aboriginal communities receiving culturally appropriate home care services.³⁹⁷ Changes were made to the assessment system, which now has an Aboriginal person taking the referrals and going out to meet the person and link them to the local home care branch.
- 5.149** Ms Qian expressed disappointment that Stronger Together has not delivering for people from non-English speaking backgrounds.³⁹⁸ She stated that implementation of this policy may have caused further inequity for people from non-English speaking backgrounds with disability, since:
- ... the more money you invest into a system that is inequitable you are actually increasing the inequity because the people from NESB are not getting the benefit of the additional funding. We are not even getting onto the waiting list for the additional placements. There are some small pilot projects in Stronger Together but in comparison with the amount of funding it is hugely inadequate to address the needs of people from NESB with disability.³⁹⁹
- 5.150** Ms Katrakis stated that ADHC fund Carers NSW to provide part of the Older Parent Carer program for Aboriginal communities, which has been successful through:
- ... not only just employing Aboriginal people because we have also employed non-Aboriginal people to work in that program, but to have some targeted responses and to really work within the local communities to work and partner with other Aboriginal and culturally and linguistically diverse providers to really work with different models of service provision to those different communities. There are pockets of good examples out there. It needs to be more across the State.⁴⁰⁰
- 5.151** A/Professor Baldry identified that "... everybody who works in these systems and who is likely to work with indigenous families and people with a disability needs to have that cultural competence as well."⁴⁰¹ A/Professor Baldry undertook some work with A/Professor

³⁹⁵ Submission 30, p 3

³⁹⁶ Mr Griffis, Evidence, 27 September 2010, p 36

³⁹⁷ Ms McAlpine, Evidence, 9 August 2010, p 25

³⁹⁸ Ms Qian, Evidence, 26 August 2010, p 44

³⁹⁹ Ms Qian, Evidence, 26 August 2010, p 44

⁴⁰⁰ Ms Katrakis, Evidence, 9 August 2010, p 53

⁴⁰¹ A/Professor Baldry, Evidence, 26 August 2010, pp 6-7

Sue Green to look into the "... take-up of the services by indigenous communities and their attitude." They found that once workers attitude changed when working with Indigenous service users and that there was an assumption that the service users would want to see an Indigenous worker:

The impression that many indigenous people that we spoke to had was, "You can't be bothered making sure that you know how to work with us appropriately." ... So everybody who works in these systems and who is likely to work with indigenous families and people with a disability needs to have that cultural competence as well. ⁴⁰²

5.152 A/Professor Baldry also recommended that resources need to be directed to schools where there are number of Aboriginal children with disability:

I think the money is also needed in schools. There is absolutely no question that we need much better education attention in schools where there are a number of Aboriginal children as to how to work with those children who have a disability in whatever form it happens to be, and for it to be able to be recognised because the signs are not going to be the same necessarily. ⁴⁰³

5.153 Ms Llewellyn, stated that the capacity of Aboriginal people needs to be supported so that they can "... support their folk rather than it being outsourced back to the mainstream services where that may not be culturally appropriate." ⁴⁰⁴

5.154 The MDAA identified that the following recommendations would improve access of people from non-English speaking backgrounds to disability services:

- free access to interpreters for ADHC provided and funded services
- develop translated material in partnership with multicultural communities
- run a social marketing campaign to promote the rights of people with disability, and to promote the concept of rights and services to multicultural communities
- incorporate diversity measures and outcomes in all program guidelines
- develop and implement equity benchmarks to look at quality of service outcomes for people from a non-English speaking background with disability
- build the internal capacity of ADHC to integrate diversity in core planning and invest in staff capacity to work with people from non-English speaking backgrounds with disability
- invest in building sector capacity to be more culturally competent and capable of working with diversity. ⁴⁰⁵

⁴⁰² A/Professor Baldry, Evidence, 26 August 2010, pp 6-7

⁴⁰³ A/Professor Baldry, Evidence, 26 August 2010, p 7

⁴⁰⁴ Ms Llewellyn, Evidence, 26 August 2010, p 28

⁴⁰⁵ Ms Qian, Evidence, 26 August 2010, p 45

Committee comment

- 5.155** The Committee acknowledges the current gaps that exist in the provision of culturally appropriate services to Aboriginal people and people from non-English speaking backgrounds with disability. The Committee notes that these gaps have resulted in the under-representation of Aboriginal people and people from non-English speaking backgrounds in accessing disability services.
- 5.156** The Committee notes success of the Western Australia local area coordinator model of service delivery and believes that, if relevant, it should be considered for implementation in NSW.
- 5.157** The Committee acknowledges the large disparity that exists between the percentage of people from non-English speaking backgrounds with disability in the community compared with the percentage who access services. The Committee further notes that there is currently only one advocacy organisation funded by ADHC that provides services for people from a non-English speaking background with disability. The Committee questions whether one advocacy organisation can provide for the advocacy needs of the number of people from a non-English speaking background with disability that may require assistance accessing services.
- 5.158** The Committee acknowledges ADHC's cultural competency strategy and the ongoing work undertaken to improve the availability and accessibility of culturally appropriate services to Aboriginal people.
- 5.159** The Committee notes that the agency has implemented some programs in an effort to improve the availability of culturally appropriate services to Aboriginal people. The work that is being undertaken by ADHC to increase the number of Aboriginal staff in the organisation is also recognised and commended by the Committee.
- 5.160** The Committee agrees that more culturally appropriate information needs to be developed and made available to relevant communities. The Committee also agree that the lack of free interpreter services to people with disability from a non-English speaking background is a barrier to them receiving services.
- 5.161** The Committee believes that *all* staff need to be able to work with Aboriginal people and people from non-English speaking backgrounds with disability, to ensure that these people have an appropriate level of choice in the services they receive. The Committee agrees with A/Professor Baldry that implementing cultural competency training is important in ensuring this happens.
- 5.162** The Committee agrees with Ms Qian, that it would be beneficial to include diversity measures and outcomes in all program guidelines.

Recommendation 30

That the Minister for Disability Services consider the Western Australian local area coordinator model of service delivery and implements the model in NSW if appropriate.

Recommendation 31

That the Minister for Disability Services provide culturally appropriate disability services information.

Recommendation 32

That the Minister for Disability Services provide free interpreter services to people with disability from non-English speaking backgrounds.

Recommendation 33

That the Minister for Disability Services ensure that all staff in ADHC funded and provided services receive cultural competency training to enable them to work effectively with Aboriginal and Torres Strait Islander people and people from a non-English speaking background.

Recommendation 34

That the Minister for Disability Services incorporate diversity measures and outcomes in all program guidelines.

Chapter 6 Unmet and under-met need

This chapter examines issues regarding the level of unmet and under-met need in the provision of disability services in NSW. The level of unmet need in specific service types is examined, including in supported accommodation, home care, community transport, equipment programs, attendant care and services for people in the criminal justice system. The impact of unmet need on service users, carers and their families is examined, including challenges regarding effective measurement of unmet need.

Overview

- 6.1** Unmet need was identified as a significant issue by many Inquiry participants which affects many service types and service users.⁴⁰⁶ Key areas of unmet need that were identified by Inquiry participants include supported accommodation, home care, respite, equipment programs, attendant care and community transport.
- 6.2** This section provides an overview of unmet need in the disability service system, prior to the examination of issues regarding unmet need within specific service types. Issues regarding the unmet planning needs are examined in Chapter 4, while the unmet needs of carers are examined in Chapter 7.
- 6.3** Mr Dougie Herd, Executive Officer, Disability Council of NSW, told the Committee that the level of unmet need in disability services has improved, however, there is still a long way to go:

Things have undoubtedly improved. There is no doubt about that at all. But I can put the caveat - I think you heard Jim Moore put it and I am absolutely sure you will hear from non-government representatives both in the service provision sector and in the advocacy sector - that as much things have improved and as good as things are now in comparison to how they have been in the past, we still have an awful long way to go. Your earlier conversations about the unmet need are critical conversations in this inquiry.⁴⁰⁷

- 6.4** Several Inquiry participants identified specific areas of unmet need. The NSW Council for Intellectual Disability, for example, identified significant unmet need in accommodation services, therapy places, respite and advocacy services.⁴⁰⁸ Similarly, Council of Social Service of New South Wales identified the following 'priority areas' of unmet need:
- increased funding for HACC;
 - access to Seniors Card benefits for Aboriginal people;
 - acceleration of accommodation options for people with disability;
 - self-directed support funding options;
 - parity for post-school programs; and,

⁴⁰⁶ See for example, Submissions 11, 35, 39, 61, 66, 68 and 101

⁴⁰⁷ Mr Dougie Herd, Executive Officer, Disability Council of NSW, Evidence, 9 August 2010, p 29

⁴⁰⁸ Submission 39, NSW Council for Intellectual Disability, p 10

- *Towards 2030* priorities for older people.⁴⁰⁹

6.5 Mr Patrick Maher, Chief Operating Officer and State Manager of National Disability Services (NDS), identified that ADHC has a finite budget to meet a need that is "... far in excess of that which they can fund."⁴¹⁰ Mr Maher stated that "... without significant additional funding being brought into the sector" unmet need will remain.

6.6 Mr Damian Griffis, Executive Officer, Aboriginal Disability Network (ADN), identified issues regarding the level of unmet need in disability services for Aboriginal people and communities. He stated that Aboriginal people who live in Sydney are more likely to have choice and options of disability services and that these people are "... more likely to be able to work the system in their favour." He stated that there is a high level of unmet need in the regional areas of NSW, which is where half of the Aboriginal population live:

This is not a new issue, but we are concerned that once we get beyond Newcastle, Wollongong and the Blue Mountains, where half the Aboriginal population lives, there is extraordinary unmet need. There are not the services available to be able to meet demand. Aboriginal people with disabilities in regional areas are more or less hidden, not in an abuse and neglect sense, but there is such a lack of services and confidence in the sector. Parents and carers are reluctant to seek help because they are concerned that they will be judged to be bad parents. There is more choice in the Sydney metropolitan area. By definition, that should mean that more Aboriginal people access services in the city. There is also a much more robust community transport sector and Aboriginal controlled sector.⁴¹¹

6.7 Ms Jackie Dufty told the Committee that there is also a level of unmet need that results from ADHC's respite guidelines, especially for people who may relocate from another state or overseas.⁴¹²

6.8 Ms Lauren Murray, Deputy Director General, ADHC, explained that ADHC maintain a register of request for services which indicates that approximately 8,000 people do not currently have a service:

Half of those 8,000 people are receiving another type of service, probably from our community support teams. Then another 35 per cent have completed a service within the last three months. People may request a number of things when they request a service. So they may be waiting for some but receiving others. The vast majority of people have received a service. Then there is another 10 per cent who have received a service within the last three months. If you count all that, you have a substantive number of people who have received some sort of service but may be waiting for a different one. There are about 780 people who have not received any service at all. So it is a much smaller number. Of that number, about half have waited less than three months. Of that other half, they wait equally between under six months and under 12 months or over 12 months.⁴¹³

⁴⁰⁹ Submission 30, NCOSS, p 7

⁴¹⁰ Mr Patrick Maher, Chief Operating Officer and State Manager, NDS, Evidence, 9 August 2010, p 38

⁴¹¹ Mr Damian Griffis, Executive Officer, ADN, Evidence, 27 September 2010, pp 36-37

⁴¹² Ms Jackie Dufty, Public Forum, 30 September 2010, p 24

⁴¹³ Ms Lauren Murray, Deputy Director General, ADHC, Evidence, 9 August 2010, p 13

6.9 Ms Renee Goossens identified that "[t]here is a serious shortage of affordable housing for pensioners who have few or no assets" and that additional options are required.⁴¹⁴

6.10 The author of Submission 11 identified that there is unmet need in the provision of services for children with autism and intellectual disability due to a lack of funding and lengthy waiting lists:

There is not enough funding for children with Autism and intellectual disabilities at school. These children are struggling in the classroom and so are their teachers. Often only children with moderate disabilities receive funding whilst children who are mild but have Autism are left out. DADHC won't help children with Autism on a mild level because of lengthy waiting lists which puts financial pressure on families as they are struggling to cope with the cost of speech and Occupational therapy which is essential for these children.⁴¹⁵

6.11 The author of Submission 11 identified that there is unmet need in the provision of services for children with autism and intellectual disability due to a lack of funding and lengthy waiting lists:

There is not enough funding for children with Autism and intellectual disabilities at school. These children are struggling in the classroom and so are their teachers. Often only children with moderate disabilities receive funding whilst children who are mild but have Autism are left out. DADHC won't help children with Autism on a mild level because of lengthy waiting lists which puts financial pressure on families as they are struggling to cope with the cost of speech and Occupational therapy which is essential for these children.⁴¹⁶

6.12 The National Disability Agreement (NDA), described in section Chapter 2, commits states and territories to improving how unmet need is measured. It stated:

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

Better Measurement of Need – Under this priority: a national model to estimate demand will be developed by mid 2010; there will be improvements in the data collected through the Survey of Disability, Ageing and Carers (SDAC), which will provide a stronger basis for demand estimates; and improvements in the quality of data reported under the National Minimum Data Set, and jurisdiction-level unmet demand data.⁴¹⁷

6.13 Mr Martin Laverty, Chairman of the Board, The Lorna Hodgkinson Sunshine Home, recommended that an advisory group is established to assess unmet need in every region at least every four years:

⁴¹⁴ Submission 2, Ms Renee Goossens, p 1

⁴¹⁵ Submission 11, Name suppressed, p 1

⁴¹⁶ Submission 11, p 1

⁴¹⁷ National Disability Agreement (site accessed 13 October 2010) <www.coag.gov.au/intergov_agreements/federal_financial_relations/docs/IGA_FFR_ScheduleF_National_Disability_Agreement.pdf>

A needs assessment advisory group be established to be chaired by the ADHC Director General and comprising equal numbers of AD1 IC staff, service provider representatives, and independent community members with terms of reference to assess on a rolling basis unmet need within every region at least once every four years with the purpose of making recommendations on how current and future unmet need can best be addressed.⁴¹⁸

- 6.14 Mr Maher believes that additional funding is required to address unmet need and growing demand for disability services.⁴¹⁹

Supported accommodation

- 6.15 Numerous Inquiry participants identified issues regarding the high level of unmet need for supported accommodation services.⁴²⁰ This issue recurred throughout the Inquiry. Issues include a significant shortage of accommodation options, growing demand, poor use of waiting lists, carers unable to effectively plan to transition their children into supported accommodation and a crisis-driven provision of accommodation.
- 6.16 The Disability Investment Group, in its 2009 report *The Way Forward: A new disability policy framework for Australia* observed that, "... of all disability services, the most significant unmet demand and the greatest anxiety for families relates to housing and accommodation."⁴²¹
- 6.17 While ADHC has already met service targets identified in Stronger Together across most service categories, it has yet to meet targets for provision of specialist supported accommodation. Stronger Together aimed to introduce 990 supported accommodation places by June 2011 but by 30 June 2010 only 677 had been made available.⁴²²
- 6.18 The Association of Children with a Disability wrote that the current shortage of supported accommodation in many states is inhumane:

There is a chronic lack of out-of-home long term supported accommodation for adults with a disability in Australia.

In some States, it is impossible to obtain a place in supported accommodation without relinquishing your rights over your child in order to satisfy the authorities that your child is "homeless or at risk". No parent wants to do that.

Even then, the likelihood is that your child will end up simply blocking a bed in a respite service, or your child will be placed in a nursing home because there will not be a permanent bed available. **This situation is inhuman and has to be remedied.** [emphasis as per original]⁴²³

⁴¹⁸ Submission 61, The Lorna Hodgkinson Sunshine Home, p 3

⁴¹⁹ Mr Maher, Evidence, 9 August 2010, p 37

⁴²⁰ See for example, Submissions 13, 38, 39, 101 and 110

⁴²¹ Report of the Disability Investment Group (2009) *The Way Forward: A new disability policy framework for Australia* (accessed 18 October 2010) <www.fahcsia.gov.au/sa/disability/pubs/policy/way_forward/Pages/default.aspx>

⁴²² Submission 31, ADHC, p 34

⁴²³ Submission 96, Association for Children with a Disability NSW, p 10

- 6.19** Examination of the use of ADHC's vacancy management system in providing supported accommodation services is provided in Chapter 5. Examination of issues regarding service users' ability to plan to access supported accommodation is provided in Chapter 4. Carers' experience of supported accommodation is examined in Chapter 10.
- 6.20** In his submission on behalf of Anglicare Sydney, Mr Kell stated that it is "... generally acknowledged that there is a chronic shortage of supported accommodation for people with a disability." This includes "... a significant gap in the provision of such accommodation which would allow both ageing parent carers and their adult children with a disability to be co-located in the same or adjoining facilities."⁴²⁴
- 6.21** Ms Berry also explained that there is significant unmet need for supported accommodation services. She stated "[t]here is still major unmet need in appropriate supported accommodation. We receive many calls from the community about this."⁴²⁵
- 6.22** The author of Submission 110 believes that there is an "... extreme shortage of supported accommodation ..." and that this is the "... most critical and pressing problem amongst the services funded by ADHC."⁴²⁶
- 6.23** Ms Susan Smidt, Coordinator, Disability Information Advocacy Service, stated "[t]here is an urgent need to plan for more supported accommodation at different levels to accommodate the increasing number of persons with disability that will require varied levels of support."⁴²⁷
- 6.24** Ms Bernadette Moloney, the mother and carer of Charley, told the Committee that "... the only way to get a supported accommodation place is to keep going until you cannot possibly go any longer and then to leave your child ... at respite."⁴²⁸ Ms Moloney identified that ADHC is responding to this through "... building policy and procedure around it. It now offers parents counselling because they know it is traumatic to leave your most vulnerable child at respite."
- 6.25** An addition concern identified by Ms Moloney is the belief that there is no effective waiting list for supported accommodation. Ms Moloney stated "[i]n the future we will require supported accommodation. I have not bothered putting Charley's name on the list because I know that the list is never referred to."⁴²⁹
- 6.26** Issues regarding the use of waiting lists by ADHC and funded services are examined in more detail in Chapter 5.
- 6.27** Ms Christine Regan, Senior Policy Officer, NCOSS conveyed the experience of a carer who could not access equipment to help her care for her son, and that it was only after she broke down and was no longer able to care for him that supported accommodation was made available:

⁴²⁴ Submission 66, Anglicare, Diocese of Sydney, p 15

⁴²⁵ Submission 39, p 9

⁴²⁶ Submission 110, Name suppressed, p 1

⁴²⁷ Submission 57, Disability Information Advocacy Service, p 1

⁴²⁸ Ms Bernadette Moloney, Public Forum, 30 September 2010, p 18

⁴²⁹ Ms Moloney, Public Forum, 30 September 2010, p 18

I know of one woman who could not get equipment into her house in order to have her son, who had very high support needs, seated and into bed. This was only about three years ago. She used to put a sleeping bag on the floor and she fed him on the floor until her own shoulders gave out and she had to go into hospital. Only at that point was she offered supported accommodation for her son, when she had completely broken down. These stories just happen over and over. It is shameful.⁴³⁰

- 6.28** Ms Estelle Shields, a mother and carer, stated that supported accommodation is only provided to people "... whose parents have died, whose support arrangements have totally broken down and who are homeless and destitute."⁴³¹ Ms Shields identified that most carers will pass away before the child they are caring for, which is "... why it is so essential that we can see our family members settled in their local community, preserving their family and community ties."⁴³²
- 6.29** Case study 4 illustrates the stress and frustration experienced by the Shields family during their efforts to plan and access supported accommodation for their family member.

Case study 4 - Ms Estelle Shields⁴³³

The truth is that this side of the grave, there is no hope of supported accommodation for any family in this state, unless it is strong enough to relinquish care of its disabled member. I am part of a group of parents in the Ryde area who formed RASAIID (Ryde Area Supported Accommodation for Intellectually Disabled). For seven years we have been trying to achieve our dream of a cluster development in our local area for our sons and daughters. Despite intense media coverage and the support of several politicians, we always come back to this one obstacle: the few places must go to the most needy, and we, being still alive, cannot be considered a high enough priority.

There remains no way we can plan for the futures of our sons and daughters, no way we can see them gradually transitioned into a new residential setting, no way we can avert the tragedy and trauma that will befall them when they will lose, in one fell swoop, the p h a r y carer, the only home ever known and the local community. And this will be for a person who, because of his or her disability, has adaptive capacities that are less developed than in the general population. I rail at the injustice of it, in a rich and prosperous nation enjoying a mining boom, with waste afoot at every turn and money for everything, it would seem, except our most needy citizens.

Grass roots groups of families, such as our RASAIID organization, are springing up throughout the country. They are a response to both the lack of supported accommodation and to the Vacancy Management Policy. We all know that if we were ever to be fortunate enough to achieve a residential placement for our son or daughter, it would unfortunately be in a far-flung suburb.

- 6.30** Mr Frank Francis, Chief Executive Officer of Sunnyfield Independence, also believes that supported accommodation is provided on a crisis basis.⁴³⁴

⁴³⁰ Ms Christine Regan, Senior Policy Officer, NCOSS, Evidence, 9 August 2010, p 62

⁴³¹ Submission 15, Ms Estelle Shields, p 2

⁴³² Submission 15, p 5

⁴³³ Submission 15, p 2

⁴³⁴ Submission 59, Sunnyfield Independence, p 2

6.31 Ms Epstein-Frisch stated that "[a]ccommodation support is crisis driven" and that "[i]t is allocated at the point of family breakdown and teaches families that crisis is rewarded with 'a bed'." Ms Epstein-Frisch believes that a crisis-based system has many risks and consequences including:

- people believing that crisis is the only way of moving from the family home;
- a reluctance to plan for or trial arrangements without having first secured funding;
- a generalised reduction in community capacity arising from too great a dependence on funded supports that push out welcoming inclusive practices and leave people with disability isolated;
- trauma and mental health problems for people with disability as well as their families;
- growth of unmet need to such levels that addressing it seems overwhelming for government policy makers and funders;
- people living in accommodation that is inappropriate to their needs;
- people being moved between vacant 'beds' in a way that is dislocating, destabilising and dehumanising.⁴³⁵

6.32 Ms Louise Bannerman, Disability Development Officer, Warringah Shire Council, also believes that the current disability service system requires parents to care for their children until they pass away:

Under the current system every carer is expected to care for their child from cradle to death and this completely inequitable. Every carer must be entitled to supported accommodation for their child with a disability. A variety of appropriate accommodation options must also be made available under such a scheme.⁴³⁶

6.33 Ms Emily Caska, State Policy Coordinator, NDS, identified that the number of supported accommodation places funded through the first five years of Stronger Together (2006/07 to 2010/11) is 1,370.⁴³⁷ The Physical Disability Council of NSW and Council on the Ageing NSW submission also acknowledged the increase in accommodation services available through Stronger Together.⁴³⁸

6.34 Ms Marshall expressed that "Stronger Together one failed to address the issue of lack of future planning for supported accommodation and the total crisis and misery of families."⁴³⁹ She also believes that "... the need for supported accommodation is only going to get worse."

6.35 Ms Marshall recommended that future planning is required to ensure that families can transition to supported accommodation in an organised and timely manner. She stated:

Solution 1 - Future Planning: Families should have the right to future planning for an organised and timely transition for their loved one into an appropriate

⁴³⁵ Submission 23, Family Advocacy, p 5

⁴³⁶ Submission 108, Warringah Council, p 4

⁴³⁷ Submission 32, NDS, p 8

⁴³⁸ Submission 51, Physical Disability Council NSW and Council on the Ageing NSW, p 4

⁴³⁹ Ms Janice Marshall, Public Forum, 30 September 2010, p 21

accommodation setting, with quality services and a degree of family control, at a time when family still has the health and energy to do this. This will relieve families of a burden of stress, improve their mental and physical health, encourage them to be greater partners in the process, and reduce total costs.⁴⁴⁰

6.36 The ADHC submission stated that the agency "... is building more comprehensive and accurate administrative data on demand for supported accommodation" to quantify the number of people who require this accommodation.⁴⁴¹

6.37 ADHC has developed a Register of Requests for Supported Accommodation, which 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." ADHC stated:

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.⁴⁴²

6.38 There are currently 723 people on the Register who require a 24 hour supported accommodation placement "... and are willing to take up a place immediately on offer."⁴⁴³

6.39 Ms Caska stated that the "... future need and immediate need registers collated by ADHC indicate and continuing demand for supported accommodation services across all regions."⁴⁴⁴

6.40 Mr Moore acknowledged the limitations of the Register, stating that "... the list is only growing into being a credible list. We have been building it up. Only in the last six months we have had the right policy settings in terms of definitions and so on."⁴⁴⁵

6.41 Estimates of unmet demand for accommodation services vary. For example, Dare to Care, an advocacy group based in the Nepean and surrounding areas, wrote that "... there is a vast unmet need in the Nepean LGA with regard to Supported Accommodation. Funding under Stronger Together, although very welcome, has not met this need."⁴⁴⁶ Ms Regan observed that the shortfall in NSW may be as high as 6,000 places:

A really good example of the unmet need is that...when Stronger Together finally delivers, with some of the promised Commonwealth positions, just under supported accommodation, NSW will have benefited by about 1,400 places since 2005. That is a

⁴⁴⁰ Ms Marshall, Public Forum, 30 September 2010, p 21

⁴⁴¹ Submission 31, p 48

⁴⁴² Submission 31, p 48

⁴⁴³ Submission 31, p 49

⁴⁴⁴ Submission 32, p 10

⁴⁴⁵ Mr Jim Moore, Chief Executive ADHC, Evidence, 9 August 2010, p 11

⁴⁴⁶ Submission 22, Mrs Joyce Bellchambers, Dare to Care, p 3

good increase. But in 2005 the Australian Institute of Health and Welfare said NSW needed, at crisis, 7,300 places, but more probably 10,400 places.⁴⁴⁷

- 6.42** However, Mr Moore disputed the use of population-based estimates of unmet need such as those made by the Australian Institute of Health and Welfare:

In NSW the single biggest question that people keep throwing at us is, “But have you met enough of the need? There is more need. You’re not meeting enough.” That one cannot be answered in an objective way by looking at the population data and service delivery data...the Australian Institute of Health and Welfare has done its best to extrapolate from ABS data what will be the level of unmet need. They tell us that nationally it is about 30,000 supported accommodation places that they believe the data says need to be met but are not being met.

That would mean, on just general population dynamics, 10,000 in NSW. I do not deny there is not a lot of unmet need, and I did not see 10,000 worth of unmet need...We have about 750 people at the moment who are saying, were they to be asked, they could accept a place immediately. We have another thousand who would say they would like a place sometime in the future. It is still a long way to go from there to get to 10,000.⁴⁴⁸

Committee comment

- 6.43** The Committee acknowledges that there is evidence of significant unmet need for supported accommodation services in NSW.
- 6.44** The Committee recognises that a shortage of supported accommodation is one of the most significant issue facing the disability services sector and sympathises with the families who are under considerable stress caused by a lack of support to plan for the future of their children.
- 6.45** ADHC itself acknowledged that there is immediate need for 750 supported accommodation places and need for another 1,000 places in the future. Even if the number of places in Stronger Together were created immediately, there would still be significant unmet need. However, the Committee considers that it is crucial as a first step that ADHC meet the targets for supported accommodation places in Stronger Together. The second phase of Stronger Together should contain further targets in the magnitude of those identified by Mr Moore. The research recommended by the Committee in Recommendation 1 will inform the targets to be set.
- 6.46** The Committee acknowledges the steps that ADHC is taking to increase the number of supported accommodation placements through Stronger Together. The Committee further notes the contribution that the Register of Requests for Supported Accommodation may have in quantifying the demand for accommodation and planning an appropriate level of service.
- 6.47** The Committee notes the requirement of the NDA to better measure unmet need of disability services. The Committee supports the development of a national model to estimate demand, however, notes that the need for increased supported accommodation options in NSW required more immediate solutions.

⁴⁴⁷ Ms Regan, Evidence, 9 August 2010, p 58

⁴⁴⁸ Mr Moore, Evidence, 9 August 2010, p 6

- 6.48** The Committee notes, however, that there are still many families who feel despondent about being able to effectively plan for and receive supported accommodation for their children before the families reach crisis point. The Committee has heard that there are many people who are not confident in ADHC's use of registers and waiting lists, as discussed in Chapter 5. This may mean that there is a significantly higher number of people who require supported accommodation than the Register describes.
- 6.49** The Committee believes that improved communication is required from ADHC to families who are waiting for supported accommodation, so that these people are aware of whether they are eligible for supported accommodation, how long the wait is and to ensure that families receive an appropriate level of support while waiting.
- 6.50** The Committee recommends that ADHC should regularly communicate with all families on the Register of Requests for Supported Accommodation to assess eligibility, advise how long the anticipated wait for accommodation is and to ensure that families receive an appropriate level of support while waiting for these services.
- 6.51** The Committee believes that phase two of Stronger Together provides an opportunity for supported accommodation unmet need to be addressed. The Committee recommends that the number of supported accommodation options increases as a priority through Stronger Together two to meet the need on the Register and the anticipated ongoing, growing demand.
-

Recommendation 35

That the Minister for Disability Services increase the number of supported accommodation options available as a priority, through phase two of Stronger Together to meet the need on the Register and the anticipated ongoing, growing demand.

Recommendation 36

That ADHC regularly communicate with all families on the Register of Requests for Supported Accommodation to assess their eligibility for supported accommodation, communicate how long the anticipated wait is and to ensure that families receive an appropriate level of support while waiting for accommodation.

That in cases where a family has remained on the Register of Requests for Supported Accommodation for more than six months, ADHC is to advise the Minister of the unfulfilled request.

Home care services

- 6.52** Many Inquiry participants expressed concern about the home care program, including the availability out-of-office hours support, quality of services provided, including regional variation of service quality and poor communication.
-

- 6.53** Mr Moore explained that the Home Care Service of NSW is one of four business streams in each region that "... 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."⁴⁴⁹
- 6.54** ADHC also administers the Home and Community Care (HACC) Program, which is funded by both the NSW and Australian Government.⁴⁵⁰ ADHC advised that "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 Department of Health (NSW Health) and the Home Care Service of NSW, local governments and non-government organisations.

- 6.55** The HACC program is described in Chapter 2.
- 6.56** Mr Killeen explained the importance of government services in enabling people to live in the community:

Government funded and/or provided services and programs are essential to enable people with disability to live in the community as we would simply not survive without them. Appropriately funded, administered and coordinated services and programs, that are also flexible and affordable for people with disability, generally have an ongoing positive impact on the quality of life' of people with disability, including their families and carers, enabling them to participate in the community as active members of society.⁴⁵¹

- 6.57** Mr Sean Lomas, Policy and Advocacy Manager, Spinal Cord Injuries Australia, told the Committee that ADHC provided home care services do not have out-of-office hours staff available to communicate with service users when, for example, staff are not able to make an appointment.⁴⁵² Mr Lomas stated:

You certainly have two testimonials from people saying that they spend the nights sitting in their chairs because no-one contacted them. They do not know when someone is coming. They have no idea what has happened. They will sit there for the evening, generally in quite a foul state, risking skin breakdown and a whole host of issues.

- 6.58** Mr Killeen advised that ADHC require funded services to ensure an after-hours contact is available, however, do not require this of their funded services.⁴⁵³ Mr Killeen noted that the

⁴⁴⁹ Submission 31, p 10

⁴⁵⁰ Submission 31, p 18

⁴⁵¹ Submission 42, Mr Greg Killeen, p 2

⁴⁵² Mr Sean Lomas, Policy and Advocacy Manager, Spinal Cord Injuries Australia, Evidence, 26 August 2010, p 34

⁴⁵³ Mr Greg Killeen, Senior Policy Officer, Spinal Cord Injuries Australia, Evidence, 26 August 2010, p 34

Randwick-Botany Bay Home Care Branch is the only home care branch that currently has an out-of-office hours staff contact.

Clients with high needs and the field staff, if they are unable to turn up to work the next morning or that night, can ring that mobile number. That person carries not a laptop but a couple of sheets of paper; one with clients' numbers, and one with field staff numbers, and tries to coordinate, as best she can, a back-up service.⁴⁵⁴

- 6.59** Mr Lomas recommended that the ADHC home care program should require staff to communicate when they are unable to attend an appointment, to provide improved certainty for service users:

That is a simple way for a properly created scheme to provide some degree of certainty, that should a carer not turn up, for whatever reason ... and call in outside regular hours to say that they would not be in tomorrow because they do not feel very well, then you have some degree of support for that individual.⁴⁵⁵

- 6.60** Mr Killeen identified that there is a discrepancy between what ADHC provides and what it requires of funded organisations:

... as the NSW Home Care Service is one of the largest service providers across NSW it needs to practice what it preaches and implement an appropriately funded an "Out Of Office Hours backup service"... The Home Care Service is an essential service that is greatly valued by service users, particularly people with severe physical disability, and it deserves nothing less than to provide an appropriately funded and coordinated backup service.⁴⁵⁶

- 6.61** Ms Dufty, the wife and carer of a person who is quadriplegic, expressed frustration at her experience of the home care program:

My spouse went into the hospital for unexplained condition. He was not even in the hospital 1 hour before we got a call from the homecare respite service saying we had been dropped from the program and that the hospital would have to sort it out. The Home Care company had already billed the government for the time but refused to provide the care even after he was discharged from hospital.⁴⁵⁷

- 6.62** Case study 5 provides an example of the challenges and limitations of the home care program meeting the needs of service users.

Case study 5 – Name suppressed⁴⁵⁸

I am a wheelchair user with a spinal cord injury, and I have been receiving Home Care services since an accident several years ago. The majority of my care workers have been lovely, with a genuine desire to help people, backed up with an ability to do so. One such care worker changed my life in very positive

⁴⁵⁴ Mr Killeen, Evidence, 26 August 2010, p 35

⁴⁵⁵ Mr Lomas, Evidence, 26 August 2010, p 34

⁴⁵⁶ Submission 42, p 2

⁴⁵⁷ Submission 105, Name suppressed, p 1

⁴⁵⁸ Submission 40, Name suppressed, pp 1-2

way. As I'm largely independent, the service I receive only includes cleaning. As I work 4-5 days a week and lead a busy extra-curricular life (volunteering, training and contesting parking fines, among other things), I need a cleaner to be able to come while I am not at home. Where I was living previously, this was arranged without issue. When I moved to another suburb, I changed ADHC areas and was told that only under exceptional circumstances could a care worker be given a house key, and my circumstances were not exceptional ... Imagine telling people, week after week, that you can't make a meeting, training, a dinner or other event because the cleaner was coming.

I then wrote to the Minister, who made it happen, and there hasn't been an issue since. When Government policies at both Federal and State level are focussing on getting people with disabilities off the pension and into paid employment, other programs need to support this, and they need to do it consistently across geographical areas. A further source of frustration is the clear delineation that care workers can't do anything outside the house. I have a small back deck, which is level with the kitchen, and it gets covered in leaf litter. Every week, the house is cleaned, and the back deck can't be swept. This is ridiculous. Taking this further, my garden is generally unkempt, as there are no services available to assist with this. When making enquiries to an Eastern Sydney service, I was informed that they were no longer accepting people on the waiting list. The windows don't get washed, there are cobwebs on the ceiling, the grout on the bathroom floor is black. I hate to think about what's living under my lounge. Anything extra simply doesn't happen.

While I have never had an issue with the attitude of care workers, the attitudes of office staff, on occasion, have been disturbing. I'm a professional, I have a professional phone manner, and the office staff who answer the phone don't immediately know that I am a client. There have been a few occasions (fortunately rare, but memorable) where upon being informed that I was a client, there was an abrupt and cutting change of attitude by the staff member, changing from positive and helpful, to something that sounded like they thought I was opportunistic and complaining scum. Having worked for a similar State Government Department, I know this kind of attitude is rife amongst the corporate staff. I had never thought to be on the receiving end of it, and it was eye opening. Nothing but exposure will change attitudes like this, and education needs to be driven from the top.

6.63 The NCOSS submission also identified problems with the home care program, including a lack of waiting lists and regional variation in service provision:

The Home Care Service of NSW maintains no waiting lists, despite the recommendation of the 2005-6 NSW Public Accounts Committee Inquiry into Home and Community Care Program and Services. While talking to the regions, NCOSS hears constant frustrations from people and providers who try to access support services from Home Care Service. If capacity is full on the day, the caller is asked to call another time and/or given other phone numbers. Ordinary people may interpret this as being rejected by the entire HACC system and may not call again. There has been some improvement in recent times but regional variations still occur, despite the centralised system.⁴⁵⁹

⁴⁵⁹ Submission 30, p 8

- 6.64** Mr Lomas also described challenges regarding poor communication in the home care program in ADHC regional areas, which has resulted in his organisation acting as intermediary between ADHC head office and its regions:

This often relates to home care provision in the regions. I receive perhaps one or two calls a month on this basis from people living in regional NSW saying they have been informed by their home care manager that an element of their service will be changing. My response is usually that I have not heard anything about it. I contact the ADHC head office in Sydney and I am told that they have it wrong. I am then piggy in the middle and have to inform ADHC regional staff that that is not the case. I certainly should not be playing that role as an advocacy worker; it is not my role to educate regional ADHC staff or to ensure that they are complying with policies created through consultation in Sydney.

- 6.65** Mr Lomas observed that "... managers generally rolled over every two years and there was not necessarily reinforcement of training or re-emphasis of the guidelines and the policies to the new managers." Mr Lomas stated that information is passed on through word of mouth, "[i]t was like Chinese whispers and over an extended period things can get skewed."⁴⁶⁰

- 6.66** In answers to questions taken on notice the Deaf Society of NSW advised that many older deaf service users, including those from CALD backgrounds, are "... missing out on support from the services available through HACC." Reasons for this include:

The staff employed by agencies funded by HACC are not equipped to provide effective support to deaf people as they are not trained to communicate or understand the needs of deaf people. A further barrier to access to this program is that funding made available for people from culturally and linguistically diverse backgrounds is not accessible to the DSNSW [Deaf Society NSW] as Auslan is not recognised as a language by that program. Many older deaf people are isolated in their homes without communication or basic support services.⁴⁶¹

- 6.67** The Deaf Society of NSW recommended that a partnership is developed with HACC so that the Deaf Society can delivery services:

The Deaf Society of NSW (DSNSW) would like to see a partnership develop between the DSNSW and HACC so that the DSNSW can deliver services such as case management, social support, domestic assistance and personal care to senior members of the Deaf community. As the exact demand is not known, we recommend that a pilot project is conducted over one year to deliver the program and assess the needs of the over 65 deaf population in the Sydney Metropolitan and Hunter regions in terms of what HACC can provide.⁴⁶²

Committee comment

- 6.68** The Committee acknowledges the frustration experienced by many service users who depend on the home care program to deliver essential services. The Committee is concerned by the

⁴⁶⁰ Mr Lomas, Evidence, 26 August 2010, pp 32-33

⁴⁶¹ Answers to questions taken on notice during evidence 27 September 2010, The Deaf Society of NSW, Question 3, p 2

⁴⁶² Answers to questions taken on notice during evidence 27 September 2010, The Deaf Society, Question 3, p 2

apparent absence of an out-of-office hours staff contact in ADHC provided home care programs. The Committee believes that this is a significant risk for service users who depend on home care services at all times of the day and night.

- 6.69** The Committee believes that service users are entitled to be informed if staff are unable to attend, and for the ADHC home care program to coordinate appropriate communication and back-up staff in their absence. The Committee further notes the discrepancy created through ADHC requiring funded services to ensure that after-hours contacts are available to communicate with service users, however, that ADHC do not require this of their own home care program.
- 6.70** The Committee believes that an out-of-office hours staff member should be available to coordinate after hours changes to service delivery for *all* home care programs. The Committee recommends that out-of-office hours staff are available in all regions to coordinate after hours changes to service delivery for all ADHC provided home care programs.
- 6.71** The Committee notes the poor quality of home care service delivery experienced by some Inquiry participants, including the example of a service user being dropped from the respite program at short notice. The Committee further notes the regional variation in the provision of home care services.
- 6.72** The Committee acknowledges the reasons provided by Mr Lomas for poor regional communication, including lack of reinforcement and training of guidelines when staff leave. The Committee believes that there should be a formal process in place to ensure that all relevant staff are aware of current procedures and policy in the home care program.
- 6.73** The Committee recommends that relevant staff are made aware of current policy and procedures in the home care program through participating in regular training.
- 6.74** The Committee notes with concern the gap in the HACC program for older deaf service users, and the isolation experienced by older deaf people from CALD backgrounds. The Committee agrees with the Deaf Society that there should be HACC staff available that are trained to communicate and understand the needs of deaf people.
- 6.75** The Committee recommends that HACC staff are available in every region to communicate with, understand and respond to the needs of deaf people.

Recommendation 37

That the Minister for Disability Services establish an out-of-office hours staff member in all regions to coordinate after hours changes to service delivery for all ADHC provided home care programs. That this staff member communicates with service users when there are after hours changes to service provision.

Recommendation 38

That the Minister for Disability Services ensure that all relevant staff are aware of current policy and procedures in the home care program, to improve consistency in this program across regions, through the implementation of regular training.

Recommendation 39

That the Minister for Disability Services ensure that there are HACC staff available in every region who are trained to communicate with, understand and respond to the needs of deaf people.

Community Transport

- 6.76** Inquiry participants were keen to impress upon the Committee the importance of regular, accessible community transport. Transport is an enabling service to other support services, such as out-of-home respite and day therapies, and is critical to the effectiveness and responsiveness of supports to an individual.⁴⁶³ Also, an efficient transport system allows for people with disabilities to be more active participants in community life.
- 6.77** Community transport is funded by ADHC through the HACC program and is commonly delivered by NGOs and/or local councils.⁴⁶⁴ Community transport provides transport for social group outings, as well as individual transport, including hospital and medical appointments.⁴⁶⁵ Frail older people and people with disability, including their children and carers, are eligible for these services. Service users are expected to pay a fee for service, however they will receive services regardless of their capacity to pay.⁴⁶⁶
- 6.78** Certain Inquiry participants expressed frustration at current community transport provisions. Mr Killeen, a service user, noted a number of problems with the delivery of this service:
- services are usually limited to 9.00 am – 5.00 pm, Monday to Friday
 - services are not available to transport people to and/or from employment, education or training
 - people in rural areas are often restricted to using a limited number of buses and wheelchair accessible taxis
 - each provider is required to have at least 70 per cent of its fleet with wheelchair access.⁴⁶⁷
- 6.79** The Committee received evidence about the unsatisfactory level of community transport in rural and regional areas of NSW. The Physical Disability Council of NSW and Council on the Ageing noted that access to services and supports for people with disability can be hampered by poor transport facilities in these areas:

... PDCN and COTA have additional concerns about the under utilisation of some respite and other services because the need for personal transport is much more

⁴⁶³ Submission 30, p 7

⁴⁶⁴ Submission 42, p 4

⁴⁶⁵ Submission 42, p 4

⁴⁶⁶ NSW Government Transport, Home and Community Care (HACC) Community Transport Sub-Program, (accessed 18 October 2010) < <http://www.transport.nsw.gov.au/lact/hacc.html> >

⁴⁶⁷ Submission 42, p 4 and Submission 42a, p 1

prevalent in regional areas where accessible public transport is not as available. The Audit office also found that carers indicated that distance was a major factor limiting their ability to use respite. Even where a centre is close by, some carers are not able to use it. For example an 82 year old carer may not have a license or the car needed to get his son/daughter to and from a respite centre.⁴⁶⁸

6.80 Northcott Disability Services had similar concerns, saying that "[a]ccess to services is also limited for people in regional and rural areas due to inadequate transport facilities and because clients are unable to use funding to cover the cost of accessing disability support services."⁴⁶⁹

6.81 The Local Government and Shires Association further supported this argument stating that funding impedes the provision of adequate community transport services:

Services in remote areas face additional costs, especially for transport. The HACC Resource Allocation Formulation does not consider remoteness as a factor which influences the cost of services. Councils in rural and remote areas of NSW argue strongly that transport costs due to long distances are significant factors in service delivery in isolated areas.⁴⁷⁰

6.82 Funding concerns were also addressed by the NSW Council on Intellectual Disability who said that "[i]n some regional areas there are options in providers, but the smaller provider cannot always offer transport or as many hours due to a smaller pool of money being available."⁴⁷¹

6.83 The Committee was informed of specific examples of unmet need for community transport services in metropolitan regions. The Local Government and Shires Association told of the problems accessing community transport in Sydney:

Greenwich Hospital has the only hydro-therapy pool in area and is very difficult to get to by public transport. Community transport has a limit to the number of trips it can provide per person i.e.: 20 return trips per year which is inadequate for clients having chemotherapy or dialysis treatments or other rehabilitation programs.⁴⁷²

6.84 The Physical Disability Council of NSW and Council on the Ageing also expressed concerns about the availability of community transport in eastern Sydney:

... essential Health Related Transport (HRT) is booked out in the Eastern Sydney Region and long waiting lists occur on a daily basis. People are refused service simply because there are no more available vehicles and workers available to deliver the service required. People are unable to access HRT for kidney dialysis; others cannot access HRT for chemotherapy. HRT is booked out months ahead, and others are denied access to specialists, clinics and therapy due to the fact that there is no spare capacity.⁴⁷³

⁴⁶⁸ Submission 51, p 9

⁴⁶⁹ Submission 70, Northcott Disability Services, pp 5-6

⁴⁷⁰ Submission 72, Local Government and Shires Association of NSW, p 7

⁴⁷¹ Submission 39, p 11

⁴⁷² Submission 72, p 4

⁴⁷³ Submission 51, p 9

- 6.85** The South East Neighbourhood Centre was fearful that the community transport services it provides will be placed under significant pressure by the ageing population of the areas it services.⁴⁷⁴ The South East Neighbourhood Centre also noted that the increase in frail aged and/or people with disability requires additional room for mobility aids and carers.⁴⁷⁵
- 6.86** Concern was also conveyed about the practices of certain community transport service providers. Spinal Cord Injuries Australia offered an example an issue that arose with one of their service users:
- ... we have been made aware of a Molong consumer who has expressed concerns after being told the local Community Transport HACC funding guidelines apparently stipulate that the service exists primarily for the Aged, not for people with disabilities.⁴⁷⁶
- 6.87** Inquiry stakeholders recommended that the Government increase funding to community transport providers in an effort in to address problems with service delivery. Mr Killeen explained why increased funding would assist in rectifying these issues:
- ... the NSW Government must ensure community transport services have at least one vehicle with wheelchair accessibility with the aim of requiring all community transport services to have 100 per cent accessibility of their fleet with the capacity to transport at least one person using a wheelchair. To achieve this, ADHC should provide funding now to ensure each community transport service has at least one vehicle with access for one person using a wheelchair. If an existing community transport vehicle is considered too old to update with wheelchair access, then when that same vehicle is being retired (or traded in) the replacement vehicle must be wheelchair accessible and have the capacity for at least one wheelchair user. Preferably, recurrent NSW Government funding should be provided to community transport service providers that can be accumulated and budgeted for vehicle replacement that could be done in conjunction with the existing vehicle trade in.⁴⁷⁷
- 6.88** Physical Disability Council of NSW Council of the Ageing proposed ADHC provide additional and targeted funding to community transport providers so they can expand their services in areas that are found to have low levels of accessible transport options.⁴⁷⁸

Committee comment

- 6.89** The Committee recognises the importance of an accessible, efficient community transport system. Community transport enables people with disabilities to access other services and to participate in the community. It is disappointing to receive evidence of unmet need for services across the State, particularly as this situation will become increasingly worse as the population ages. It is imperative that sufficient funding is directed towards community transport in both metropolitan and regional areas.

⁴⁷⁴ Submission 18, South East Neighbourhood Centre, p 1

⁴⁷⁵ Submission 18, p 1

⁴⁷⁶ Submission 67, Spinal Cord Injuries Australia, p 9

⁴⁷⁷ Submission 42a, p 1

⁴⁷⁸ Submission 51, p 13

- 6.90** The Committee did not receive information about the provisions for community transport services after responsibilities for the HACC program are split between the State and Federal Governments in 2012. As such, the Committee has insufficient evidence to make an appropriate recommendation about funding to the community transport program.
- 6.91** The Committee recommends that the Government ensures community transport concerns are addressed, particularly the need to make the service more person-centered, as a priority through the phase two, of Stronger Together.

Recommendation 40

That the NSW Government ensures community transport concerns are addressed, particularly the need to make the service more person-centered, as a priority through the phase two, of Stronger Together.

Attendant Care Program

- 6.92** The Attendant Care Program (ACP) provides funding for the provision of 15 to 35 hours of high-level in-home personal care and support services to assist people with physical disability with their daily tasks.⁴⁷⁹ The program is funded by the National Disability Agreement and administered by ADHC. Concerns about the program included its stringent practice guidelines, funding provisions, the possible impact of payments to family members and the skills of attendant care workers.
- 6.93** The ACP has three different funding models. The service user/care worker relationship is dependent on the funding model the service user chooses. ADHC describes the three funding models as:
- **Employer Model** - Funds are paid to an approved service provider who employs the attendant carers and is accountable to ADHC for expenditure and service quality. Clients can be involved in the selection, rostering and management of attendant carers to different degrees.
 - **Cooperative Model** - Funds are paid to an approved service provider who manages the funds, provides administrative support and is accountable to ADHC for expenditure and service quality. Clients are the employers of attendant carers and are responsible for managing them.
 - **Direct Funding Model** - Funds are paid directly to the client who is responsible for purchasing approved services and managing their care. Clients take on the full employer/service provider responsibility and are accountable to ADHC for expenditure and service quality under a Funding Agreement.⁴⁸⁰

⁴⁷⁹ ADHC, *Attendant Care Program Direct Funding Model Guidelines*, 2008, p 1, (accessed 2 November 2010) <www.dadhc.nsw.gov.au/NR/rdonlyres/F2249DF5-BB20-412E-8513-FED30662FFD9/4229/ACPDirectFundingModelGuidelinesV10_final.pdf>

⁴⁸⁰ Ageing, Disability and Home Care, *Attendant Care* (accessed 12 October 2010) <<http://www.dadhc.nsw.gov.au/dadhc/People+with+a+disability/Attendant+Care.htm>>

- 6.94** The take-up rate for the Direct Funding Model is very low with only 18 ADHC service users currently accessing it.⁴⁸¹
- 6.95** A reason for the low take-up rate may relate to the strict guidelines and procedures of the ACP. While the application of these policies is necessary, certain inflexibilities caused the ire of Inquiry participants. Mr Adam Johnston was accepted into the ACP but declined to take up the package because of the requirement that he renounce the use of Home Care.⁴⁸² Mr Johnston said that it would be inappropriate to take such action because his Home Care care workers had become attuned to his intimate personal care needs.⁴⁸³
- 6.96** The Committee heard that the eligibility criteria for the ACP discriminated against certain groups. The Deaf Society of NSW noted that deaf people with additional disabilities cannot access the program and recommended that this be amended.
- 6.97** Certain Inquiry participants highlighted the inefficiencies that the stringent adherence to the ACPs guidelines and procedures can have on the disability services sector and the health of service users. ParaQuad shared the experience of one of its service users who was on the waiting list for the ACP for 3 years:

ParaQuad accepted a gentleman, into our residential care facility, for transitional care whilst his home modifications were being done and he awaited allocation of an Attendant Care Package. As the client was 60 at the time of his injury, he was not prioritized on the wait list. The said client passed away at the age of 63 whilst still in residential care, despite having a fully renovated property to return to with his family. His family therefore went through the expense of modifying his home and never had the chance to live with him after his injury. Representation was made to Metro North ADHC staff throughout this time to support his application, however little was done, too late to assist this gentleman.⁴⁸⁴

- 6.98** An additional inefficiency related to when attendant care workers can work. In its submission Allowance Inc alerted the Committee to the fact that service users cannot be attended to by their attendant care worker during hospital stays.⁴⁸⁵ It is suggested that this hinders the service users' recovery and leaves the attendant care worker without employment during the course of the hospital visit.⁴⁸⁶
- 6.99** There was some discussion about the funding structure for the ACP by Inquiry participants. Allowance Inc recommended that the federal government fund and administer the program to allow people from around Australia to access it:

The main problem I see with the attendant care package is the source of funding. We strongly feel that funding should come from and be administered by the Federal Government. Perhaps ADHC could retain an assessment and compliance role using "live" criteria, but if someone meets eligibility criteria in Sydney, they should have the same entitlements as a person that meets the same criteria in Cloncurry and vice versa.

⁴⁸¹ Submission 31, p 72

⁴⁸² Submission 104, Mr Adam Johnston, p 2

⁴⁸³ Submission 104, pp 2-3

⁴⁸⁴ Submission 21, ParaQuad, p 7

⁴⁸⁵ Submission 53, Allowance Incorporated, p 4

⁴⁸⁶ Submission 53, p 4

I am unaware of what packages exist in other states, but I do know that we've had at least two people forced to move to NSW to enjoy the benefits of the NSW ACP.⁴⁸⁷

- 6.100** Inquiry participants debated whether the employment of family members as attendant care workers is detrimental to family relationships. It was feared that the introduction of payments for tasks that are traditionally completed by a carer would have a destabilising effect on family dynamics. It was pointed out to the Committee that as most service users do not access the Direct Funding Model, they are afforded the protection of a financial intermediary.⁴⁸⁸ The financial intermediary is the employer of the care worker thereby limiting potential problems.⁴⁸⁹ The financial intermediary also fulfills occupational health and safety requirements and provides industrial protections.⁴⁹⁰
- 6.101** The impact of undertaking a carer role on family relationships is examined in Chapter 10.
- 6.102** Another issue brought to the Committee's attention was the skills of attendant care workers, particularly their ability to use of Australian Sign Language, Auslan. The Deaf Society of NSW recommended that funding being increased to the ACP to ensure attendant care workers are able to communicate with deaf program applicants and service users.⁴⁹¹

Committee comment

- 6.103** The Committee understands that the ACP provides important services to people with disability and that Inquiry participants are frustrated by many aspects of this program.
- 6.104** The evidence presented to the Committee highlights the inefficiencies in the delivery of this service. It is particularly disappointing to note that service users can wait up to three years to receive these essential services. While the Committee understands that ADHC has many pressing priorities, it is recommended that the ACP, particularly its eligibility requirements, be reviewed. The recommendation for a review of the eligibility requirements for the ACP can be found in Chapter 5.

Equipment programs

- 6.105** Many aged people and people with a disability require equipment or aids to help keep them mobile or to assist their general care. The NSW Ombudsman reported that for many children with disabilities, having appropriate aids and equipment is critical to enable them to do regular activities, such as move around, attend school and access the community.⁴⁹² For some people with disabilities, ADHC plays a role in relation to aids and equipment through case management, occupational therapy assessment and referral. NSW Health is also responsible for administering disability support programs relating to aids and equipment.

⁴⁸⁷ Submission 53, p 2

⁴⁸⁸ Ms Regan, Evidence, 9 August 2010, p 64

⁴⁸⁹ Ms Regan, Evidence, 9 August 2010, p 64

⁴⁹⁰ Ms Regan, Evidence, 9 August 2010, p 64

⁴⁹¹ Mr Stephen Nicholson, Manager, Consumer and Community Services, Deaf Society of NSW, Evidence, 27 September 2010, p 57

⁴⁹² Submission 100a, NSW Ombudsman, p 5

- 6.106** Ms Cathrine Lynch, Director, Primary Health and Community Partnerships, NSW Health, explained to the Committee that service users who reside in an ADHC facility receive their disability equipment through ADHC, whilst those who are not in one of those residential facilities receive equipment from a NSW Health program called Enable:

Clients that are in ADHC facilities get their equipment through ADHC. Those with disabilities who are not in those residential facilities use the Enable program, which has a number of component parts. One is the PADP program, or the Program of Appliances for Disabled People, and there is also the home oxygen equipment for people program and the ventilator dependent program. There is one other...now called the Prosthetic (Artificial) Limbs program.⁴⁹³

- 6.107** The NSW Ombudsman has completed a considerable amount of work in the area of access to specialised disability equipment. He has found that there are extensive waiting times for equipment. For example, the length of time between assessment of need and receipt of equipment can take up to two years. In addition, the administrative processes involved in obtaining this equipment were burdensome and lengthy. The adverse effect on families on these time lags for receipt of equipment were noted by the Ombudsman:

Families reported that the primary issue affecting access to necessary aids and equipment is the extensive waiting times - from assessment to application; from application to approval; and from approval to receipt of the equipment. We heard that the time between assessment and receipt of the equipment can take up to two years, depending on the type of equipment. Families pointed to the adverse effects on their children of delays in obtaining appropriate aids and equipment, including delays in starting school, decline in health, and reduced independence.

We were told that the administrative processes involved in obtaining aids and equipment are lengthy, often due to the number of parties that may be involved in the process, including ADHC, area health services, and Enable NSW. We note that, for some children with disabilities, numerous applications have to be made to meet their changing needs as they grow, and in circumstances where multiple aids are required.⁴⁹⁴

- 6.108** Mr Herd, told the Committee that children can wait up to a year or 18 months for equipment, which for a five year old is 'an eternity':

We are particularly concerned in relation to the provision of equipment to children which is causing extensive costly problems for the public purse because you would have delays in the assessment and provision of equipment that could take up to a year or 18 months. In the life of a five-year-old that is an eternity and we have to reassess, re-provision. That is what goes directly to the question about ADHC funded services ...⁴⁹⁵

- 6.109** Case study 6 provides an example of the challenges faced by a family who require equipment to assist their disabled daughter. The case study questions why families must depend on charities to receive essential equipment, in absence of government support.

⁴⁹³ Ms Cathrine Lynch, Director, Primary Health and Community Partnerships, NSW Health, Evidence, 27 September 2010, p 29

⁴⁹⁴ Submission 100a, p 5

⁴⁹⁵ Mr Herd, Evidence, 9 August 2010, p 33

Case study 6 - Mr Martin Boers⁴⁹⁶

We have a 6-year old child with Muscular Dystrophy. She cannot walk, stand, or roll over. As well as requiring a wheelchair to mobilise, our daughter requires essential therapeutic equipment along with regular speech, physio and occupational therapies. Without these, our daughter's condition will deteriorate more quickly, making it less likely that she will be able to attend mainstream school, more likely that she will require extended periods in hospital, and more likely that she will die earlier than she otherwise would.

We are constantly amazed at the lack of basic equipment and services available from the NSW and Australian governments, not just to our daughter, but to all the families with disabled children that we read about on www.australiansmadashell.com.au. Even if you ignore the obvious ethical questions, it just makes basic economic sense to for the government to help keep people out of hospital. What possible explanation can there be for this lack of both compassion and financial common sense?

What about Enable NSW? They recently refused our request for a "Stander", a piece of therapeutic equipment that has been clinically proven to help children with physical conditions like our daughter's. Based on Enable's response to our application, we would have had more luck applying for a hang-glider for our daughter. Enable NSW is a failure. With nowhere else to go, we were forced to apply for funding from Variety. While the people who are involved in charities like Variety are wonderful, the fact that charities need to fill this gap in government services is shameful. My friends overseas thought that we lived in The Lucky Country, but they had to think again when they heard about the disgraceful treatment of our daughter by the people in this government.

It is clear from our experience that the Department of Ageing, Disability and Home Care (ADHC), and the other government departments who passed the buck when we contacted them, is completely ineffective in the delivery of disability services. Disability services need to be completely restructured. The proposed National Disability Insurance Scheme would be a good start. In both the federal and state elections, my vote (and the votes of all my family and friends) will be going to the candidate that supports the NDIS.

- 6.110** Ms Regan, NCOSS, shared with the Committee some of her experiences with people facing unmet needs for equipment, and the devastating effect this can have on their life:

I know of one woman who could not get equipment into her house in order to have her son, who had very high support needs, seated and into bed. This was only about three years ago. She used to put a sleeping bag on the floor and she fed him on the floor until her own shoulders gave out and she had to go into hospital. Only at that point was she offered supported accommodation for her son, when she had completely broken down. These stories just happen over and over. It is shameful.⁴⁹⁷

- 6.111** ParaQuad NSW is a not-for-profit organisation which provides care, support and clinical services to people with a spinal cord injury, their families and carers. Currently it has a membership of 1,700 people with SCI. ParaQuad explained to the Committee that its

⁴⁹⁶ Submission 36, Mr Martin Boers, p 1

⁴⁹⁷ Ms Regan, Evidence, 9 August 2010, p 62

members would like to have access to interest free loans to purchase equipment that is not supplied by the PADP program. Its membership also indicated that funding is required to support fitness exercise programs and fitness equipment.⁴⁹⁸

- 6.112** The Committee also heard that ADHC and NSW Health are working together in certain areas to try and improve the outcome for patients. Ms Lynch gave the example of ADHC service users who are reliant on being fed intravenously presenting to hospital emergency departments with problems of infection or the intravenous fitting coming out. NSW Health identified that part of the problem was training, but also inappropriate equipment. The solution was a greater pre-emptive role for NSW Health and networking closely with ADHC and other health workers:

It might seem like a small example but I think it has been quite an important piece of work - the Home Enteral Nutrition, or HEN, piece of work that we have done with them [ADHC]. This is where people need to be fed intravenously. A lot of residents in ADHAC houses have the HEN as feed. We have worked with ADHAC to identify what some of the problems were. Often these clients were presenting to the emergency department with either the fitting coming out or with infection. We have worked closely with them to identify the source of the problem. One of the things was training and the other appropriate equipment. We have worked quite closely to analyse the problem, look at the data and look at the role of Health. ADHAC staff can do that work but they need appropriately trained clinicians to help them with the training. That has a benefit not just for the clients but it also for our emergency departments. We are being pre-emptive. We have put in an earlier recognition of the problem by providing training. We did that with ADHAC and Health and also our Agency for Clinical Innovation, which is a network of clinicians with an interest area. We have a network of those clinicians and dieticians as well who are interested in particular in that area. That has worked really well, again, looking at the problem, looking at the client and then looking at what we can do together to solve it. Rather than saying, "This is your bit, this is my bit", we work closely together with the patient or the client as the focus.⁴⁹⁹

Committee comment

- 6.113** The Committee is very concerned at the reports of service users having to wait up to two years between assessment of need for a piece of equipment and receiving it. This is clearly unsatisfactory, and a huge area of unmet need. ADHC need to ensure that service users receive equipment when they need it. 18 months is too long for a young child and their family to wait.
- 6.114** The Committee understands the devastating impact waiting for equipment can have on carers and recognises their frustration that equipment appears to be provided on a crisis basis. It is disappointing to note that in most cases the provision of equipment is not in line with ADHC's person-centred approach to service planning and delivery.
- 6.115** The Committee acknowledges the importance of an efficient needs assessment system. Recommendations concerning the needs assessment process can be found in Chapter 5.

⁴⁹⁸ Submission 21, p 4

⁴⁹⁹ Ms Lynch, Evidence, 27 September 2010, p 33

- 6.116** The Committee considers inflexible program guidelines, such as those described by Mr Johnston, as ludicrous and not in keeping with ADHC's person-centred approach to service planning and delivery.
- 6.117** The Committee supports ParaQuad's proposal that interest free loans be provided for clients and their families to purchase equipment. The loans would allow for greater flexibility and a more person-centred approach to service provision. The Committee recommends that the NSW Government provide interest free loans for equipment and aids for ADHC service users.
- 6.118** The Committee is heartened to hear that NSW Health and ADHC have been successfully working together in areas such as the Home Eternal Nutrition program. The Committee fully supports, and would like to see more of, this cross agency networking and cooperation.

Recommendation 41

That the NSW Government investigate the implementation of a program of interest free loans for equipment and aids for ADHC service users and other people with disabilities.

Chapter 7 Large Residential Centres

This chapter examines the NSW Government's policy to redevelop rather than devolve Large Residential Centres (LRCs).

- 7.1** There are approximately 1600 people with disability living in nine government-operated and 22 non-government LRCs in NSW.⁵⁰⁰ LRCs are residences that offer 24 hour assistance to 20 or more people with disabilities. There was debate during the Inquiry about the value of such accommodation and whether it complies with the NSW Disability Service Standards, the *Disability Services Act 1993* and whether person-centred services are able to be provided.
- 7.2** The Government argued that LCRs can achieve the appropriate outcomes for certain groups and therefore should be included in the 'mix' of supported accommodation options.⁵⁰¹ Opponents of the facilities countered that LRCs impinge upon the rights of people with disability, do not comply with relevant standards and legislation and should be abolished.
- 7.3** In 1998 the Government announced it would devolve all LRCs over a ten year period.⁵⁰² This process was to see large institutions in NSW closed and residents housed in smaller community-based supported accommodation options in accordance with the *Disability Services Act 1993*.⁵⁰³ The *Disability Services Act 1993* aims to ensure that people with disability in NSW have the same basic rights as other members of the community.⁵⁰⁴
- 7.4** In 2006 the Government revised this policy and announced that LRCs were to close over time rather than by a specific date.⁵⁰⁵ The revised approach to LRCs included the adoption of a wider range of accommodation and support models, including the redevelopment of some large institutions.⁵⁰⁶ During Parliamentary debate the Hon Peter Primrose MLC, Minister for Disability Services, explained the Government's approach:

Under Stronger Together the Keneally Government is pushing ahead with its plan to close large residential centres, some of which will be redeveloped to provide specialist support to people with complex needs who cannot live in other settings.⁵⁰⁷

- 7.5** During the Inquiry, the NSW Ombudsman released a report entitled *People with disabilities and the closure of large residential centres*. In it, the Ombudsman reported that "[s]ince 2006, one ADHC residential centre has closed and two others are in the process of redevelopment. In June 2010, the Minister for Disability Services announced plans for the closure and redevelopment of another ADHC residential centre, to occur over three years."⁵⁰⁸

⁵⁰⁰ NSW Ombudsman, *People with disabilities and the closure of large residential centres*, August 2010, p 1

⁵⁰¹ Mr Jim Moore, Chief Executive, Ageing, Disability and Home Care (ADHC), Evidence, 27 September 2010, p 7

⁵⁰² NSW Ombudsman, *People with disabilities and the closure of large residential centres*, August 2010, p 1

⁵⁰³ Ongaurd!, August 2004, (accessed 20 October 2010), <[http://www.lawlink.nsw.gov.au/lawlink/opg/ll_opg.nsf/vwFiles/August%202004.pdf/\\$file/August%202004.pdf](http://www.lawlink.nsw.gov.au/lawlink/opg/ll_opg.nsf/vwFiles/August%202004.pdf/$file/August%202004.pdf)>

⁵⁰⁴ NSW Ombudsman, *People with disabilities and the closure of large residential centres*, August 2010, p 5

⁵⁰⁵ ADHC, *Stronger Together: A new direction for disability services in NSW 2006–2016*, p 7

⁵⁰⁶ NSW Ombudsman, *People with disabilities and the closure of large residential centres*, August 2010, p 1

⁵⁰⁷ NSWPD, *Legislative Council*, 22 June 2010, p 24378

⁵⁰⁸ NSW Ombudsman, *People with disabilities and the closure of large residential centres*, August 2010, p 1

- 7.6 Ms Julie Hourigan-Ruse from the Homeless Person's Legal Service recommended that ADHC "... improve its practices in relation to the monitoring of LRCs and publicly disclose what actions it is taking to address the concerns raised in the June 2006 Ombudsman's Report to Parliament."⁵⁰⁹
- 7.7 The facilities referred to in the Ombudsman report are the Peat Island Centre, the Lachlan Centre, the Riverside Centre and the Grosvenor Centre. The redevelopment plans for each facility is described in Table 7.1:

Table 7.1 Redeveloped Large Residential Centres in NSW

Centre	Redevelopment plans/ new accommodation
Peat Island Centre	The centre will close in late 2010 and be redeveloped at two different sites. The site at Hamlyn Terrace will host an aged care village for 100 people and the site in Wadalba will have four five-bedroom houses. ⁵¹⁰
Lachlan Centre	The centre will close in late 2010 and be redeveloped at a different location on the same site. The new facilities will have ten five bedroom houses designed as specialist services for people with challenging behaviour. ⁵¹¹
Riverside Centre	Funds to redevelop the centre were announced in 2010-2011 Budget. The centre will be replaced by: a specialist supported living cluster on-site for people with challenging behaviour; five community-based houses for people with additional care needs, located close to the cluster; and, 40 houses across the Western region for people not requiring specialist support. ⁵¹²
Grosvenor Centre	The centre closed in January 2009 and has been redeveloped on site. The new accommodation has two ten bedroom houses designed as specialist support for people with complex health needs. ⁵¹³

- 7.8 The size and scope of LRCs vary greatly. For example, the Government-operated facility at Stockton houses approximately 450 people while other small facilities accommodate only 20 people.⁵¹⁴

⁵⁰⁹ Submission 81, Homeless Persons' Legal Service, p 4

⁵¹⁰ NSW Ombudsman, *People with disabilities and the closure of large residential centres*, August 2010, p 1

⁵¹¹ NSW Ombudsman, *People with disabilities and the closure of large residential centres*, August 2010, p 1

⁵¹² NSW Ombudsman, *People with disabilities and the closure of large residential centres*, August 2010, p 1

⁵¹³ NSW Ombudsman, *People with disabilities and the closure of large residential centres*, August 2010, p 1

⁵¹⁴ Ms Carol Berry, Executive Officer, NSW Council on Intellectual Disability, Evidence, 26 August 2010, p 15

- 7.9 In September 2010, Minister Primrose assured Parliament the accommodation services would comply with the Act, including access to advocacy services.⁵¹⁵ When questioned on the planned timeframe of these projects, the Minister Primrose replied:

This is not something that can be done precipitously or according to a rigid timetable. We are talking about the lives of 1,350 people, many of whom have lived in these residences for many decades and who have formed strong relationships there. Residents must be at the centre of these service developments. Planning is occurring in close consultation with every resident and his or her family or guardian. We are ensuring that residents and their families are treated with respect and care.

This process involves a major undertaking with large financial implications. In recurrent dollars alone, we are talking about \$200 million to support these clients, and capital solutions will cost in the vicinity of \$500 million.⁵¹⁶

- 7.10 It is important to note that discussion during the Inquiry centered on the devolution of LRCs for people with disabilities as opposed to those with mental health issues. Ms Christine Regan, Senior Policy Officer at the Council of Social Services NSW (NCOSS), provided a definition of this group:

We are talking about people whose primary disability is physical, intellectual, cognitive, sensory, brain injury, and dementia; not people whose primary disability is mental health. We are not talking about mental health patients, although we must identify that many people with disabilities have a co-morbidity with mental health issues.⁵¹⁷

- 7.11 The evidence provided to the Committee was divided, with a small number of participants in support of the current redevelopment policy and the majority of participants opposed. Both arguments are presented in the following sections.

Support for LRCs

- 7.12 During the Inquiry the Government defended its decision to redevelop rather than close certain centres. Mr Moore stated "[t]hat redevelopment phrase is saying that not in all instances will a large residence be closed and replaced by small community-based housing, which is what the word "devolution" was meant to imply. Redevelopment embeds the concept that you have to have horses for courses."⁵¹⁸
- 7.13 Mr Moore expanded on this argument telling the Committee that increasing the mix of accommodation options available to people with disability better caters to individual needs:

It made no sense to say 2,000 beds need to be built in the community. Why? Because we have 2,000 beds in large residential centres so that is what we will do. You have got to chunk it down and deal with smart decisions about individual facilities with a view to: What do you want to see across the totality of NSW ' capacity? You know you are going to need some forensic units, some aged care facilities, lots of community

⁵¹⁵ NSWPD, *Legislative Council*, 7 September 2010, p 25231

⁵¹⁶ NSWPD, *Legislative Council*, 7 September 2010, p 25231

⁵¹⁷ Ms Christine Regan, Senior Policy Officer, NCOSS, Evidence, 9 August 2010, p 58

⁵¹⁸ Mr Moore, Evidence, 27 September 2010, p 7

housing. And our challenge is to try and get away from even the community-housing model because I think there are a significant number of clients that we have already in the facilities that we operate and, more importantly, some of the people who are going to need some form of supported accommodation, that are not about 24-hour, 7-day per week life supervision. The labels we are using are things like "drop-in support". But there are people who need to be in some proximity to paid workers who can visit them from time to time, and if they need to they can have a lot more help put in at a particular time for a week or a month or whatever, but not have the concept that there is a 24-hour, 7-day per week all year long staff arrangement around you.⁵¹⁹

- 7.14** The Government maintained that the redevelopment of LRCs best served the interests of certain client groups. Mr Moore said that the recent redevelopment of the Grosvenor Centre, assists individuals with high-support needs by providing a more conducive work environment for nursing staff:

... what we are trying to do with the replacement to the Grosvenor centre is to provide a facility that has high-quality medical and quasi-medical care; you need a certain body of nursing staff and you cannot run that out of group homes. People say you can if you spend enough money, well you can spend all the money alike and you're not get enough qualified nurses to run it out of an environment where you have completely separated one facility from another. They need supervision and they need networking among themselves to work effectively. We know that we need to provide high-quality nursing care to be able to provide the basis for a quality of life outcome for individuals.⁵²⁰

- 7.15** Mr Moore suggested that the ageing population and higher life expectancy of people with disability further supports the need for LRCs because it is proving particularly difficult to get these individuals access to residential aged care centres.⁵²¹

- 7.16** The Committee was informed that ADHC is currently undertaking an ageing-in-place project, which examines older residents in large institutions and group homes. Mr Mike Blaszczyk, General Manager of McCall Gardens Community Ltd, and Futures Alliance member, said that ADHC has been working with 14 NGOs for the past six months to evaluate the best kind of accommodation support arrangements for older people living in LRCs.⁵²²

- 7.17** Paraplegic and Quadraplegic Association of NSW (ParaQuad) is currently in the process of redeveloping Ferguson Lodge, an LRC in Lidcombe. Mr Max Bosotti, Chief Executive Officer of ParaQuad, supported the Government's stance on offering clients a greater range of accommodation options:

It is quite clear from our experience that there is a variety of accommodation models that will suit. Certainly we have a facility that can cater for up to 40 people. Some of the residents of that facility have lived in group homes and prefer to live in a congregate facility. There is a range of options that we are looking at.⁵²³

⁵¹⁹ Mr Moore, Evidence, 27 September 2010, p 7

⁵²⁰ Mr Moore, Evidence, 27 September 2010, p 7

⁵²¹ Mr Moore, Evidence, 27 September 2010, p 7

⁵²² Mr Mike Blaszczyk, General Manager, McCall Gardens Community Limited and Futures Alliance member, Evidence, 3 September 2010, p 44

⁵²³ Mr Max Bosotti, Chief Executive Officer, ParaQuad NSW, Evidence, 3 September 2010, p 6

7.18 Mr Bosotti stressed that providing LRC-style accommodation offered greater choice to clients:

There are a number of models that will suit quite a range of individuals. It is that choice which is one of the main things that our organisation tries to provide to our membership and the wider community. That is what it is all about... I think that there are a number of models that need to be deployed to give people those different choices.⁵²⁴

7.19 ParaQuad also contended that LRCs provided acceptable accommodation to particular client groups. Ms Tonina Harvey, General Manager, Community Services at ParaQuad, noted that ParaQuad's redevelopment plan for Fergusson Lodge will cater to the high-care needs of their clients.⁵²⁵

7.20 Certain advocacy groups supported the argument that specific groups may benefit from congregate care. The Disability Trust noted that its experience has shown congregate care can be appropriate in some circumstances:

... we have seen some people build very real relationships within environments such as licensed residentials and after many years of living in these surroundings some clients may not choose an option to relocate even if available. We have seen this expression of choice amongst people with physical disabilities over recent years and it also needs to be respected. Where people are aging congregate care is also acceptable within the wider community and there is no reason why this shouldn't also therefore be an option for people with a disability.⁵²⁶

7.21 Alternatively, People With Disability Australia noted that while the current approach to redeveloping LRCs may cater to the needs of certain groups, it fails to offer appropriate levels of choice.⁵²⁷

7.22 It was also suggested that LRCs may be capable of providing the same outcomes for people with disability as community-based supported accommodation. ADHC claimed that moving people from institutions into smaller, supported accommodation placements failed to recognise that group homes are not averse to becoming 'institutionalised.' Mr Moore explained this position:

By mid-2005 there was an extensive process of revisiting the policy settings around accommodation - not just around large residences but more generally - which brought to the discussion a concept that it was not just about bricks and mortar, and that you do not address an issue by changing the bricks and mortar. That works both in relation to large spaces - large numbers of people being accommodated together - and to small spaces. There is nothing inherent in the way in which a group home could operate - a group home with five or six people with a disability - that would prevent it from being institutionalised and having poor institutionalised outcomes.⁵²⁸

⁵²⁴ Mr Bosotti, Evidence, 3 September 2010, p 6

⁵²⁵ Ms Tonina Harvey, General Manager, Community Services, ParaQuad NSW, Evidence, 3 September 2010, p 6

⁵²⁶ Answers to questions taken on notice during evidence, Ms Margaret Bowen, Chief Executive Officer, The Disability Trust, 3 September 2010, p 5

⁵²⁷ Ms Denise Beckwith, Acting Manager, Individual Advocacy, People With Disability, Evidence, 3 September 2010, p 34

⁵²⁸ Mr Moore, Evidence, 27 September 2010, p 7

- 7.23 Ms Harvey agreed with this suggestion, noting that "[t]he model of care is really about where institutionalisation can determine how people's lives will progress. What we need to ensure is that there are good programs around social inclusion and community participation which are streamed through any model of service delivery, regardless of the setting."⁵²⁹

Opposition to LRCs

- 7.24 Although ADHC support the position to redevelop LRCs, the agency acknowledged that there can be problems with larger accommodation facilities. Mr Moore told the Committee that there are certain inherent limitations to community engagement that can occur in larger facilities, however, the Government is moving to overcome these barriers.⁵³⁰

- 7.25 Additionally, ParaQuad acknowledged that social inclusion can be difficult for residents of LRCs. To overcome this problem, Mr Bosotti said that the redevelopment plans for Ferguson Lodge allow residents to participate in the community more thoroughly than traditional institutions:

That is one of the big points about the redevelopment of Ferguson Lodge. It is at the old Lidcombe hospital site and it is surrounded by the TAFE university. The rest of the site is being developed by Australand into a residential facility so that in fact the community is coming to Ferguson Lodge. The residents of Ferguson Lodge feel that they will well and truly be integrated into the community. They have access to public transport, good facilities, and they are free to come and go.⁵³¹

- 7.26 There was vehement opposition to the redevelopment of large institutions by some Inquiry participants. Discussion on the issue focused on whether redeveloping these sites impedes on the rights of people with disability and if LRCs conform to the requirements of the Act.

- 7.27 Opponents of the use of LRCs clarified their definition of institutionalised care. Ms Therese Sands, Executive Director, PWD said that institutional accommodation congregates, segregates and isolates people with disability. Therefore, LRCs and other forms of supported accommodation, such as cluster housing and villas are considered institutionalised care.⁵³²

- 7.28 PWD admonished the Government for failing to close institutional accommodation, particularly LRCs, and was frustrated by the number of people still living outside of the mainstream community:

... we have not come very far in shifting to inclusive forms of accommodation where people genuinely live in the community and are able to be included in a different way than if they are living with their peers in an isolated environment. That is quite different from being able to live in the community.⁵³³

⁵²⁹ Ms Harvey, Evidence, 3 September 2010, p 7

⁵³⁰ Mr Moore, Evidence, 27 September 2010, p 7

⁵³¹ Mr Bosotti, Evidence, 3 September 2010, p 7

⁵³² Ms Therese Sands, Executive Director, PWD, Evidence, 3 September 2010, p 34

⁵³³ Ms Sands, Evidence, 3 September 2010, p 34

7.29 Many Inquiry participants were frustrated, disappointed and perplexed about the Government's change in policy position. Mr Le Breton, Chief Executive Officer of Disability Enterprises, contended that a number of factors could have contributed to the policy change:

I guess it would be a little bit too reductionist to just say it is a lack of leadership. I think it is a few things. Obviously, we need money put into that, but also it needs to be driven with commitment because it is an area where it is very easy to present issues that are not necessarily real, but can create great fear in the eyes of parents and the community. It is very, very easy to politicise it: it is very easy to do that. I think the other big issue here too, of course, is that there is a strong self-interest within the staffing ranks for the status quo.⁵³⁴

7.30 The Council on Intellectual Disability NSW suggested that the Government may have shied away from its previous commitment because of concerns voiced by certain elements of the community and for economic reasons.⁵³⁵ Ms Berry explained the rationale for this suggestion:

In some communities where institutions are located families may have expressed reluctance or concerns about their family members being moved into more community-based settings. That is certainly the international experience. A lot of research has been done on this issue. At first families feel concerned and nervous about their loved ones, but with the experience of devolution they become quite robust supporters of the process. Presumably the Government is mindful of the reservations in some communities. I imagine that there is some economic reasoning behind it.⁵³⁶

7.31 It was claimed that LRCs fail to meet Commonwealth obligations under the United Nations Convention on the Rights of Persons with Disabilities. The NSW Ombudsman damningly found that the fundamental human rights of residents in LRCs are currently not being met, particularly:

- the right and opportunity to communicate with others and make decisions and choices;
- the right to participate in the community, and to develop social networks; and,
- the right to develop skills to increase independence.⁵³⁷

7.32 Some Inquiry stakeholders were adamant that the redevelopment of LRCs contravened the provisions of the Act. The NSW Ombudsman also found that LRCs failed to conform to the *Disability Services Act 1993*, because LRC residents:

- received services in a way that restricted their rights and opportunities;
- do not have access to advocacy support where appropriate
- had lives that were very different to those valued in the mainstream community; and,
- had most, or all, aspects of their lives controlled by one service.⁵³⁸

⁵³⁴ Mr John Le Breton, Chief Executive Officer, Disability Enterprises, Evidence, 27 September 2010, p 4

⁵³⁵ Ms Berry, Evidence, 26 August 2010, p 16

⁵³⁶ Ms Berry, Evidence, 26 August 2010, p 16

⁵³⁷ NSW Ombudsman, *People with disabilities and the closure of large residential centres*, August 2010, p 5

7.33 PWD expressed similar frustrations, noting that the Government's policy does not meet international and state responsibilities:

Our concern is based on the objects of the *Disability Services Act* as well as the Convention on the Rights of Persons with Disabilities, which outlines that people with disability should be able to be included in the community and live independently and have the same and equal choices as other people. People with disability have historically been congregated together and isolated in that way because that is the only way they can receive a service. It is not a choice being made; it is actually to receive a service through the service system.⁵³⁹

7.34 The ability of LRCs to provide the appropriate environment for people with disabilities to successfully achieve their personal outcomes and to 'live a good life' questioned during the Inquiry. NCOSS elucidated this concern, claiming that research proves that LRCs do not adequately meet the needs of residents:

NCOSS is concerned at the re-development of traditional institutions into smaller disability villages which are still segregated from the local community, have shared staff, and still operate on group rules rather than the needs of the individual person. Australian and overseas research has consistently demonstrated that the outcomes for people who live in these village situations more closely reflect the outcomes of people in large disability institutions rather than the outcomes of people with disability who are integrated into dispersed housing in the community.⁵⁴⁰

7.35 Similarly, Ms Berry, was disappointed that LRCs continue to accommodate people with disability because of the negative repercussions they have on their individual outcomes:

... where larger groups of people are living together in one setting there is an inevitable compromise with regard to the individual outcomes that can be achieved. That point was emphasised in NSW Ombudsman's report released in 2009, which looked specifically at individual planning and outcomes that could be achieved in ADHC-operated large residential centres. That was a comprehensive report and its conclusions were clear that the model could not deliver for individuals. That is a problem.⁵⁴¹

7.36 Mr Le Breton has worked in the disability services sector for a number of years and told the Committee of his recent experience visiting a former client who lives in a LRC:

Six months ago I went back to what was called a ward in those days where I first started. When I walked into a room that had a court yard off it I saw a woman. I said to the staff member, "Is that Michelle?" - I will not say her surname - and I was told "Yes, it is". She is in exactly the same place that she was 36 years ago. When I was there she was eight years old so you can imagine how long ago that is. She was a ragdoll type of child with no challenge or behavioural problem to anyone, not a child that would make you think "How are we going to provide a service for her?" She is now a woman in a wheelchair. I think of what a whole lot of other people with disabilities with whom I have worked over the many years have done, and I just

⁵³⁸ NSW Ombudsman, *People with disabilities and the closure of large residential centres*, August 2010, p 5

⁵³⁹ Ms Sands, Evidence, 3 September 2010, p 35

⁵⁴⁰ Answers to questions taken on notice during evidence, NCOSS, 9 August 2010, p 3

⁵⁴¹ Ms Berry, Evidence, 26 August 2010, p 15

despair for her that she is in this ageing large institution, and she is still there in exactly the same place.⁵⁴²

7.37 Mr Le Breton said his experience highlighted the failure of LRCs to meet the individual outcomes of people with disability.⁵⁴³

7.38 It was noted that people with disabilities residing in LRCs often exhibit poor behaviour. PWD claimed that the behaviour of residents can be attributed to their living conditions:

There is evidence to show that that isolation, congregation and segregation for the purposes of providing a service do not allow a person to develop skills to their maximum ability. In fact they may develop behaviours that are quite negative but which are called challenging behaviour. Those behaviours change when they are in more appropriate settings and the capacity of people and their ability to function changes when they are in different settings.⁵⁴⁴

7.39 Inquiry participants expressed concern that LRCs perpetuate negative ideas about people with disabilities. The Disability Trust said that LRCs create a stigma toward people with disability and negate their inclusion in mainstream society.⁵⁴⁵

7.40 The Committee received evidence that it is more cost effective to house people with disability in smaller residences rather than LRCs. NSW Council for Intellectual Disability reported that "... the Government spends significantly more on housing people in LRCs rather than providing supports in their own homes or smaller community settings."⁵⁴⁶

7.41 Mr Le Breton was unable to provide a cost comparison between running the Greystanes Children's Home and the supported accommodation provided by his organisation, Disability Enterprises.⁵⁴⁷ Mr Le Breton did concede that it is substantially cheaper for an NGO to operate supported accommodation facilities for people with high medical needs because they are not bound to pay their staff the same award rate as ADHC.⁵⁴⁸

7.42 A number of Inquiry participants continue to lobby the Government to reverse its redevelopment policy and to close LRCs. It was suggested that current residents be moved into supported accommodation within community living settings.

7.43 In its recent report, the NSW Ombudsman stated that although ADHC has improved its practice and service delivery in LRCs, this model of care fails to allow residents to fully exercise individual choice and participate as full members of the community thus should not continue to be used. The report recommended ADHC move towards devolution and should continue to report to the Ombudsman's office until devolution occurs.⁵⁴⁹

⁵⁴² Mr Le Breton, Evidence, 27 September, 2010, p 3

⁵⁴³ Mr Le Breton, Evidence, 27 September, 2010, p 3

⁵⁴⁴ Ms Sands, Evidence, 3 September 2010, p 35

⁵⁴⁵ Answers to questions taken on notice during evidence, Ms Bowen, The Disability Trust, 3 September 2010, p 5

⁵⁴⁶ Submission No. 39, NSW CID, p 6

⁵⁴⁷ Mr Le Breton, Evidence, 27 September, 2010, p 8

⁵⁴⁸ Mr Le Breton, Evidence, 27 September, 2010, p 8

⁵⁴⁹ NSW Ombudsman, *People with disabilities and the closure of large residential centres*, August 2010, pp 5-6

- 7.44** Ms Regan explained that people with disability currently residing in LRCs are capable of living in the community if they are afforded the appropriate supports and trained staff.⁵⁵⁰ Thus, NCOSS recommended that "ADHC recommits to closing all disability institutions in favour of person-centred small, community based, dispersed responses to supported accommodation for people with disability."⁵⁵¹
- 7.45** PWD highlighted the benefits of supporting people with disability to live in the community, noting that its current president grew up in an institution and has been living independently for the past 15 years.⁵⁵²
- 7.46** Inquiry participants acknowledged that the process of closing LRCs would be difficult but considered the outcomes worthwhile. Mr Le Breton gave the Committee a vivid personal account of working within an LRC during the time it devolved its operations into smaller supported accommodation facilities.

I asked them how they [parents of the residents] felt when Greystanes was told it was closing. Overwhelmingly, every one of them said, "We were horrified, we were terrified and we were scared. We objected to it." On two occasions two parents said to me in slightly different words that had the same meaning; "If only we had known how much better it would have been for our sons and our daughters it would have saved us a lot of angst and we could have put a lot more energy into doing what we really needed to do for our sons and daughters." They talked about how their sons and daughters now have their own private space. They live alongside ordinary neighbours in ordinary houses on ordinary streets.⁵⁵³

- 7.47** Mr Le Breton continued:

The point that I would like to emphasise is that they are living in ordinary houses and not in specially built facilities or purpose-built facilities, which is the term used by the department. These are ordinary houses in ordinary streets alongside ordinary neighbours. These people have high support needs and high and complicated medical needs and they are used to having nurses all around them. However, they now live in ordinary houses that are appropriately equipped and appropriately accessible.⁵⁵⁴

- 7.48** Additionally, Mr Le Breton impressed upon the Committee his belief that smaller accommodation settings allowed families and people with disabilities to have greater control and authority over their short and long term goals.⁵⁵⁵
- 7.49** The NSW Council for Intellectual Disability takes the initial concept of devolution further, suggesting that people with disability should be free to live in whatever way they like:

We feel that ideally people should be supported to live in whatever arrangement they feel is appropriate, just as the rest of us have that right. Most of us do not put our hand up to live with large groups but with a partner, siblings or a friend or two

⁵⁵⁰ Ms Regan, Evidence, 9 August 2010, p 58

⁵⁵¹ Submission 30, Ms Christine Regan, NCOSS, p 13

⁵⁵² Ms Sands, Evidence, 3 September 2010, p 35

⁵⁵³ Mr Le Breton, Evidence, 27 September 2010, p 1

⁵⁵⁴ Mr Le Breton, Evidence, 27 September 2010, p 1

⁵⁵⁵ Mr Le Breton, Evidence, 27 September 2010, p 4

friends. That is the ideal model. People with a disability should have the right to choose who they live with and under what circumstances.⁵⁵⁶

7.50 It was noted that closing LRCs would bring NSW in line with other jurisdictions. Ms Berry said that closing these facilities would align with international trends:

... there has been an international trend to move from congregate settings for people with a disability to smaller more individual settings. There is a recognition that grouping people together just because they have a disability and housing them in one location is not perhaps the best outcome and that from a fundamental rights perspective we should be shifting towards more individualised outcomes. We are not talking about units but people with real needs and a real right to be able to engage in community life. That is the broad debate.⁵⁵⁷

7.51 Likewise, Mr Phillip French, Director of the Disability Discrimination Legal Centre, was quoted in the media as saying that "NSW is the only place in the developed world that is rebuilding institutions contrary to international law".⁵⁵⁸

7.52 Other Australian jurisdictions have moved towards devolution as initially described by the NSW Government. The Committee was informed that Victoria had almost closed all its facilities and that Western Australia has had a model of local area coordination for some years.⁵⁵⁹

Committee comment

7.53 The Committee is shocked and concerned to learn that approximately 1,600 people with disability currently live in LRCs. The Committee received overwhelming evidence regarding the problems with LRCs. LRCs can exclude people with disability from the community. Additionally, LRCs do not provide adequate opportunities for people with disabilities to meet individual outcomes.

7.54 LRCs fail to meet international and State obligations regarding people with disabilities exercising their rights and responsibilities as citizens.

7.55 The Committee acknowledges the view that LRCs are required to ensure that there is an appropriate 'mix' of accommodation for people with disabilities, particularly for individuals with high-support needs. However, the evidence presented to the Committee strongly illustrates that these people can live in small, community-based residences if appropriately supported. The experience of residents in Disability Enterprise's new accommodation is an excellent example of how people with high-support needs can live in small, community settings.

7.56 The Committee agrees with the Government that small, community-based accommodation settings can also become 'institutionalised'. While this may be the case, the evidence presented overwhelmingly demonstrated that the inherent characteristics of LRCs, such as their delivery of

⁵⁵⁶ Ms Berry, Evidence, 26 August 2010, p 16

⁵⁵⁷ Ms Berry, Evidence, 26 August 2010, p 16

⁵⁵⁸ Horin, A, 'Empty promises of freedom', *Sydney Morning Herald*, October 9 2010

⁵⁵⁹ Ms Berry, Evidence, 26 August 2010, p 16

services and the level of control over residents' lives, make LRCs more susceptible to such a condition.

- 7.57** The Committee acknowledges that redeveloping LRCs may continue to exclude people with disabilities from the community. As discussed by the proponents of devolution, housing people with disabilities in facilities that are distinct from their immediate surrounds does not encourage interaction with mainstream society and perpetuates the stigma of disability. This situation is unacceptable and people with disability deserve to have choice, flexibility, person-centred planning and have their services provided in community setting if they choose.
- 7.58** The Committee accepts that international and Australian research has found that people with disability reach their outcomes more readily in small, community-based supported accommodation facilities rather than LRCs. Supporting and encouraging people with disabilities to meet their full potential is an important part of their social and emotional development.
- 7.59** The Committee commends the findings and recommendations of the recent NSW Ombudsman's report, *People with disabilities and the closure of large residential centres*. This report clearly elucidates the difficulties people with disabilities face when housed in LRCs. It also noted the community's disappointment at the failure of the Government to achieve their original policy to close these facilities by 2010.
- 7.60** On the balance of evidence received during the Inquiry the Committee recommends that the Minister for Disability Services maximise the devolution of LRC's through providing person-centered planning and support for every service user who is currently housed in these centres. The Committee believes that if every service user received person-centred planning, a very small number who had extremely high support needs may remain in congregate settings such as LRCs.
- 7.61** Additionally, the Committee recommends that the Minister for Disability Services ensures that service users who are transitioned out of Large Residential Centres are adequately supported during the transition period and while they settle into their new accommodation.

Recommendation 42

That the Minister for Disability Services maximise the devolution of Large Residential Centre through providing person-centered planning and support for every service user who is currently housed in these centres, and that:

- accommodation needs and preferences of individuals are the centre of decisions to relocate residents.
 - all accommodation options offered to service users transitioning out of Large Residential Centres, complies with the NSW Disability Service Standards, *Disability Services Act 1993* and the United Nations Convention on the Rights of Persons with Disabilities.
-

Recommendation 43

That the Minister for Disability Services ensure that service users who are transitioned out of Large Residential Centres are adequately supported during the transition period and while they settle into their new accommodation.

Chapter 8 Home modification and maintenance

This chapter examines issues regarding the Department of Human Services, Ageing, Disability and Home Care (ADHC's) administration and implementation of home modification and maintenance services. Issues regarding long waiting periods in the program are examined, including the impact of a lack of funding and a shortage of Occupational Therapists (OTs). The quality of work completed through the program is also examined, which includes the use of unlicensed builders to complete home modifications.

Home Modification and Maintenance

- 8.1** Many Inquiry participants expressed concern regarding the ADHC funded Home Modification and Maintenance program. Key issues identified include the long waiting period experienced by service users, quality of work completed, use of unlicensed builders and the insufficient level of funding provided.
- 8.2** Ms Stacey Sheppard-Smith, Executive Officer, NSW Home Modification and Maintenance Services State Council (NSW HMMS State Council), described the purpose of the modification and maintenance service industry:

The Home Modification and Maintenance and Services industry provides support to clients. We modify people's homes so that they may remain in their homes and remain independent but we also provide support to other HACC [Home and Community Care] services so that they may go in and provide care services. A modified bathroom will assist home care, for example, in going in and providing personal care services to clients in their homes. We have three levels of service provision within the home modification and maintenance services industry. There is level one, two and three. The work is reflected on monetary bands and work progresses through the system according to the cost and the level of complexity.⁵⁶⁰

- 8.3** The different levels of home modification that are funded for home modification and maintenance services were also described by Ms Sheppard-Smith:

Level one is between the value of \$0 and \$7,500. Level two is work that is more complex and is between the value of \$5,000 to \$25,000 and level three which is for the clients who have high complex care needs is for the value of \$20,000 and over.⁵⁶¹

- 8.4** Mr Sean Lomas, Policy and Advocacy Manager, Spinal Cord Injuries Australia, expressed that "living in the community with a disability is very tenuous," referring to it as like a 'see-saw':

Things balance and you exist, you can do things. You can go out and you can engage in employment. You can travel or whatever it is you wish to do but if anything tips that see-saw slightly off-line then you have got troubles and that can be shoddy

⁵⁶⁰ Ms Stacey Sheppard-Smith, Executive Officer, NSW HMMS State Council, Evidence, 3 September 2010, p 12

⁵⁶¹ Ms Sheppard-Smith, Evidence, 3 September 2010, p 12

modifications, it can be care staff not turning up for rostered hours, it can be a whole host of things.⁵⁶²

- 8.5** In his submission Mr Greg Killeen, a service user, identified that there is a lack of funding for home modifications and that the budget for level 3 home modifications for 2009/10 was exhausted by December 2009:

Many people with a disability that live in their own home or in private rental properties may require major home modifications such as installing ramps, renovating a bathroom/toilet, remodelling a kitchen and/or laundry, widening doorways including wider doors etc. The Homemods Scheme (level III) provides funding greater than \$20,000 for such renovations but, due to the lack of appropriate NSW Government funding to meet the needs of eligible applicants, the program exhausted the 2009/10 Level 3 budget prior to December 2009.⁵⁶³

- 8.6** The importance of home modification and the impact that insufficient funding for the program has on the lives of people with disability was described by Mr Killeen, who is also a Policy and Advocacy Officer at Spinal Cord Injuries Australia. He explained that the lack of funding in this program results in some people with disability compromising on the appropriateness of accommodation they move into after leaving hospital. This includes living in an unmodified houses that requires them to be carried in and out of the house:

The home modification scheme where people own their own home and they need to have it modified, if there is a lack of funding to modify the home and people do not have their own means of funding to modify it there can be a requirement for them to be transitioned to another type of accessible accommodation before they can go home. We are aware of some people going home when the home is not modified and making do, getting carried up and down a few stairs to get in and out of the home. They want to be home, they want to be out of hospital and they are well enough to leave hospital but they have to make that sort of compromise, which is unfortunate.⁵⁶⁴

- 8.7** The following case study was provided by the author of Submission 99. It illustrates some of the challenges faced by a service user and her partner when they required a home modification. The home modification did not respond adequately to the needs of this couple.

Case study 7 – Name suppressed⁵⁶⁵

Jean uses a wheelchair for mobility. She and her husband Simon purchased a villa and applied to HMMS to assist in modifying the home. Three months after the application an OT arrived to assess Jean's requirements. On receipt of her report the local HMMS team assessed the cost of the modifications required and negotiated with Jean and Simon (based on their combined income) what percentage of costs they would be required to pay for modifications. Due to the high costs of the modifications the decision was escalated to a regional body for approval.

⁵⁶² Mr Sean Lomas, Policy and Advocacy Manager, Spinal Cord Injuries Australia, Evidence, 26 August 2010, p 40

⁵⁶³ Submission 42a, Mr Greg Killeen, p 2

⁵⁶⁴ Mr Greg Killeen, Policy and Advocacy Officer, Spinal Cord Injuries Australia, Evidence, 26 August 2010, p 37

⁵⁶⁵ Submission 99, Name suppressed, p 5

Work began on modifications nine months post application. In this time Simon lifted Jean to and from the inaccessible bath (or over the shower hob) and up and down the front steps. As access was difficult from the front Jean and Simon agreed that access should be provided through the rear kitchen door. However, the HMMS assessor decided that the laundry door would provide less costly access.

Jean and Simon pointed out that due to Jean's short stature and the narrow wheelchair Jean was capable of accessing the house from the laundry even though her friends in larger wheelchairs could not. Further, for Jean to get to the laundry door a path would be needed the length of the house and if it was not covered Jean would be soaked in heavy rain.

After negotiations it was decided (by HMMS) that a lift from the garage to the kitchen was needed. This necessitated the loss of a car space in the tandem garage and Jean and Simon are required to pay for annual maintenance of the lift.

The bathroom also required modification. The shower hob was removed and non-slip tiles replaced the old tiles in the shower. Jean pointed out that she would rather have one set of tiles across the floor and that non-slip tiles were unnecessary as she used a shower chair. She agreed to pay additional costs to ensure the bathroom met her requirements but the new tiles were only applied in the shower area.

As a concession to the couple the entire bathroom was tiled (rather than just the shower). A mirror was provided to suit Jean's height. Simon noted it was too low for him to use. The argument from the builder was that the bathroom was modified for Jean, not him. A handrail was needed so that Jean could transfer to the toilet. The builder placed it where the OT had determined it should go based on the Australian Standard. Jean pointed out that she could not reach the handrail due to her short stature but the OT had to be called before the builder would adjust the rail to a height she could use. Because a lift was installed through the garage and there is a step from the rear of the garage to the back yard Jean can still not access the yard herself. HMMS provided a portable ramp that Simon could lay down when his wife needed to access the yard - no means were provided for Jean to access the yard independently. The kitchen was not modified to meet Jean's need. The bathroom leaked and needed repair (as did the lift following a breakdown).

8.8 Mr Killeen identified that the lack of a whole-of-government approach to the provision of home modification services impacts the delivery of this service. Mr Killeen identified that service users are required to coordinate services from different agencies for equipment, home modification, personal care and community care. The receipt of these services is sometimes dependent on other services so it can be a very challenging system for service users to navigate:

Often the equipment and the home modification and the care are all provided by the Government. You apply for the home modifications to this department, equipment from that department which is Health and not ADHC and the personal care support from ADHC. Instead of having a whole of government approach and fixing the problem in one go, some people have the threat of their service being withdrawn because the bathroom is not right, or they now need a piece of equipment that they are waiting 6 to 12 months for from PADP—Program of Appliances for Disabled People, which is run through Enable NSW, which is ... one of the services that people with disability and older people will need to access possibly at some stage. Some people have difficulty trying to get support in the community when they are dealing with different departments from seeking funding. Often they have all got different eligibility requirements.⁵⁶⁶

⁵⁶⁶ Mr Killeen, Evidence, 26 August 2010, p 40

8.9 Insufficient choice and a decreasing number of home modification service providers available in regional NSW was also pointed out to the Committee by Mr Lomas:

In terms of regional choice it is certainly very complex. Greg and I are in the process at the moment of writing up a regional issues paper where we are polling all of our members out in the regions and trying to get details coming in around that. But it certainly looks as if choice is not really an option just simply because there is not the number of agencies willing to go out there. Certain agencies that do have presence out in the regions at the moment are starting to pull themselves back because it just is not profitable and they cannot keep themselves going with the number of staff they need out there to provide a decent service. So in terms of choice I would not have thought there is really that much choice out there.

Service quality

8.10 The poor quality of services provided through the Home Modification and Maintenance program was identified as a concern by some Inquiry participants. Mr Lomas identified that some home modifications are so poor that the service users cannot get into some rooms of their house:

We are aware of a number of companies that have done some very poor modifications to the homes of some people as a result of which the people in regional areas cannot even get into the rooms or down the hallways. I do not want to name the company but as reported through our regional offices they have been having all sorts of problems with people who undertake certain work which is all paid for by the home modifications scheme.⁵⁶⁷

8.11 Using unlicensed builders was suggested as a possible reason for poor quality work. Mr Steve Malvern, Vice Chairperson, NSW HMMS State Council and Project Manager, NSW Statewide Level 3 Project, stated that a building licence is required by law for home modifications that exceed the value of \$1,000. Mr Malvern told the Committee that 40 out of the approximately 106 home modification service providers do not have a building licence:

This is one of the biggest issues we have. If I may, you questioned the quality assurance program that State council runs. The reason behind that is that essentially we are all builders. By law, we are meant to have a builder's licence to undertake the type of work we do when the value of work exceeds \$1,000. Unfortunately, of the 106-odd home modifications services out there, there are approximately 40-odd services that continue to remain unlicensed. Basically they do not have the technical expertise to undertake the work that they are funded to do. This has been brought up with ADHC over many years and they continue to fund these projects. In 2006 under the building Act, we must provide a statutory warranty on all the work we do up to a period of seven years.⁵⁶⁸

8.12 Ms Sheppard-Smith also explained that there are 40 home modification service providers that are not licensed under the Office of Fair Trading licensing requirements.⁵⁶⁹

⁵⁶⁷ Mr Lomas, Evidence, 26 August 2010, p 39

⁵⁶⁸ Mr Steve Malvern, Vice Chairperson, NSW HMMS State Council and Project Manager, NSW State Wide Level 3 Project Manager, Evidence, 3 September 2010, p 18

⁵⁶⁹ Ms Sheppard-Smith, Evidence, 3 September 2010, p 19

- 8.13** The NSW HMMS State Council *Annual Report 2008/09* identified that unlicensed home modification and maintenance services receive the largest amount of NSW HMMS State Council Quality Assurance Rectification Program (QARP) funding. It also stated that there are many other significant issues regarding the use of unlicensed home modification and maintenance services:

... 38% of applications received in the 2008/09 FYE were to rectify poor workmanship by unlicensed HMMS. The clear absence of technical expertise resulted in situations where no clear scope of works could be provided, contractors were over-quoting, and a lack of supervision of Contractors resulted in poor workmanship. The largest allocation of QARP funding in the 2008/09 FYE was to the Riverina Murray Region to rectify major works completed unlicensed HMMS, the total sum of \$37,545.46. Therefore, as the data shows, there is a direct correlation between unlicensed HMMS and their increased reliance on QARP funding. The NSW HMMS State Council cannot stress the importance of the resolution of licensing in the HMMS industry. If HMMS were adequately licensed and funded to employ Builders resulting in the building of technical expertise in their services, the drain on QARP funding would be substantially minimised.⁵⁷⁰

- 8.14** The Committee was told by Mr Malvern that service providers who participate in tender processes to provide home modification and maintenance services are not asked as part of the process, whether they are licensed to undertake the building work:

At no time, not even as part of the tendering process for providing you money, do they [ADHC] ask the question whether or not your service is licensed to undertake the work they are funding you to do. At the same time, State Council are running around providing a quality assurance program, which is basically fixing up a lot of the work that has been done, and defective work that has been done in some cases, by home modification services. We continue to have this battle with ADHC so that they gain some understanding of the type of work we actually do. A lot of the work is complex and not simplistic. We do have cranes in streets. We are lifting lifts and taking roofs off houses and putting lifts in residential homes. We are doing major works in some cases. Yet, I do not believe they understand the complexity and the reasoning around us having to provide some consumer protection.⁵⁷¹

- 8.15** In response to the claim that many service providers funded through the Home Modification and Maintenance program use unlicensed builders, Ms Lauren Murray, Deputy Director General, ADHC, stated:

I understand what they [NSW HMMS State Council] are saying, in the sense that each individual's home modification service provider does not necessarily have a licensed builder employed with them but there are a number of mechanisms in place to ensure that is covered off.⁵⁷²

- 8.16** Ms Murray advised that under Home and Community Care (HACC) guidelines for home modification services, service providers are required to comply with all state legislation and guidelines, including the *Home Building Act 1989*.⁵⁷³ She also stated that “[t]he service providers

⁵⁷⁰ NSW HMMS State Council, *Annual Report 2008/09*, p 17

⁵⁷¹ Mr Malvern, Evidence, 3 September 2010, p 18

⁵⁷² Ms Lauren Murray, Deputy Director General, ADHC, Evidence, 27 September 2010, p 1

⁵⁷³ Ms Murray, Evidence, 27 September 2010, p 1

themselves are required to indicate that they are complying with relevant legislation and guidelines, which does indicate that there is a requirement that builders are to be licensed.”⁵⁷⁴

8.17 The claim that approximately 40 per cent of builders were unlicensed was also questioned by Ms Murray who clarified that there is a total of 98 service providers rather than 106, and that of the 98 service providers 96 indicated in their annual compliance return “... that they comply 100 per cent with the requirements, including legislative requirements.”⁵⁷⁵

8.18 Ms Murray acknowledged that a number of service providers do not employ licensed builders, however most home modification service providers “... subcontract their work and it is a requirement that they use licensed builders to do that.”⁵⁷⁶

8.19 Ms Murray also explained that quality technical officers are funded to provide quality assurance on home modification works:

In addition, we fund at level 2 and level 3 the degree of work and the size and scale of the work; we fund at both regional and State levels quality assurance technical officers who are required to check on the quality and provide advice and assistance around quality assurance in respect to the works. In addition to that, all local governments require certifications of works - qualified people, the same as for any of modifications work.⁵⁷⁷

8.20 Another factor impacting on the overall quality of the service was identified by Mr Malvern who stated that with the high staff turn-over rates in ADHC, “... we are continually basically explaining our service to any new staff.” Mr Malvern stressed the importance of ADHC retaining staff with a knowledge of each service that they are applying:

we had to explain [to ADHC], in pretty much the same way we did here today, about the levels of funding, the services and all the rest. It is not uncommon for us to have to do exactly the same thing to ADHC, which is funding us. I guess what we are looking for is somebody within the department who fully understands the projects that it is funding.⁵⁷⁸

8.21 The NSW HMMS State Council regulates the sector through the Quality Assurance Program, however, the State Council advised that funding issues in this program may result in client outcomes being compromised:

The NSW HMMS State Council has implemented the Quality Assurance Program for all Major Modifications as these works are exempt from Home Owners Warranty Insurance. No further funding has been received to continue the QA Program and monitor these works. Client outcomes may potentially be severely compromised due to the absence of the Quality Assurance Program.⁵⁷⁹

⁵⁷⁴ Ms Murray, Evidence, 27 September 2010, p 2

⁵⁷⁵ Ms Murray, Evidence, 27 September 2010, p 2

⁵⁷⁶ Ms Murray, Evidence, 27 September 2010, p 1

⁵⁷⁷ Ms Murray, Evidence, 27 September 2010, p 1

⁵⁷⁸ Mr Malvern, Evidence, 3 September 2010, p 20

⁵⁷⁹ Submission 34, NSW HMMS State Council, p 3

- 8.22** Mr Killeen recommended that an urgent review of the Home Modification and Maintenance program is required:

NSW Government undertake an urgent review of the Homemods Scheme, audit of all outstanding applications that have received an assessment and quotation, as well as review all current applications that have not received an assessment as yet. ADHC should seek funding from Treasury to clear the backlog of assessed and quoted home modifications as well as yet to be assessed home modifications.⁵⁸⁰

- 8.23** Mr Jim Moore, Chief Executive, ADHC, told the Committee that a “review of home modifications is being implemented to look at equity of funding and improvements to the delivery of these services.”⁵⁸¹ Ms Murray further advised that the evaluation, which will 'address issues of quality assurance in the program' is expected to be completed in early 2011.⁵⁸²

- 8.24** The HMMS State Council submission acknowledged the review that is taking place, but reiterated the importance of addressing waiting lists and the funding shortfall.⁵⁸³

Waiting lists

- 8.25** Issues regarding waiting lists and lengthy waiting periods were also identified as a concern in the home modification and maintenance services. Mr Lomas told the Committee that ADHC does not keep a waiting list for this program or require funded organisations to communicate the unmet need indicated by waiting lists maintained by these services. Mr Lomas criticised ADHC for not using this information to “correctly forward plan a budget to meet that need and meet the people that are waiting.”⁵⁸⁴

- 8.26** Issues with waiting lists are examined in more detail in Chapter 5.

- 8.27** Ms Sheppard-Smith acknowledged that the ADHC “minimum data set refers to past episodes of service and it does not capture funding shortfalls and waiting lists and unmet need” in the home modification and maintenance program.⁵⁸⁵

- 8.28** The Committee heard that the requirement that an OT to complete an assessment before home modification can be arranged was identified as a reason for the delay in providing home modification services by Ms Ruth Ley, Service Coordinator and Builder Blue Mountains, Blue Mountains Home Modification and Maintenance Service (BM HMMS):

This assessment will result in recommendations and specifications being prepared which will detail the type of work required (eg grab rail in shower) and the exact dimensions and location appropriate for the client (eg on shower wall opposite the

⁵⁸⁰ Submission 42a, p 2

⁵⁸¹ Submission 31, ADHC, p 143

⁵⁸² Ms Murray, Evidence, 27 September 2010, pp 1-2

⁵⁸³ Submission 34, p 2

⁵⁸⁴ Mr Lomas, Evidence, 26 August 2010, p 41

⁵⁸⁵ Ms Sheppard-Smith, Evidence, 3 September 2010, p 20

taps, 800mm from the floor). This report is essential to ensure the modification will actually work for the client and not put them at risk of injury.⁵⁸⁶

- 8.29** Due to the lack of recurrent recurrent funding or brokerage funding available for the BM HMMS to employ an OT, Ms Ley advised that applications are generally referred to Community Health intake for this assessment, where waiting lists are very long:

The waiting list for this is frequently 8 months or longer. Recently ... the service trialled brokering private OTs [Occupational Therapists] using non-recurrent funding. This had a negative outcome for the clients and the service, as the private OTs were not able to do full assessments (non-recurrent funding not for full assessments) and had little local knowledge. Also the demand was so significant the waiting list was moved to the private OTs.

- 8.30** In an attempt to alleviate the length of the waiting list for home modification, Ms Ley told the Committee that the BM HMMS has recently accessed brokerage funding to hire private OTs because their waiting list had reached up to 18 months.⁵⁸⁷ Ms Ley recommended that "... either SWSAHS [South West Sydney Area Health Service] needs appropriate funding for OTs or BM HMMS requires funding to engage an OT with the appropriate skills and connections."⁵⁸⁸

- 8.31** Ms Sheppard-Smith also advised the Committee that there are long waiting periods to receive an assessment in the Home Modification and Maintenance program:

We have two competing scenarios in NSW. In the metropolitan area we have a huge number of OTs that we can draw from. A lot of them are young new graduates coming out of university and so they are quite inexperienced, but there is a high demand for service because of the population so there are huge waiting lists. Sometimes people can wait anywhere from 12 to 18 months for an OT assessment. In the regional and rural areas of NSW we have a very limited pool of OTs. In some areas there are just no OTs available at all.⁵⁸⁹

- 8.32** Ms Sheppard-Smith explained that "... part of the longest waiting period was for an occupational therapist assessment to take place because the occupational therapists sit within NSW Department of Health (NSW Health) and they have competing priorities and clients on waiting lists."⁵⁹⁰ The 'serious shortage' of OTs in rural and remote areas of NSW further exacerbates the waiting period in those areas.⁵⁹¹

- 8.33** Another factor affecting waiting lists that was identified by Ms Ley is the inability of service users to make a 'client contribution' to the cost of their home modification:

The Service works out the approximate cost of the work and calculates a client contribution which recovers the cost of the materials and a subsidised labour charge.

⁵⁸⁶ Submission 28, BM HMMS, p 1

⁵⁸⁷ Ms Ruth Ley, Service Coordinator and Builder Blue Mountains, BM HMMS, Evidence, 3 September 2010, p 14

⁵⁸⁸ Submission 28, pp 1-2

⁵⁸⁹ Ms Sheppard-Smith, Evidence, 3 September 2010, p 14

⁵⁹⁰ Ms Sheppard-Smith, Evidence, 3 September 2010, p 13

⁵⁹¹ Submission 34, p 3

This process is in accordance with the NSW Home Modification Guidelines. The labour "rate" is determined by the Service Committee and reflects the economic capacity of the client group. ... It is increasingly common for clients to be unable to make the contribution. Yet work cannot be refused so the job sits on the list till funding can be found.⁵⁹²

- 8.34** Ms Sheppard-Smith explained that it would be useful for an OT to be funded for each level 2 service:

One of the things we would like to see, and which we continue to ask for, is that an occupational therapist should sit with each level 2 service so that they get some expertise in the type of work we are dealing with, which is the work over \$7,500, and that we get some consistency in their referrals.⁵⁹³

- 8.35** Mr Killeen suggested that streamlining the application process for home modification services so that only one application was required from service users would improve the current process. This would reduce the need for separate applications "with all the administration and bureaucracy that goes with that."⁵⁹⁴

- 8.36** To clear the existing waiting list, Spinal Cord Injuries Australia stated that a 100 per cent increase in funding is required, and that "this increase [is] to be implemented as a priority."⁵⁹⁵

Committee comment

- 8.37** Many people depend on the home modification and maintenance service to enable them to live in their own homes. The Committee sympathises with the many challenges faced by both service providers and service users in accessing these services. The Committee acknowledges the numerous issues that currently exist in the home modification and maintenance program.

- 8.38** The Committee recognises that the lack of OTs employed by home modification and maintenance services and the long waiting periods for NSW Health OT assessments results in delays for service users accessing this program.

- 8.39** The Committee is concerned by the lack of certainty regarding the use of licensed builders in the home modification and maintenance program. As the NSW HMMS State Council is responsible for, amongst other things, implementing the Quality Assurance Program, the Committee believes that this organisation has a strong understanding of issues affecting the Program, such as the use of unlicensed builders.

- 8.40** The Committee accepts that ADHC requires service providers to indicate whether they comply with relevant legislation through the Annual Compliance Return. However, based on the evidence received during the Inquiry, particularly the uncertainty expressed by the NSW HMMS State Council regarding compliance with the *Home Building Act 1989*, the Committee is not assured that this process provides adequate certainty of compliance. The increased risk to service users resulting from this is noted as a significant issue by the Committee.

⁵⁹² Submission 28, p 2

⁵⁹³ Ms Sheppard-Smith, Evidence, 3 September 2010, p 15

⁵⁹⁴ Mr Killeen, Evidence, 26 August 2010, p 41

⁵⁹⁵ Submission 67, Spinal Cord Injuries Australia, p 12

- 8.41** The Committee believes that ADHC should address the issues identified by the NSW HMMS State Council to provide improved assurance that service providers that are funded to complete home modifications are *all* either licensed or use licensed builders as sub-contractors. Service users, their carers and families deserve assurance that the work that is being completed on their homes complies with applicable legislation.
- 8.42** The Committee has not received sufficient evidence to be able to determine whether all service providers are either licensed or used licensed builders, and recommends that this issue is examined and addressed in detail as a priority by ADHC through the current review.
- 8.43** The Committee believes that service providers should be well supported to provide home modification services, including having a mechanisms to report the level of unmet need in the programs to ADHC and having access to ADHC funding staff who understand the programs they fund and manage. The Committee recommends that this also is addressed through the current review.
-

Recommendation 44

That the NSW Government ensure that the current evaluation of the ADHC funded Home Modification and Maintenance program includes consultation with stakeholders and includes review of:

- funding levels and shortages
- waiting lists, including for Occupational Therapist assessments
- potential non-compliance with the *Home Building Act 1989*, including the use of unlicensed builders
- options to streamline the application process for home modification services so that only one application is required from service users for assessment, quotation and home modification
- quality evaluation of services provided through the program
- options for home modification and maintenance service providers to provide waiting list information to ADHC, for example regarding unmet need
- review of all outstanding applications that have received an assessment and quotation but have not been completed.

That the evaluation and ADHC's response to the recommendations is published on ADHC's website once finalised.

Chapter 9 Quality monitoring and evaluation

Three of the Committee's terms of reference relate to quality, monitoring and evaluation – terms of reference 1 (d), (e) and (f). This chapter examines issues regarding compliance with the NSW Disability Service Standards (NSW DSS) for services provided and funded by Ageing, Disability and Home Care (ADHC), including mechanisms to monitor and act upon non-compliance. Compliance with the *Disability Services Act 1993* (NSW) is also examined in this chapter, with regard to the provision of the quality of services provided to people with disability. The quality of services provided in licensed boarding houses is also examined.

The handling of complaints and grievances regarding the provision of disability services is examined in relation to compliance with the NSW DSS and the quality of services provided. This chapter also examines the current monitoring processes for disability services and access to disability services data.

Disability standards and legislation

- 9.1 The NSW DSS and the *Disability Services Act 1993* set the framework for the funding and provision of disability services in NSW. This policy and legislation also establishes the quality standards that disability services are required comply with in NSW.
- 9.2 Additional background to the NSW DSS and *Disability Services Act 1993* is provided in Chapter 2.
- 9.3 Some Inquiry participants expressed concern that ADHC and funded services do not always comply with the NSW DSS or the *Disability Services Act 1993*, with regard to the quality of services that are provided to people with disability. These issues are explored in this section.

Disability Service Standards

- 9.4 Some Inquiry participants told the Committee that ADHC and funded organisations do not always act in compliance with the NSW DSS.⁵⁹⁶ Key issues identified include the quality of some disability services staff, inadequate understanding of the NSW DSS, limited monitoring of compliance with the NSW DSS and limited availability of mechanisms to address issues of non-compliance.
- 9.5 The ADHC submission stated that "[i]t is a condition of ADHC's Funding Agreement that service providers comply with the NSW Disability Service Standards."⁵⁹⁷ ADHC monitor service providers' compliance with the Funding Agreement through the Annual Compliance Return (ACR), which is described in Chapter 2.
- 9.6 The process used by ADHC to monitor the compliance of funded services with the NSW DSS is described in Chapter 2 as is the Quality Assurance and Improvement Program (QAIP).
- 9.7 The author of Submission 56 believes that the introduction of NSW DSS and legislation is a "significant achievement" by the Government, however, "... in so many instances, these have

⁵⁹⁶ See for example, Submissions 50, 56, 74 and 89

⁵⁹⁷ Submission 31, ADHC, p 83

become just words in rhetoric ... due to the lack of funding and resources to make it possible."⁵⁹⁸

9.8 The author of Submission 56 told the Committee that "ADHC are quick to quote the NSW DSS but very slow in implementing them on the broader scale, specifically in the area of community access."⁵⁹⁹

9.9 Despite there being a requirement for individualised service provision under the NSW DSS, the author of Submission 74 stated that treatment by an ADHC caseworker made them feel pressured and stressed and that an individualised service was not received:

I feel the Caseworker patronises us and speaks to me like I am stupid, she has pressured us to fulfil her timeframe rather than what is best for and our family. She has remarked that transition to respite is the 'longest she has ever known' and I feel pressurised and stressed by her, it's clear we are just a number to her as opposed to trying to provide us with an individualised service as per the Disability Service Standards that ADHC are supposed to abide by. She seems quite focused on merely 'closing the referral' and meeting ADHC needs first.⁶⁰⁰

9.10 The author of Submission 71, a mother and carer, also reported a poor quality of service from ADHC, which included being lied to and demeaned by her case worker:

ADHC have never been supportive of my and my child's life, we are constantly lied to, their so called services are never attending our needs, there is red tape on just about anything you can think of. I have never felt so demeaned as I have by my case workers and their management, I have never been promised things and lied to as much as they have to me and my family, I have tried everything, from acquiring an advocate to involving my local MP ...⁶⁰¹

9.11 Additional issues regarding disability services staff are examined in Chapter 11.

9.12 The author of Submission 44 is a Speech Pathologist with NSW Health. This author identified the impact of poor quality service provision by ADHC on other government agencies and the reluctance of families to access ADHC services due to the perceived quality of services provided:

ADHC's inability to meet the needs of children and families affects the care of children across Health, Education, Disability, and non government sectors. Some families are reluctant to have a formal assessment and diagnosis that will require transfer from Health to ADHC. Families may withhold information about previous assessments and diagnosis in order to access Health therapy services. Speech pathologists working in Health receive many calls from parents and professionals asking us to see children with identified significant disability because they are not receiving adequate services via ADHC.⁶⁰²

⁵⁹⁸ Submission 56, Name suppressed, p 2

⁵⁹⁹ Submission 56, p 5

⁶⁰⁰ Submission 74, Name suppressed, p 2

⁶⁰¹ Submission 71, Name suppressed, p 1

⁶⁰² Submission 44, Name suppressed, p 1

- 9.13** Services received in a group home were also criticized by the author of Submission 8 for not complying with the NSW DSS:

Disability standards and ADHC own standards are nonexistent in my personal group home. As far as an implementation of standards goes, when dealing with the area manager, I have to first talk and then write cc-ing superiors and still receive a vague response. The system sets up residents to fail in personal needs and goals as these cannot be achieved without additional funding or resourcing.⁶⁰³

- 9.14** The author of Submission 10 identified that non-compliance with the NSW DSS can put service users at risk. The author stated that "[t]he failure of ADHC to comply with their own standards caused our sister and the other household members to be put at risk."⁶⁰⁴

- 9.15** The author of Submission 6 explained that that her 8 year old son who has autism, intellectual disability and is non-verbal, was left without behavioural support after she, the mother and carer, questioned the use of a restrictive procedure:

... her style was simply not to take seriously the real and very distressing concerns we had regarding our son's well-being. It has since transpired that the restrictive procedure has in fact been abused on at least one occasion that we have written evidence of. The therapist in question certainly could never ever be described as family-centred or even flexible in my view.⁶⁰⁵

- 9.16** Dr Robert Leitner, Chairperson of the Association of Doctors in Developmental Disability (ADIDD), agrees that ADHC and funded organisations do not always comply with the NSW DSS. Dr Leitner stated that "ADHC and especially NGOs may fall short with their compliance [with] the Disability Standards."⁶⁰⁶

- 9.17** Different interpretations of the NSW DSS were also identified as an issue by Inquiry participants. Ms Mary Dallow, Community Planning Co-ordinator from Maitland City Council, stated that "Service Providers and service user's interpretations of the standards at times can differ. Whilst service providers' policy and procedures documents confirm they are complying there are people with disabilities that would not agree."⁶⁰⁷

- 9.18** The Committee heard that inconsistent application of the NSW DSS can lead to confusion and frustration about the standard of service that can be expected. Ms Carol Berry, Executive Director, NSW Council for Intellectual Disability, explained that parents and carers often refer to the NSW DSS when they are trying to improve the services they are receiving. Ms Berry stated "[m]any are often exasperated and express the standards are useless as they cannot be enforced. The sentiment is also expressed that they are used in a fashion that is restrictive rather than which is of course the original intent of the standards."⁶⁰⁸

⁶⁰³ Submission 8, Name suppressed, p 1

⁶⁰⁴ Submission 10, Name suppressed, p 14

⁶⁰⁵ Submission 6, Name suppressed, p 1

⁶⁰⁶ Submission 94, ADIDD, p 18

⁶⁰⁷ Submission 102, Maitland City Council, p 3

⁶⁰⁸ Submission 39, NSW Council for Intellectual Disability, p 15

- 9.19** Dr Leitner identified that there is variation between ADHC central office policy and regional office practice, in relation to the application of the NSW DSS:

The policies from ADHC Central Office may not be reflected in the practices of the Regional Offices. Inconsistency in the implementation of policies between Regional Offices may disrupt service delivery. Example: a Group Home may not allow a resident with complex epilepsy to wear a safety helmet prescribed by a specialist neurologist on the grounds of restrictive practice but another may allow the resident to wear the safety helmet on medical grounds.⁶⁰⁹

- 9.20** Variation between central office policy and local implementation was also noted as an issue by Mr Sean Lomas and Mr Greg Killeen, Spinal Cord Injuries Australia:

As an organisation that provides an Advocacy service we are consistently being made aware of some rather negative situations that people with a disability currently experience living in the community when in receipt of ADHC directly delivered services. Despite the positive wording of both the Disability Services Standards (DSS) and the Disability Services Act (DSA) there seems to be a breakdown between positively written, centrally created, ADHC policies and local management directing front line staff.⁶¹⁰

- 9.21** It was not only service users that expressed their frustration with the NSW DSS. Service providers were also frustrated. An example provided to the Committee was from Mr Gary Blaschke, the National President of the Disabled Surfers Association of Australia Inc, who conveyed his organisation's experience of complying with the NSW DSS:

In 1986 the DSA [Disabled Surfers Association] wanted to be seen as complying with standards and subsequently applied to join the NSW Sports Council for the Disabled. Standards were in place and the DSA needed to comply to become a member group. It did not take long before the DSA realised that being a member was nothing more than ticking the correct boxes to make not only ourselves look like we were complying, it also helped make the bureaucracy fulfill their duty and again allow for further funding, whether they and member organisations were providing correctly for the disabled or not.⁶¹¹

Responding to non-compliance

- 9.22** Many Inquiry participants expressed concern regarding the processes available to address issues of alleged non-compliance with the NSW DSS. The author of Submission 50 expressed concern about the way that ADHC responds to NSW DSS breaches:

There is an expectation that ADHC should comply with Disability Service Standards. However we are gravely concerned that due to a lack of resources and or the lack of willingness to listen to community complaints means that ADHC is not able to respond to breaches in their standards in a reasonable time frame or in a reasonable manner in at least a significant proportion of cases.⁶¹²

⁶⁰⁹ Submission 94, p 18

⁶¹⁰ Submission 67, Spinal Cord Injuries Australia, p 9

⁶¹¹ Submission 9, Disabled Surfers Association of Australia Incorporated, p 5

⁶¹² Submission 50, Name suppressed, p 2

- 9.23** Case study 8 provides an example of a mother and carer whose experience of group home services have resulted in a lack of confidence in the capacity of the NSW DSS to provide quality services.

Case study 8 – Name suppressed⁶¹³

It is my opinion what happened to my daughter and our family as a whole, is a case of total system failure. We used every avenue and mechanism available to us in a vain hope of having our concerns, and fears addressed, thoroughly investigated and acted upon. There were also professional people who also had their concerns for our daughters welfare ignored and not acted upon ...

NSW Disability Services Standards are not worth the paper they are written on if they are not rigidly followed and practicably applied in every day service provision to clients. There needs to be a better system for enforcing and monitoring their use. There are too many people with disabilities and family/carers unaware of their very existence. There seems to be a lack of staff knowledge and training in the use and importance for not only complying with but implementing these standards in their everyday care role and service provision. Both ADHC and [NGO name suppressed] dismissed most all Disability standards in their service provision to my daughter and our family, either has been held accountable or has there been any consequences of their failings, which have adversely impacted on my daughter and others. Perhaps it, should be mandatory for all service providers to not only display disability standards in their service but to explain and provide information to service users and family/carers when first entering their service provision explaining their rights and how the service endeavours to implement disability standards in their service provision and of their legal obligation in doing so.

- 9.24** Ms Roz Armstrong, an Official Community Visitor, explained that services are not "... monitored adequately in order to ensure that every service to a person with a disability meets the standards under which that accommodation service is auspiced."⁶¹⁴
- 9.25** The ADIDD believes that there is no transparent mechanism for "... managing agencies that are non-compliant with the Disability Standards. Even if an agency is clearly non-compliant, the problem appears to go 'unnoticed' by ADHC." Dr Leitner suggested that documentation regarding compliance with the Standards should be publically available.⁶¹⁵
- 9.26** Case study 9 provides an example of how certain services provided by ADHC do not meet the NSW DSS and the *Disability Services Act 1993*. The issues regarding out of office hours support identified in this case study are addressed in more detail in Chapter 6.

Case study 9 – Spinal Cord Injuries Australia⁶¹⁶

An example of [ADHC not meeting the Disability Service Standards] would be out of ADHC office hours contact support (support required between 1600 and 0830). Up until recently the procedure was if a carer had not turned up then you were pretty marginalised for that evening. This could be spending the night in a wheelchair which is sadly quite a common occurrence or even spending the night with

⁶¹³ Submission 14, Ms Carolyn Mason, p 19

⁶¹⁴ Ms Roz Armstrong, Official Community Visitor, Evidence, 27 September 2010, p 48

⁶¹⁵ Submission 94, p 18

⁶¹⁶ Submission 67, p 9

your toileting not dealt with leading to a heightened risk of infection through skin deterioration owing to prolonged exposure to moisture. If you required emergency support in the night for an event such as a blocked catheter then you needed to call an ambulance. ADHC had not planned to provide a telephone number for staff to call to report that they were unwell and unable to fill a shift outside of hours or for people receiving service to telephone the non turn up of a carer. Strangely enough ADHC funded services are required to provide this service. As this is a growing issue local management are now endorsing an 'Option B' model.

This is basically that you need to have a friend on standby as ADHC cannot guarantee service. The question is then what if you have no friends or relatives, as sadly many isolated people in the community do not? 'Option B' is no option for many people. In terms of compliance with the DSA this case shows breach under 3 (a), 3 (b) (i), (ii), (iii) and 3 (c) 3(e) and 3(f). Under the disability service standards we see a breach under (2), (3), (4), (5), (6), (8), and (10).

Committee comment

- 9.27** The Committee understands that many service users have observed a lack of accountability and transparent mechanism to monitor and manage issues of non-compliance with regard to the NSW DSS. The Committee understands that this has resulted in many service users feeling skeptical about the usefulness, effectiveness and the role of the NSW DSS in maintaining the quality of disability services.
- 9.28** The behaviour of some disability services staff is clearly not in compliance with the NSW DSS, including the ADHC caseworkers described by the authors of Submission 71 and 74. Issues regarding disability services staff are examined in more detail in Chapter 11.
- 9.29** The Committee believes that the variation between ADHC central office and local implementation of NSW DSS policy is an issue that is required to be addressed, so that there is a more consistent understanding of what the standards mean and how they are required to be implemented.
- 9.30** The Committee notes with concern the experience outlined in case study 8, which identified a lack of staff knowledge and training in the use and implementation of the NSW DSS. The Committee agrees that non-compliance increases the risk of service users receiving inappropriate services.
- 9.31** The Committee notes the view of many Inquiry participants, that services are not monitored adequately to ensure that every disability service meets the NSW DSS. The Committee acknowledges the concern expressed by Inquiry participants that ADHC is not able to respond to breaches of the NSW DSS in a reasonable time frame or in a reasonable manner in some cases. Complaints handling by ADHC is a significant concern to the Committee and is examined in detail later in this chapter.

Disability Services Act 1993

9.32 The Committee heard evidence regarding issues of non-compliance with the *Disability Services Act 1993*.⁶¹⁷ Key issues relate to the redevelopment of large residential centres, individual planning and inadequate action taken when the Act is breached.

9.33 Mr Phillip French, Director of the Disability Discrimination Legal Centre, stated that redevelopment of large residential centres is not in compliance with the Act. Mr French also stated that although ADHC claim the redevelopments conform to the *Disability Services Act 1993*, this claim has not been subject to independent merits review:

... Stronger Together states that the government will pursue a new accommodation policy and a range of new accommodation options. This includes the redevelopment of the Lachlan, Grosvenor and Peat Island Centres and of Ferguson Lodge (each non-conforming institutional accommodation services). In Stronger Together the government claims that these developments 'will be consistent with contemporary accommodation and care standards and will comply with the NSW *Disability Services Act 1993*'. However, in reality, these redevelopments represent a reversion to service models that congregate, segregate and isolate persons with disability from the community, and very obviously fail to conform to the requirements of the DSA [Disability Services Act] NSW. ADHC's failure or refusal to administer funding for these services in accordance with Division 2 of the DSA has the purpose or effect of preventing merits review of these redevelopment decisions (that was the application in Peat Island). So while ADHC claims these redevelopments conform to the DSA NSW, it has in reality done everything in its power to prevent that claim from being subject to independent merits review.⁶¹⁸

9.34 In the report *People with disabilities and the closure of residential centres*, Mr Bruce Barbour, the NSW Ombudsman, also stated that residential centres cannot comply with the *Disability Services Act 1993*, because of the nature of institutional care:

Residential centres are funded under the *Disability Services Act 1993*, which, among other things, requires services to be provided to people with disabilities in a way that results in the least restriction of their rights and opportunities. Numerous reports and inquiries have found that residential centres in NSW do not fully conform to the DSA and are incapable of doing so. This is because the nature of institutional care – including the segregation of the centres from the broader community, and the structured and inflexible routines – restricts the rights and opportunities of the people with disabilities who live in these settings.⁶¹⁹

9.35 Additional issues large residential centres are examined in Chapter 7.

9.36 Ms Christine Regan, Senior Policy Officer, National Council of Social Services (NCOSS) NSW, also believes that services such as those provided through large residential centres do not comply with the Act. She stated that NCOSS "shares the view of many people with disability and their families as well as disability advocacy organisations and others in the disability sector" that "large groups of people with disability living on one site with shared

⁶¹⁷ See for example, Submissions 14, 20, 30, 41 and 100a

⁶¹⁸ Submission 20, NSW Disability Discrimination Legal Centre Incorporated, p 9

⁶¹⁹ NSW Ombudsman, *People with disabilities and the closure of residential centres*, August 2010, p 1

supports does not comply with either the spirit or the letter of the NSW Disability Services Act".⁶²⁰

- 9.37** Ms Roz Armstrong, Official Community Visitor, identified further elements of disability service provision that do not meet the requirements of the Act, including individual planning, privacy, dignity and confidentiality, respect and valued status, dignity of risk and areas of financial management. She stated:

Based on ... Standards in Action Practice Requirements and Guidelines for Services Funded under the Act, Official Community Visitors still report instances where service supports do not meet DSA requirements. Some common areas include Individual Planning, Privacy, Dignity and Confidentiality, Respect & Valued Status, Dignity of Risk and Areas of financial management. Official Community Visitors believe that these issues are in most cases due to lack of policies, oversight, lack of supervision of poorly trained staff and staff attitude.⁶²¹

- 9.38** The United Nations Convention on the Rights of Persons with Disabilities (UNCRDP) signifies a shift away from a social welfare response to people with disabilities to a rights based response. Ms Carol Berry, Executive Director, NSW Council for Intellectual Disability, explained that many states have amended disability service legislation to emphasise the rights of people with disability and the importance of a person-centred approach, and stated that this approach would also be welcomed in NSW:

Across Australia there is an increasing emphasis on the rights of people with disability and the importance of person-centred approaches to the development and delivery of service responses. Some jurisdictions have recently revised their disability services legislation to further emphasise the rights of people with disability and their place at the centre of service provision. There are a few key pieces of legislation in particular: the Disability Services Act in Western Australia, the Disability Services Act in Queensland, and the Disability Act in Victoria. I think it is no accident that these jurisdictions that are probably the more innovative; namely, Victoria, Western Australia and Queensland, have amended the legislation in order to further rights objectives. This would be a very welcome development in NSW. Many jurisdictions are implementing reforms to make their service systems more person-centred, and many have developed key policy and strategy documents that reflect this focus on the individual.⁶²²

How could compliance with legislation and the NSW DSS be improved?

- 9.39** While the Committee heard of many instances where services were non-compliant with the *Disability Services Act 1993* and NSW DSS, some participants also offered suggestions for ways to improve compliance. Mr Martin Laverty, Chairman of the Board, the Lorna Hodgkinson Sunshine Home, recommended that a research and development advisory group be established to improve the quality of disability services provided in NSW. He stated:

⁶²⁰ Submission 30, NCOSS, p 13

⁶²¹ Submission 41, Official Community Visitor Scheme, p 5

⁶²² Ms Carol Berry, Executive Director, NSW Council for Intellectual Disability, Evidence, 26 August 2010, p 12

That a research and development advisory group be established by ADHC comprising equal numbers of ADHC staff, service provider representatives, and independent community members with terms of reference to assess and commission research and policy creation that will lead to innovation and improvements in the quality of services provided to people with disabilities.⁶²³

- 9.40** Ms Carolyn Mason expressed concern that there is no accountability and little action taken against services that breach legislation and recommended that an independent arbitrator is established to investigate serious complaints about services:

I believe this highlights an urgent need for accountability, greater regulation and improved monitoring of both ADHC and in particular non-government accommodation and respite services directly funded by ADHC. There is a need for a new system to be developed such as an independent arbitrator with legislated powers to fully and comprehensively investigate serious complaints about both government and non-government services. For example as in cases of breaches of NSW disability service standards, the use of restricted practices, and the non-compliance with practices, procedures and guidelines which govern these issues. At the moment there seems to be no accountability extracted and little action of any real consequence taken against a service provider that has breached legislated imperatives, which are tantamount to Human Rights abuse.⁶²⁴

- 9.41** Mr Lomas and Mr Killeen recommended that an "... independent auditor is appointed to conduct an assessment both at ADHC head office and in each of the regional offices. This assessment should also include service recipients' experiences." The independent assessment would assess compliance with "... all current Disability Service Standards and the *Disability Services Act*."⁶²⁵

- 9.42** The issue regarding establishment an independent organisation to address compliance with the NSW DSS and the *Disability Services Act 1993* is examined in more detail from paragraph 9.58.

- 9.43** Ms Sue Crane, Advocacy and Research Officer, Vision Australia, explained that different states have different services standards and that preparing for multiple assessments "is time consuming and costly and most importantly takes staff away from service delivery to clients." She suggested a national standard be developed and implemented:

Vision Australia believes that it would be advantageous to look to replace all state specific Disability Standards with the National Disability Service Standard. A National standard should mean the one compliance assessment system, which must be easy and manageable. Where a compliance assessment has been completed within the reporting or assessment period these results should be accepted or considered in subsequent audits by other service performance audits.⁶²⁶

- 9.44** A stand-alone standard "that relates to culturally appropriate service delivery" was recommended by Mr Damian Griffis, Executive Officer, Aboriginal Disability Network (ADN).⁶²⁷

⁶²³ Submission 61, The Lorna Hodgkinson Sunshine Home, p 3

⁶²⁴ Submission 14, p 20

⁶²⁵ Submission 67, pp 13-14

⁶²⁶ Submission 60, Vision Australia, p 5

⁶²⁷ Submission 97, ADN, p 5

- 9.45** In order to assist staff 'own the standards', Mr Jim Moore, Chief Executive, ADHC, explained that ADHC is developing fact sheets and simple language resources to explain the requirements imposed on staff:

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 frontline staff to own the standards.⁶²⁸

- 9.46** Mr Moore also explained that a Quality Framework is being developed that is underpinned by the National Standards for Disability Services:

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.⁶²⁹

- 9.47** The Quality Framework places responsibility on "... service providers to demonstrate compliance against the standards through a process of self-assessment, independent assessment or accreditation by a third party." The ADHC submission provided detail on how the Framework will assist the industry:

[The Quality Framework] 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.⁶³⁰

Committee comment

- 9.48** The Committee recognises the fundamental importance of the NSW DSS and the *Disability Services Act 1993* in providing a foundation for the quality of services provided to people with disability in NSW. Examples of non-compliance with the NSW DSS and the Act by ADHC and funded organisations are of significant concern to the Committee.
- 9.49** The Committee agrees with Mr Griffis, that a new disability service standard that requires culturally appropriate services to be delivered should be developed and implemented. This

⁶²⁸ Submission 31, p 83

⁶²⁹ Submission 31, p 98

⁶³⁰ Submission 31, pp 98-99

new standard would also assist in addressing some of the issues identified in Chapters 4 and 5. The Committee recommends that the NSW DSS are revised to include a requirement for culturally appropriate services to be delivered.

Recommendation 45

That the Minister for Disability Services revise the NSW Disability Service Standards to include a new standard that requires culturally appropriate services to be delivered.

- 9.50** The Committee is very concerned that the decision to redevelop large residential centres has not been subject to independent merits review and that the decision to redevelop these centres is not in compliance with relevant legislation. Further examination of this issue and relevant recommendation regarding residential centres are provided in Chapter 7.
- 9.51** The Committee acknowledges the work that ADHC is undertaking to improve the use of the NSW DSS within the agency, including developing policies, fact sheets and simple language resources for staff. The Committee notes that ADHC require service providers to annually self-assess against the Funding Agreement through the ACR. It is also recognized that ADHC use the Quality Assurance Rectification Program to monitor its own delivery of services.
- 9.52** However a limitation of the ACR is that it is not designed to handle complaints as they arise throughout the year, for example in relation to concerns expressed about non-compliance with the NSW DSS. The Committee believes that a transparent and consistent process is required to ensure that issues of non-compliance are adequately addressed, to provide service users, carers and their families with an avenue to improve service quality. Examination of complaints processes is provided later in this chapter.
- 9.53** The Committee has not received evidence to identify how ADHC provided services are monitored for compliance with the NSW DSS, including through the QAIP. However, the Committee notes that *all* disability services are required to comply with the NSW DSS and it is therefore essential that services provided by ADHC are monitored for compliance and that non-compliance is addressed as efficiently and effectively as possible.
- 9.54** The recommendation by Spinal Cord Injuries Australia and Ms Mason to establish an independent organisation to monitor ADHC and funded organisations for compliance with the NSW DSS is supported by the Committee. This issue and recommendation is examined in the next section.
- 9.55** The Committee acknowledges that a Quality Framework is being developed by ADHC to improve the quality of services provided to people with disability, carers and their families. The Committee believes that the Framework needs to address the significant gap that exists between the theoretical standards, the practical implementation of the standards and compliance monitoring.
- 9.56** The Committee recommends that tools are developed as part of the framework for both ADHC and funded organisation staff to work towards embedding the NSW DSS in their daily work. These tools should act to increase awareness of the standards, improve staff and service users' understanding of the standards and how they apply to service delivery. Without the development of practical tools and a process to monitor compliance, the Committee is

concerned that the Quality Framework will become another theoretical policy layer that does not address the serious issues identified by Inquiry participants.

- 9.57** The Committee strongly supports the development of an independent third party accreditation process for disability service providers, including ADHC, as this should strengthen the quality of services provided, improve the consistency of services provided and improve transparency of monitoring for compliance with the NSW DSS. In the next section on complaints handling, the Committee has recommended that an independent organisation be established to monitor and accredit the disability services sector (see Recommendation 47).

Complaint handling

- 9.58** This section examines the effectiveness of disability service complaint and grievance handling by ADHC and funded organisations. This was identified as an issue by many Inquiry participants, for reasons including poor adherence to complaint policy, poor access to relevant policy and processes by deaf and blind people, complaints not being taken seriously, inadequate responses to complaints, fear of retribution by service users who express complaints, including threats of services being withdrawn and a lack of involvement by ADHC in complaints about funded organisations.

- 9.59** Ms Susan Smidt, Coordinator, Disability Information Advocacy Service, identified that the NSW DSS (standard number seven) relates to how complaints and disputes should be handled. It states that "Each consumer is free to raise and have resolved, any complaints or disputes he or she may have regarding the agency or the service."⁶³¹

- 9.60** In evidence, Mr Moore advised the Committee that funded organisations are required to maintain a complaint handling process through the requirement to comply with the NSW DSS:

We require all non-government organisations, through our funding agreement, to comply with disability standards, one of which is about complaints and disputes resolution. So through that vehicle we place upon them an obligation to maintain a complaints handling process and to handle disputes appropriately. The first port of call for somebody to come to us is we would be going back to the non-government organisation to understand whether or not the complaints handling process had been done well enough.⁶³²

- 9.61** Ms Emily Caska, State Policy Coordinator, National Disability Service , (NDS) views "... complaints handling and grievance mechanisms as a key driver in service planning, delivery and evaluation."⁶³³ She stated that "NDS sees effective complaints handling and grievance mechanisms as being part of an organisation's governance procedures to measure service outcomes and identify areas for quality improvement."⁶³⁴

⁶³¹ Submission 57, Ms Susan Smidt, Coordinator, Disability Information Advocacy Service, p 4

⁶³² Mr Jim Moore, Chief Executive, ADHC, Evidence, 9 August 2010, p 19

⁶³³ Submission 32, Ms Emily Caska, State Policy Coordinator, NDS, NSW, p 26

⁶³⁴ Submission 32, p 26

- 9.62** Mr Moore told the Committee that the complaints system is not perfect, but "... there are a number of vehicles that are available for people to have their service quality tested or to complain about it and have an independent treatment of it."⁶³⁵

Access to complaint handling

- 9.63** The Committee was informed by ADHC that the majority of complaints received in the first three months of 2010 related to Home Care services:

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 ... 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.⁶³⁶

- 9.64** In the Committee's opinion, given the large number of clients and services accessed, 246 complaints in the first quarter of 2010 is very low. Mr Moore also acknowledged that it is low, and that ADHC does not capture enough complaints through its formal complaints mechanisms:

I do not think that we get near as many complaints through our formal complaints mechanism as we would want. There is only one area of our business where there is a significant body of complaint and that is in the home care service of NSW. I do not think that is a reflection necessarily of us doing less work in other parts of our organisation but it is just that they are much more efficient at counting complaints as complaints ...⁶³⁷

- 9.65** However, Mr Moore also referred to a separate biennial survey of home care client satisfaction which indicated approximately 95 per cent satisfaction with the Home Care service of NSW:

We get client satisfaction in the levels of 95 per cent plus in those surveys. Yes, there are about 600 complaints that we received in 2009, 662 to be precise, about the home care service and that has to sit alongside a very positive overall relationship to the home care service of those clients, but we do not believe that we get it right. I think that that number of complaints when you are dealing with 55,000 of the number of clients of Home Care Service of NSW that with a 95 per cent to 97 per cent satisfaction rate is probably a good indication of what is not working for individuals.⁶³⁸

- 9.66** Mr Moore stated that there is no such survey for the rest of the service system and that ADHC is "... endeavouring to work out what is the best way to try to gather that information."⁶³⁹

⁶³⁵ Mr Moore, Evidence, 9 August 2010, p 19

⁶³⁶ Submission 31, pp 100-101

⁶³⁷ Mr Moore, Evidence, 9 August 2010, p 18

⁶³⁸ Mr Moore, Evidence, 9 August 2010, p 19

⁶³⁹ Mr Moore, Evidence, 9 August 2010, p 19

9.67 The Committee was told repeatedly by individuals who access disability services either personally or on behalf of a family member that complaints processes are difficult to access and/or have unsatisfactory outcomes. The limited availability of complaint processes in regional areas was raised by Ms Ameila Starr, Senior Policy Officer, Disability Council of NSW:

The comments about the complaint handling did come up in the consultations - "Where do we go with ... We are not happy with the service?" That was certainly amplified in the discussions we had in regional areas where it is sometimes, "We have got nowhere else to go but the service we are using."⁶⁴⁰

9.68 The ability for ADHC to address concerns raised by organisations was identified by the Deaf Society as adequate. However, the same did not apply to clients according to the Chief Executive Officer of the Deaf Society of NSW who stated in her submission "[f]or clients, we can identify a serious problem in the accessibility of ADHC complaint mechanisms for deaf service users."⁶⁴¹

9.69 Spinal Cord Injuries Australia also identified that it is difficult for individuals to have their complaints responded to effectively:

Complaints against staff, providers and ADHC rarely seem to go answered when delivered by an individual. It is our thinking that complaints are healthy as they allow service development to happen. An advocate fulfils a very important role in driving quality service.⁶⁴²

9.70 At the Committee's Public Forum, held to hear some of the personal experiences of the disability service sector, Ms Judy Brosas read out a statement on behalf of her father, Mr Ivor Russell Nyman. He stated that he felt that his concerns were simply brushed aside by ADHC and not adequately addressed:

The result of this behaviour is that my daughter became so distressed that she, the victim, had to be temporarily removed from her home and moved to a safe group home. This has added to her anxiety as she does not understand why she is the one that was removed. In spite of frequent submissions to ADHC by the families of the three original residents, stating that the residents could be in danger of injury and they now live under constant tension and intimidation, ADHC have brushed aside all complaints and refuse to find more suitable accommodation for the newest resident.⁶⁴³

9.71 Ms Brosas, the sister and legal guardian of her sister who has Down Syndrome, told the Committee that she felt an Apprehended Violence Order was her only option to safeguard her sister against a service user who had been inappropriately transitioned into the group home. Ms Brosas stated that "[i]t was only then that they paid any attention to our complaints."⁶⁴⁴

⁶⁴⁰ Ms Amelia Starr, Senior Policy Officer, Disability Council of NSW, Evidence, 9 August 2010, p

⁶⁴¹ Submission 90, the Deaf Society of NSW, p 8

⁶⁴² Submission 67, p 10

⁶⁴³ Ms Judy Brosas, Public Forum, 30 September 2010, p 14

⁶⁴⁴ Ms Brosas, Public Forum, 30 September 2010, p 15

- 9.72** Another Forum participant, Ms Jennifer Rollo OAM, identified that parents can be afraid to "complain about inadequate service provision for fear of retribution. When they are afraid their children will lose the inadequate service they are getting, you know that the alternative is no service at all."⁶⁴⁵
- 9.73** Being fearful of a reduction in services was also identified by Fairfield Seniors Network as a reason why individuals may not complain. They stated that "[m]any seniors comment that they feel unable to complain as they feel that services may be affected if they do."⁶⁴⁶
- 9.74** Mr John Paul Carr is a service user who feels that his complaints were not taken seriously by ADHC or handled appropriately. After making a complaint, Mr Carr stated he received threats to have his service withdrawn:
- All that was fine until I had my own complaints or grievances. I went from a respected contributing member of society to a second class citizen who is not taken seriously by DADHC at any level, and frankly I just can't take it anymore. If I had been employed by DADHC I may have been treated better as a 'whistleblower' under the Protected Disclosures Act, but instead I was subjected to threats to withdraw my services, disruptions in my services etc, all designed to just wear me down.⁶⁴⁷
- 9.75** Mr Marc Kay also described the significant impact on him when, as a staff member of ADHC, he complained about issues within the agency. Mr Kay explained that he felt punished by ADHC for making a complaint, that there was no-one to turn to and his health was negatively affected by his experience. He has been on leave since this incident in 2008, even though "[t]he executive in question has been promoted several times since then. In fact, all the participants in this travesty have been promoted."⁶⁴⁸
- 9.76** Ms Mason, a mother and carer to her daughter Amy, believes that ADHC did not follow policy or procedures for complaint handling when issues were raised about the quality of care provided to Amy in a group home. She stated that "[t]here is clearly no clear avenue for service users to make complaints about support staff as to have any hope of being taken seriously or even listened too. There is often 'fear of retribution by staff.'" ⁶⁴⁹ This inquiry participant stated that "... this clearly shows breaches of legislated disability standards and restrictive practices with no accountability extracted from the service provider or their auspice authority ADHC."⁶⁵⁰
- 9.77** Mr Marc Kay also described the significant impact on him when, as a staff member of ADHC, he complained about issues within the agency. Mr Kay explained that he felt punished by ADHC for making a complaint, that there was no-one to turn to and his health was negatively affected by his experience. He has been on leave since this incident in 2008, even though "[t]he executive in question has been promoted several times since then. In fact, all the participants in this travesty have been promoted."⁶⁵¹

⁶⁴⁵ Submission 38, Ms Jennifer Rollo OAM, p 1

⁶⁴⁶ Submission 77, Fairfield City Council and Fairfield Seniors Network, p 5

⁶⁴⁷ Submission 86, Mr John Paul Carr, p 1

⁶⁴⁸ Mr Marc Kay, Public Forum, 30 September 2010, p 30

⁶⁴⁹ Submission 14, p 20

⁶⁵⁰ Submission 14, p 20

⁶⁵¹ Mr Kay, Public Forum, 30 September 2010, p 30

- 9.78** Another concern identified by Ms Mason relates to the issue that "ADHC does not have authority to directly investigate complaints about the very services it chooses to fund." She stated:

The mechanisms for handling complaints concerning ADHC funded services are totally inadequate, ADHC refers complaints back to the service provider so effectively allowing an internal investigation with often little or no consequences. There is the National Abuse and Complaints Hotline which only has the power to record a complaint not investigate, it is merely a referral agency. Referrals are then sent on to the NSW Ombudsman for investigation. It is a slow process which in our case took over two months before the ombudsman received and commenced action.⁶⁵²

- 9.79** Ms Berry also identified that ADHC's complaint handling mechanisms are inadequate and that it is not clear how complaints received by ADHC contribute to improving service delivery:

Clients have reported through our information service that complaint-handling and grievance mechanisms within the Department are poor. Many of our members and callers to our organisation have systemic complaints about the Department, but the Department seems to have few effective mechanisms and limited motivation to channel these complaints toward improved service delivery.⁶⁵³

- 9.80** Particular difficulties for people with vision impairment were pointed out to the Committee by Ms Crane who explained that ADHC's complaint process is not easily accessible for a person who is blind or has low vision:

Initially it is difficult to find the complaint section of the ADHC website. Then having located it, the Feedback and Complaint Handling Principles and Guidelines are only available in pdf which is not the most accessible format for a person who is blind and uses synthetic speech screen readers to access documentation. The ADHC complaint form is also not easy to navigate with a screen reader.⁶⁵⁴

- 9.81** Ms Caska also explained that ADHC's current policies are not accessible to service users and restrict access and use of the complaints handling process:

ADHC's Feedback and complaint handling: Principles and Guidelines support complainants requiring assistance after making their initial complaint through the provision of advocates and interpreters, but the accompanying -Information Sheet 1: Making a complaint and Information Sheet 2: Complaint process are not appropriate for service users in terms of format, language and information provided, and therefore inhibit access to the complaints handling process from the outset.⁶⁵⁵

- 9.82** Ms Estelle Shields, a mother and carer, stated that when she attempted to express concern about an ADHC funded organisation with ADHC, she was advised that ADHC "does not field complaints about NGOs."⁶⁵⁶

⁶⁵² Submission 14, p 20

⁶⁵³ Submission 39, p 16

⁶⁵⁴ Submission 60, p 5

⁶⁵⁵ Submission 32, p 24

⁶⁵⁶ Submission 15, Ms Estelle Shields, p 3

- 9.83** Case study 10 illustrates issues in ADHC's complaint handling process as experienced by the Noone family. According to the evidence received by the Committee, the complaints expressed by this family were not taken seriously until they involved the Ombudsman, an Apprehended Violence Order and wrote letter to Members of Parliament. Issues identified in this case study include a culture of blame shifting, the lengthy time it takes to address issues and the impact on the service user as a result of poor complaint handling.

Case study 10 – Ms Valerie Noone⁶⁵⁷

It has become very apparent to us that the complaint-handling process in ADHC is badly flawed and ADHC uses this to its advantage. The first major flaw is the culture of blame-shifting that exists throughout the department. It is difficult to get a complaint looked at when all it wants to do is shift the blame onto someone else and does not want to look at the situation objectively. An example of this is when ADHC would tell us that it was its job to support the service provider and that it was the service provider's job to manage the situation. It was suggested that maybe the service provider was not doing its job properly. Another proposal was that my sister could receive counselling for fear ...

Another flaw is the way the process has dragged on for weeks and months with what is euphemistically referred to as ongoing discussions. This became particularly distressing while all the time we felt our sister was in danger of being harmed when she remained in the house. This dragging out of the complaint process was achieved in a number of ways. Firstly, we were called to meetings but then told at the meetings that those present from ADHC did not have the authority to make decisions; that they would report the content of the discussions to their boss. This then resulted in more meetings and ongoing discussions with no resolution of the complaint. Secondly, we have been told that a particular matter that we wanted to discuss would have to be taken up with someone else from another section of ADHC and not the section we were currently dealing with.

It is a sad fact that we never made any real progress with our complaint with ADHC until we introduced external pressures, which included the following: A detailed letter of complaint to the office of the Ombudsman outlining ADHC's failure to follow its own policies. This process has also taken several months and has resulted in the ongoing interest of the Ombudsman, but still without a resolution. The second thing was an apprehended violence order which was taken out on my sister's behalf against the new resident. This proved to be quite effective in gaining their attention and we did get to meet with some people who could make decisions. We also wrote to various members of Parliament and made a submission to this inquiry.

What I would like to know is: why is it needed to go to such extreme lengths to get a complaint taken seriously?

- 9.84** The author of Submission 56 expressed frustration at their experience of ADHC's complaint handling system. This author stated that false information was provided to the Minister, there was not option of a review of how the grievance process and there were no face-to-face meetings to address the issues.⁶⁵⁸

⁶⁵⁷ Ms Valerie Noone, Public Forum, 30 September 2010, p 13

⁶⁵⁸ Submission 56, p 5

9.85 The experiences of complaint handling by Carers are also examined in Chapter 10.

What is required to improve ADHC's complaint handling process?

9.86 Mr Noel Baum, Director Policy, Local Government and Shires Association of NSW, believes that Councils could benefit from increased promotion of ADHC grievance processes and improved internal understanding of how to address complaints:

Some council's experiences with ADHC regional office and central office problem solving and feedback have unfortunately been poor. Many of the separate teams within the department seem to lack any formalised communication and information exchange between them. This results in councils being transferred to a number of different sections within ADHC. There seems to be a lack of understanding of the division of roles and responsibilities between planning, projects and funding teams.⁶⁵⁹

9.87 Ms Adeline Hodgkinson, Director and Chair, NSW Agency for Clinical Innovation, also believes that further clarity is required regarding ADHC's complaint handling and grievance mechanism processes:

ADHC has not made it clear what their grievance mechanisms/ complain handling procedures are for non-funded services. Their website is confusing and ineffective. We are unable to locate adequate information about services, who to contact, instruction about how to apply for services or any other support information such as grievance/ complaints handling process. This information is usually known by a senior BIRP team member (eg social worker or case manager)⁶⁶⁰

9.88 Ms Caska stated that information about complaint handling processes must be widespread and accessible. She identified that the *NSW Ombudsman Complaint Handling at Universities: Best Practice Guidelines* is a good resource regarding how to publicise complaint handling systems:

It is fundamental to the effective operation of any complaint handling system that there is widespread, if not universal, knowledge of the system and ready access to comprehensive information about its processes. The NSW Ombudsman Complaint Handling at Universities: Best Practice Guidelines identifies ways in which the complaint handling system should be publicised, such as up to date website information with user friendly links, complaints process flow charts and information in induction procedures for both staff and students.⁶⁶¹

9.89 Dealing with complaints more quickly was recommended by Mr Max Bosotti, Chief Executive Officer, Paraplegic and Quadriplegic Association (ParaQuad), who also recommended that there should be an option of having the complaints raised outside of the service delivery environment:

Complaints forwarded to ADHC staff from services are often well received however there appears to be delayed action on following up matters raised. Where individual clients voice concerns, their complaints appear to be dealt with quickly, so as not to cause political damage. Our experience with external advocacy services has identified

⁶⁵⁹ Submission 72, Local Government and Shires Association of NSW, pp 7-8

⁶⁶⁰ Submission 101, NSW Agency for Clinical Innovation – Brain Injury Rehabilitation Directorate, p 7

⁶⁶¹ Submission 32, p 24

that there is great opportunities for individuals to raise concerns outside the service arena, which is a concept that ParaQuad would support. In the past year we have worked well with the Office of the Ombudsman and Multicultural Disability Advocacy Service⁶⁶²

- 9.90** The NDS NSW submission stated that improved mechanisms need to be implemented to assist accessing, investigating and resolving complaints. The submission identified that there are limited resources for service providers to respond to a complaint and issues regarding the impartiality and confidentiality of complaints that are unable to be resolved at a local level:

NDS supports the development of quality frameworks and mechanisms for accessing, investigating and resolving consumer complaints. NDS NSW is concerned that the current policy for the management of complaints and feedback provides limited resources for service providers responding to a complaint. NDS NSW is also concerned about the impartiality and confidentiality of complaints that are unable to be resolved at the local level. NDS believes that greater inclusion of services provider rights, as well as greater access to complaint handling information and training would deliver better outcomes for the parties involved.⁶⁶³

- 9.91** Ms Everson, recommended that key policies and complaints processes be provided in Australian Sign Language to allow deaf people improved to access these policies:

We are proud of our own feedback and complaints policy, training and practices, but if a client wants to approach ADHC to complain (especially if they wished to do so without our help) they would face significant barriers. We believe it would be helpful if ADHC were to provide Australian Sign Language (Auslan) translations of key policies and processes such as the complaints process and the Disability Service Standards on their website. This would allow clients better access to complaints mechanisms outside DSNSW [Deaf Society NSW], and would be in line with Australia's obligations under the UNCRPD [United Nations Convention on the Rights of Persons with Disabilities].⁶⁶⁴

- 9.92** Improved availability of translated policies on the ADHC website was also suggested by Ms Everson as a way to bring the accessibility of ADHC policies in line with the UNCRPD:

That ADHC make it a priority to provide Auslan translations of complaints procedures and the Disability Service Standards on the ADHC website and that these be promoted to deaf people. This is in line with accessibility requirements under Article 9 of the UNCRPD which Australia has ratified.⁶⁶⁵

- 9.93** Mr Michael Hart experienced poor complaint handling by ADHC and recommends that "... any review look into how complaints are brushed aside and how complaints public servants are allowed to LIE even up to the agency Chief Executive level."⁶⁶⁶

⁶⁶² Submission 21, ParaQuad, pp 9 - 10

⁶⁶³ Submission 32, p 24

⁶⁶⁴ Submission 90, p 3

⁶⁶⁵ Submission 90, p 3

⁶⁶⁶ Submission 112, Mr Michael Hart, p 1

Advocacy services

- 9.94** Ms Berry believes that individual advocacy services are required to be expanded as a matter of urgency, to improve services provided to people with disability:

This would only add to improvements in the system, especially if an agency were funded to undertake individual advocacy and then collate issues into groups to allow for systemic feedback to the Department specifically. This would lead to improved service provision and client satisfaction, especially if the Department also improved its own internal mechanisms in line with advice provided from an independent source.⁶⁶⁷

- 9.95** Limitations on funding for advocacy services mean it is hard for the services to complete the role they are required to within available funding. The Council on the Ageing NSW and the Physical Disability Council of NSW recommended that increased funding for advocacy services is required:

There is presently not enough funding for advocacy services in NSW to perform the tasks that they have been funded for, there needs to be a commitment from the NSW Government and ADHC to Peak Bodies across the sector, particularly in relation to systemic advocacy. There are systemic problems with the current complaint handling and grievance mechanisms. Over recent years there has been a lack of organisational funding to community advocacy services, severe over demand for these services, poor recruitment and retention of advocates both employed and volunteers, and a lack of clarity to the NSW Ombudsman's role, purpose and investigative powers in regards to government services. These issues must be addressed and rectified.⁶⁶⁸

- 9.96** Ms Smidt, Coordinator, Disability Information Advocacy Service, recommended that "advocacy support should be provided by organisations that do not also undertake service provision to promote strong and effective independent advocacy." Ms Smidt stated that this would "minimise the possibility or the perception of conflict of interest."⁶⁶⁹

- 9.97** Conflicts of interest are examined further from section 9.127.

- 9.98** Mr Mark Grierson, Chief Executive Officer, Disability Advocacy NSW, explained that advocacy is an important independent safeguard to ensure people with disability are treated fairly:

Advocacy provides a crucial independent safeguard mechanism to ensure that people with a disability are not subjected to unfair treatment. Good local advocates can identify instances of unfair treatment, bring it to the attention of key decision makers and service providers then negotiate better outcomes for people with a disability.⁶⁷⁰

- 9.99** Ms Jillian McDonnell from The Aged Care Rights Service recommended that ADHC should fund advocacy services for older people in NSW, including services that assist these people in making complaints.⁶⁷¹

⁶⁶⁷ Submission 39, p 16

⁶⁶⁸ Submission 51, Physical Disability Council of NSW and Council on the Ageing NSW, p 16

⁶⁶⁹ Submission 57, p 2

⁶⁷⁰ Submission 24, Disability Advocacy NSW, p 1

⁶⁷¹ Submission 85, The Aged Care Rights Service, p 12

- 9.100** Ms McDonnell also recommended that ADHC should fund advocacy services for older people in NSW, including services that assist these people in making complaints.⁶⁷²

An independent complaints body

- 9.101** Many Inquiry participants called for a new independent complaints and review body to be established. The Physical Disability Council of NSW and the Council on the Ageing NSW submission recommended that an independent body should be established to "oversee and monitor the quality assurance process, and replace the current practices with a more accountable system of review and evaluation."⁶⁷³

- 9.102** Ms Noone stated that ADHC is not held accountable for the implementation of their policies or practices and that an independent tribunal is required to address complaints. Ms Noone believes that this independent organisation would assist in addressing complaints for people without fear of negative repercussions on their services:

One of the major reasons for this is that there is no means by which ADHC can be held accountable for their actions or decisions. ADHC needs to be held accountable for their own policies and practices without loophole clauses. I believe there needs to be an independent tribunal set up to deal with the complaints... ADHC is responsible for the wellbeing of some of the most vulnerable members of our society; many of them have no voice to defend them. It has been a long and frustrating journey for me and my family, but I do fear for those who have no-one to defend them. I hope as a result of this forum that there will be an independent body created to arbitrate complaints without the fear of negative repercussions.⁶⁷⁴

- 9.103** The Official Community Visitors also believe that there should be an independent body tasked with monitoring the services provided to people with disability:

I am happy to make a statement on behalf of all my peers and official community visitors. There is a pretty unified view that there should be a body that monitors services to people with disabilities-a body that is independent of the funder of those services.⁶⁷⁵

- 9.104** The recommendation was also put forward by the National Disability Service NSW in their submission which highlights the need for an " independent, objective and accountable external review source" to ensure that complaints are handled appropriately:

An important key practice for the efficiency benchmark is ensuring complaints are dealt with by the appropriate process or forum. ADHC provides external review contacts as part of its Feedback and complaint handling: Principles and Guidelines, namely the NSW Ombudsman, the National Disability Abuse and Neglect Hotline, the Independent Commission Against Corruption, the Administrative Decisions Tribunal and the Anti-Discrimination Board. NDS is concerned that staff in these external organisations may not be aware of alternate complaint resolution schemes.

⁶⁷² Submission 85, p 12

⁶⁷³ Submission 51, p 16

⁶⁷⁴ Ms Noone, Public Forum, 30 September 2010, p 14

⁶⁷⁵ Ms Armstrong, Evidence, 27 September 2010, p 50

NDS emphasises the importance of an independent, objective and accountable external review source.⁶⁷⁶

9.105 Mr Moore stated that service users have access to the NSW Ombudsman to complain about disability service provision:

In addition to the ability to utilise our complaints system - which I will again say I do not think is near well enough utilised - people with a disability and their family have access to the Ombudsman and the NSW Ombudsman is, for us, a very important part of the process of being able to run a system that is seen as being independent and effective because we will remain the funder of a service that person is complaining about. The Ombudsman provides us with a vehicle whereby someone independent of all of us is forming a view about the complaint.⁶⁷⁷

9.106 However, service users such as Mr Carr do not feel that the NSW Ombudsman adequately helped to address his complaint:

I followed the advice of the Ombudsmans office and 'exhausted all internal avenues of complaint', but the 'system' didn't work, it exists but it is ignored, and there is nothing you can do to help yourself if you are a consumer of the substandard services provided by DADHC. I even became aware that an 'arrangement' may exist between DADHC and the Office of The Ombudsman, on a small scale (?), where complaints phoned in by consumers were not handled using proper procedures, but phone calls were exchanged to resolve matters, therefore minimising the numbers of complaints recorded about DADHC. Specific consumers labelled as 'difficult complainants, who won't let go' and 'nuisance complainants with unreal expectations'.⁶⁷⁸

9.107 Reasons why the NSW Ombudsman may not be able to appropriately address disability service issues were suggested in the Physical Disability Council of NSW and Council on the Ageing NSW submission:

The Ombudsman's office has undergone significant reform in recent years these reforms included: A reduction in budget, a reduction in the legal powers of the Ombudsman to compel agencies to adopt recommendations, and the absorption of other similar organisations such as the Community Services Commission. This has forced significantly cut back on the amount of complaints the Ombudsman's Office is able to process whilst expanding their role. This has its own risks in relation to the openness, transparency and accountability of all agencies watched by the Ombudsman and particularly for the handling of complaints by the public. The reduction of the ability of the Ombudsman to handle complaints is of significant concern to PDCN and COTA as it is the primary means of ensuring the openness, transparency and accountability in the disability sector since the discontinuation of the Community Service Commission and replacing it with the establishment of a Disability Branch within the Office of the NSW Ombudsman in 2002. As such, PDCN and COTA fear that the Office is unable to give the disability sector the focus /attention that it requires.⁶⁷⁹

⁶⁷⁶ Submission 32, p 25

⁶⁷⁷ Mr Moore, Evidence, 9 August 2010, p 19

⁶⁷⁸ Submission 86a, Mr John Paul Carr, p 1

⁶⁷⁹ Submission 51, pp 15-16

Committee comment

- 9.108** The Committee acknowledges the frustration experienced by many service users regarding the poor complaint handling processes implemented by ADHC and funded organisations. Adequate policies and processes to effectively handle complaints are essential in ensuring compliance with the NSW DSS and in providing service users, carers and their families with an avenue to report poor quality service and have these issues effectively addressed. The Committee is not convinced that current ADHC policies and practices fulfill this need, and strongly believes that ADHC's complaint handling policies are required to be reviewed. The *NSW Ombudsman Complaint Handling at Universities: Best Practice Guidelines* should be referred to in the review of ADHC's complaint handling policies and processes.
- 9.109** The Committee understands that there are currently many barriers in place that prevent people from accessing information about disability service complaints processes, lodging a complaint and having it resolved appropriately. These barriers include poorly publicised processes, inaccessible language and formats and a lack of options to review the outcome of complaint handling processes.
- 9.110** The Committee understands that internal communication within ADHC regarding complaint handling is sometimes perceived to be inadequate. The Committee believes that the confusion of ADHC staff regarding how to handle complaints could reduce the effectiveness of how complaints are addressed.
- 9.111** The Committee believes that ADHC and funded organisation staff should be aware of how to effectively handle complaints, in a timely manner. If staff are confused by complaint handling procedures, it is little wonder that service users are also dissatisfied with this system. The Committee recommends that the complaint handling policy review includes, as a priority, the implementation of staff training and appropriate resources for the staff of funded organisations.
- 9.112** The Committee strongly agrees that the disability service sector would benefit from the establishment of an independent organisation to handle complaints about ADHC provided and funded services. The Committee notes that this was also suggested in paragraph 9.136 as a means to monitor compliance with the Act. Establishing an independent organisation will also address the issues regarding the perceived or actual conflict of interest that result from ADHC's role which is examined in more detail from section 9.127.
- 9.113** The Committee believes that establishing an independent organisation to monitor the services provided to people with disability would improve the resources available to ADHC for planning, funding and providing services.

Recommendation 46

That the Minister for Disability Services conduct a review of complaint and grievance handling policy and procedures for disability services in NSW, and that the review:

- be conducted in consultation with relevant stakeholders including service users and carers
- provides ADHC complaint policy in a format that is accessible to all service users, including people who are deaf and visually impaired
- ensures ADHC complaint policy is easy to locate on the internet
- develops processes to ensure that complaints are addressed in a timely manner
- refers to the NSW Ombudsman Complaint Handling at Universities: Best Practice Guidelines when identifying how to improve complaint handling policies and processes
- identifies and addresses gaps in complaint handling between agencies such as ADHC and the NSW Ombudsman
- implements staff training and develops appropriate resources for funded organisations to improve understanding of complaint handling processes

That the review report and actions resulting from the review are published on ADHC's website.

Recommendation 47

That the NSW Government establish an independent organisation to:

- monitor the quality of disability services provided and funded by ADHC
 - handle complaints about the provision of services (for issues that are not within the responsibility of organisations such as the NSW Ombudsman)
 - monitor compliance with the NSW Disability Service Standards and the *Disability Services Act 1993* through providing accreditation to organisations that provide disability services in accordance with the standards.
-

Evaluation and monitoring

9.114 Program evaluation and disability service monitoring are examined in this section, in relation to the effectiveness of these processes. Inquiry participants identified issues regarding a lack of monitoring and review of disability services, poor access of deaf staff to the Minimum Data Set (MDS), a lack of independent monitoring and monitoring that does not address the requirements of the *Disability Services Act 1993*.

9.115 Mr Moore acknowledged that "[p]rogram evaluation and performance monitoring are crucial in providing evidence for any service improvement initiatives."⁶⁸⁰ With regard to monitoring disability service funded organisations, Mr Moore stated that ADHC is working towards helping funded organisations build their capability to monitor their own service provision:

⁶⁸⁰ Submission 31, p 61

... we are talking about how can we get a more effective approach and how can we get an approach that does not just simply resource outsiders to come and pressure NGOs to behave in certain ways and check whether they are behaving in certain ways. You will always need some of that, but can you get more of that effect by helping NGOs build their own capability to better monitor what it is they are doing? What would it take to make sure that NGO boards are well aware of the level of complaints that are coming into their organisation? What are NGO boards doing about that?⁶⁸¹

- 9.116** Mr Dougie Herd, Executive Officer, Disability Council of NSW, stated that funded organisations should be independently monitored:

To have moved over the last five years to increasingly fund non-government organisations to deliver services to people is absolutely the right one so long as there is clear control and clear monitoring which should be independent and across-the-board, of course.⁶⁸²

- 9.117** A lack of apparent monitoring of services by ADHC is also evident to Official Community Visitors, according to Ms Armstrong who told the Committee that "Official Community Visitors express concerns that they see little evidence of ADHC monitoring role across the range of visitable services."⁶⁸³

- 9.118** Mr French believes that ADHC and its predecessor organisations have failed in conducting periodic reviews of disability services, which is a requirement of the *Disability Services Act 1983*:

The failure of ADHC and its predecessors to conduct periodic reviews of disability services in accordance with the explicit requirements of the DSA NSW is a major contributing factor to the poor quality of many disability services in NSW.⁶⁸⁴

- 9.119** While expressing overall satisfaction with ADHC auditing and monitoring processes, Ms Everson identified issues regarding the lack of access deaf staff have communicating with staff regarding the Minimum Data Set (MDS):

In general we are satisfied with ADHC processes for auditing and program evaluation. The Minimum Data Set reporting process remains inaccessible for deaf staff at our organisation. If we need to contact MDS for any information, the phone generally reaches an answering machine, and MDS staff members call us back, but only using a voice call. It would be ideal if MDS were to install a TTY [telephone type writer], publicise the TTY number, and train their staff in the use of the TTY and the NRS (National Relay Service).⁶⁸⁵

- 9.120** Mr French believes that ADHC's Integrated Monitoring System is flawed due to a lack of independence in its administration and because it does not address the requirements of the *Disability Services Act 1993*:

ADHC is currently implementing a so-called Integrated Monitoring System (IMS). This includes a 'service review and monitoring' component that incorporates a service

⁶⁸¹ Mr Moore, Evidence, 9 August 2010, p 21

⁶⁸² Mr Dougie Herd, Executive Officer, Disability Council of NSW, Evidence, 9 August 2010, p 29

⁶⁸³ Submission 41, p 4

⁶⁸⁴ Submission 20, p 7

⁶⁸⁵ Submission 90, p 3 p 8

provider self-assessment, desk audit by regional ADHC staff, then an on-site review, and service development action planning, if required. The framework for these activities is a 'service review instrument' which is structured around three domains: 'organisational capacity;' 'providing services and programs; and 'capacity building.'

There are a number of very serious problems with the Integrated Monitoring System viewed from the perspective of service recipients through the lens of s 15 of the DSA NSW. First and most obviously, there is no independence in the administration of the IMS for services provided directly by ADHC ... the performance criteria and key performance indicators do not directly or comprehensively address the matters set out in the objects and in schedule 1 of the DSA NSW.⁶⁸⁶

9.121 Issues regarding conflict of interest in ADHC's role in the disability sector are examined in the next section.

9.122 Mr French also identified that organisations can have good policies but poor service provision, and that this issue is not captured by the Integrated Monitoring System:

... the IMS method is essentially a desk audit and policy/administrative review approach. There is no, or very limited, direct evaluation of the services. A service may have excellent policies but operate poor quality services that ignore these policies and might potentially score favourably under such a methodology. Finally, there is very little, if any, opportunity for service users and their associates (family members and advocates etc) to contribute their views on service quality and quality improvement priorities.⁶⁸⁷

9.123 From the point of view of a funded service provider, Mr Baum expressed that there are many onerous reporting demands on service providers that the reporting requirements are often duplicated between different groups:

The reporting load for funded services has increased many times over the years without additional relative funding for administration. Some smaller direct service providers funded by ADHC struggle with increasingly onerous reporting requirements (often unnecessarily complex reporting processes). ADHC funded services often are audited by multiple groups - ISO, ADHC, FAHCSIA. Auditing requirements should be standardised and a single audit conducted which meets the requirements of all funding bodies.⁶⁸⁸

Committee comment

9.124 The Committee acknowledges the importance of effective monitoring and evaluation in providing quality services to people with disability. The Committee notes with concern that current monitoring and evaluation processes do not comply with the *Disability Services Act 1993*.

9.125 The Committee believes that the establishment of an independent organisation to monitor disability services (Recommendation 47) will improve how organisations are monitored and ensure that monitoring complies with relevant legislation and policy.

⁶⁸⁶ Submission 20, p 6

⁶⁸⁷ Submission 20, p 6

⁶⁸⁸ Submission 72, p 8

Conflicts of interest

9.126 This section examines issues regarding conflict of interest in the administration and provision of disability services in NSW. Inquiry participants identified that there is a potential conflict of interest in the provision of disability services, in particular ADHC's conflicting responsibilities as funder and regulator of disability services, while also being a major service provider.

9.127 The author of Submission 14 suggested that a conflict of interest occurred when the funded organisation that provided accommodation serviced to her daughter allowed the manager to employ her mother at the group home.⁶⁸⁹

9.128 The author of Submission 56 stated that senior ADHC staff have also employed family in positions and funded contracts to family:

... there are cases known where an Executive Director has let Government funded contracts to immediate kin and/or employed immediate kin in management positions. Tender may have been called for and positions advertised but outcomes were pre-established.⁶⁹⁰

9.129 ADHC funded advocacy services were another area of potential conflict of interest identified by Spinal Cord Injuries Australia that may have an impact on services provided:

Currently funding to support these organisations is provided directly by ADHC with ADHC contract managers supervising the provision of services and attempting to ensure compliance with the Disability Service Standards ... We wish to highlight that there is a clear potential for ADHC funded advocacy service providers to not 'bite the hand that feeds them' (whether real or at least perceived) at the expense of a clients ADHC related issue leading to a conflict of interest. In fact in advocacy circles it is quite widely discussed as standard that funding may be at risk if you are too adversarial with ADHC. We feel that direct funding through ADHC of advocacy service providers does not lead necessarily to better outcomes⁶⁹¹

9.130 Advocacy is also examined in the next section.

9.131 Mr Phillip French, Director, NSW Disability Discrimination Legal Centre Inc, explained that there is a structural conflict of interest within ADHC, as the funder and regulator of disability services (ADHC) is also a major providers of services:

In 1998, the specialist services provided by the NSW Department of Community Services and the Home Care Service of NSW were transferred and merged with the Ageing and Disability Department to create the Department of Ageing, Disability and Home Care. Ministerial responsibility for this new Department was vested in a Minister for Ageing and Minister for Disability Services. This merger represented a return to the structural conflict of interests associated with the funder and regulator of disability services also being a major provider of disability services, and of those services that are among the poorest quality services. This situation continues under ADHC.⁶⁹²

⁶⁸⁹ Submission 14, pp 5, 18

⁶⁹⁰ Submission 56, p 5

⁶⁹¹ Submission 67, p 10

⁶⁹² Submission 20, p 3

- 9.132** The detrimental impact of this conflict of interest was identified by Mr French, including the lack of an independent quality assurance system, conflicts in quality improvement strategies that might require additional funding and failure to comply with the *Disability Services Act*:

As we shall discuss further following, this has at least three very negative consequences for the quality of disability services in NSW. First, despite its assertions to the contrary, ADHC (and its predecessor) has not established an effective independent quality assurance system in relation to its own services. Second, it means that as the agency ultimately responsible for the funding of disability services, ADHC has a conflict of interest identifying and pursuing quality improvement strategies in disability services that might require additional funding and innovative funding approaches. Third, in spite of the explicit requirements of the DSA NSW, ADHC and its Minister have failed to ensure that the allocation of funding for direct services complies with s10 of the DSA NSW, and this has the effect, and probably the purpose, of frustrating the consumer protection measures incorporated into s 20 of the DSA NSW.⁶⁹³

- 9.133** Mr Adam Johnston, a long-term home care and personal care service user, also identified that ADHC's role of service provider and funder results in a conflict of interest:

While I am a recipient of ADHC services and am on the board of a non-government service provider, my personal view is that ADHC is an organisation in a perpetual conflict of interest: as both a service provider and funding body. Equally, for service providers dependent on government funding for a large slice of their budgets, it has to be asked just how much flexibility and choice these organisations can truly give their clients, as a consequence of the financial relationship with (dependence on) government.⁶⁹⁴

- 9.134** Mr French stated that there is an "overwhelming conflict of interest" in regards to ADHC's process for monitoring service providers.⁶⁹⁵

Recommendations to overcome conflicts of interest

- 9.135** Mr French advised the Committee that the NSW Law Reform Commission undertook a review of the *Disability Services Act* in 1998/99, which identified the "... structural conflicts of interest in the quality assurance of specialist disability services." He stated that the review provided recommendations to address these conflicts of interest, however they were never acted upon:

... the establishment of an independent Disability Quality Assurance Council (DisQAC) to accredit and monitor specialist disability services. The Commission recommended that the membership of DisQAC include representatives of consumers and service providers with recognised knowledge and expertise. The functions proposed for DisQAC included:

- establishing a new quality assurance system
- assessing and certifying services in transition

⁶⁹³ Submission 20, p 3

⁶⁹⁴ Submission 104, Mr Adam Johnston, pp 3-4

⁶⁹⁵ Submission 20, p 6

- assessing and certifying new services as conforming with the DSA
- providing advice and support to services about quality service provision;
- monitoring whether services are achieving continuous quality improvement;
- identifying and registering services of "concern", where closer monitoring may be necessary;
- notifying the Minister if a service fails to comply with the requirements of the quality assurance process; and
- recommending to the Minister that sanctions be imposed on services that fail to comply with the objects, principles and applications of principles, the revised Standards (see Recommendation 28), or their transition plans.

Unfortunately, the Commission's recommendations have never been acted upon.⁶⁹⁶

- 9.136** Ms Therese Sands, Executive Director, People With Disability, also highlighted the Law Reform Commission's review and supported the recommendation to establish an independent body to monitor and accredit disability service providers:

In reviewing ADHC provided services, it is critical to avoid conflicts of interests by establishing an independent body to accredit and monitor specialist disability services. PWD [People with Disability Australia] supports the recommendation made by the NSW Law Reform Commission following its review of the DSA in 1999, and suggests that the proposal contained in the recommendation replace the IMF [Integrated Monitoring Framework]. Recommendation 7.20 and 7.21 in the Commission's Report from its review, stated: "... the establishment of a new and independent body ... to administer the quality assurance process, and to monitor quality."⁶⁹⁷

- 9.137** Ms Sands stated that the recommendation of the Law Reform Commission should be implemented, regarding the establishment of an independent organisation to monitor, accredit and review disability services:

PWD recommends that the NSW Government establish a 'Disability Services Quality Assurance Council' to accredit, monitor and review the disability service system (as outlined in the NSW Law Reform Commission Report from its review of the DSA); and that this body replace the current IMF.⁶⁹⁸

- 9.138** Spinal Cord Injuries Australia recommended that the perceived or real conflict of interest in the provision of independent advocacy services would be addressed if advocacy services funding was "...moved to the NSW Attorney Generals department."⁶⁹⁹

- 9.139** Ms Smidt also provided a recommendation to reduce the potential for conflict of interest to occur in advocacy services:

To minimise the possibility or the perception of conflict of interest, advocacy support should be provided by organisations that do not also undertake service provision to promote strong and effective independent advocacy.⁷⁰⁰

⁶⁹⁶ Submission 20, p 6

⁶⁹⁷ Submission 91, People With Disability Incorporated, p 20

⁶⁹⁸ Submission 91, p 21

⁶⁹⁹ Submission 67, p 14

Committee comment

- 9.140** The Committee notes with concern the conflicts of interest that exist or are perceived to exist within the disability service system and believe that the need for an independent organisation to monitor disability services is strengthened by this evidence.
- 9.141** The Committee acknowledges that the recommendations made by the NSW Law Reform Commission were made many years ago, however, as the same issues remain, the recommendations are still relevant today. The Committee understands that the key issues relate to the structural conflict of interest within ADHC regarding the conflicting roles of funder and regulator of services also being a major provider of services.
- 9.142** Advocacy services were highlighted as a particular area of concern in regards to conflict of interest. The Committee understands that it is difficult for *independent* advocacy services to be provided under the current funding arrangement. The Committee understands that a conflict results from advocates being funded by the organisation they may inadvertently criticise through their role of supporting people with disability to access appropriate services.
- 9.143** The Committee agrees that people with disability would receive more impartial and person-centred advocacy services if advocacy funding was not administered by ADHC. The Committee believes that this would free advocates to provide the most appropriate services and support without fear of 'biting the hand that feeds them'. The Committee recommends that funding for advocacy services is administered by a Department that is independent of disability service provision.

Recommendation 48

That the NSW Government move funding administration of advocacy services to a Department that is independent of disability service provision.

Disability services data and research

- 9.144** This section examines issues regarding data available in the planning of disability services. Some Inquiry participants identified issues regarding disability services data, including infrequent data collection, limited data availability and a lack of reliable data on the prevalence of Aboriginal people with disability.
- 9.145** Mr Moore advised the Committee that there is a shortage of data in the disability sector. He advised that this is because the Australian Bureau of Statistics (ABS) survey upon which the sector relies for base data is conducted only once every six years:

... we have in the disability space being making significant improvements in terms of our understanding of population but we do suffer from a paucity of data in this area. We only have a once-in-six-year chance to see the totality of the population of people with a disability in NSW, through an ABS survey, and that we do our best to try to model out an understanding of just what is the level of need and what is the right way

to respond to that need in that context, but our position is somewhat limited. I put that up front because I fear that there is enormous frustration about the ability of the agency to be able to point to just how well we are doing against population data, but it is a very difficult issue which has been recognised nationally.⁷⁰¹

9.146 The impact of infrequent data collection on current planning on phase two of Stronger Together was also identified by Mr Moore:

We built our modelling on the 2003 ABS data collection to do the initial five years of funding. We are having to build plans around the second five years on exactly the same 2003 data. The data the ABS has just collected for the replacement 2003 survey will not be available until early next year. It is not that the ABS is not trying hard; it is the circumstances, difficulty and complexity of the collection. We paid - collectively in this case "we" being State, Territory or Commonwealth governments - the ABS to double the sample size and expand the questions in order to get a better survey, but it just takes time to get that data. If I had my preference I would love to see once every two or three years such a survey enabling us to then get a good sense of the population and then ask some questions about whether our programs have performed well by seeing whether there are changes in population, expressed levels of need and other issues that people are showing up.⁷⁰²

9.147 The ADHC submission identifies problems regarding data sources in the disability service sector that enable the agency to determine unmet need:

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.⁷⁰³

9.148 Mr Bosotti stated that there is also a lack of data regarding unmet need for services for people with spinal cord injury (SCI). He stated "[t]he extent of unmet need is difficult to ascertain as there is no real data available which can identify the number of people with SCI currently living in NSW."⁷⁰⁴

⁷⁰¹ Mr Moore, Evidence, 9 August 2010, p 2

⁷⁰² Mr Moore, Evidence, 9 August 2010, p 6

⁷⁰³ Submission 31, pp 45-46

⁷⁰⁴ Submission 21, p 4

9.149 Due to the absence of available data in this area, ParaQuad employed a researcher to investigate the demographic profile of people with spinal cord injuries in NSW. Key barriers experienced through this research include:

- Hospital separation data had only been kept since 1995. In addition, people with SCI are not always re-admitted to designated spinal units when they need treatment for health issues, but are more likely go to mainstream hospitals where hospital separation data is not always clear, dependant on reason for admission.
- State Spinal Services have only existed since 2003 - so data is limited
- ADHC were unable to quantify the number of people with SCI receiving funding for Attendant Care / Home care services
- Centrelink do not routinely collect data on Type of Disability
- The National injury Surveillance database was seen as a useful line of inquiry, however access was denied due to privacy concerns
- Preventing double counting is a big problem as there are no "unique identifiers" which allow separation of data⁷⁰⁵

9.150 The ADHC submission identified that the shortage of systemic disability service data collection has not been as high of a priority on the national agenda, which limits the ability for ADHC to plan strategically for the future needs of people with disability:

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.⁷⁰⁶

9.151 Ms Regan explained that data return rate in the HACC program is very low in NSW. She advised that it has improved, but it still remains low:

NSW has reported the lowest return rate of HACC data in Australia for several years. This has greatly improved in recent years following ADHC's HACC data remediation and training project and the creation of the Minimum Data Set (MDS) helpdesk. However, the NSW return rate remains very low in both HACC and disability services, resulting in evaluation problems with activity comparisons, performance assessments, client numbers and value for money.⁷⁰⁷

9.152 Mr Baum conveyed that the Minimum Data Set (MDS) is a confusing reporting system, the statistics are not accurate and limited feedback is provided to users of the system:

The MDS is seen by many as a very confusing reporting system, many services are reporting using different methods, and hence statistics are not accurate. Many councils have had no feedback since HACC and CSTDA Training on the recruitment of

⁷⁰⁵ Submission 21, pp 4-5

⁷⁰⁶ Submission 31, p 61

⁷⁰⁷ Submission 30, p 16

outreach workers to assist in MDS reporting was conducted. The MDS could be a valuable data source that should be made available for local area planning and Councils' new integrated planning processes. Changes to the MDS to collect outcomes for clients would greatly enhance the value of the data for future service planning.⁷⁰⁸

- 9.153** The NSW HMMS State Council also identified that there is a lot of information that isn't captured by the MDS, including unmet need and funding shortfall:

The NSW HMMS State Council supports the collection of the information for the Minimum Data Set (MDS) however ... there is a vast amount of information regarding unmet need, client waiting lists and funding shortfalls which is not adequately captured in the HACC sector. Whilst the MDS is used for planning purposes by both the Commonwealth and State Government, the MDS only focuses on past episodes of service and therefore does not capture the whole picture. State Council wishes to alert the Commonwealth to this issue with an aim to improving data collection for future planning purposes.⁷⁰⁹

- 9.154** A lack of reliable data on the prevalence of disability in Aboriginal communities was identified by the Aboriginal Disability Network, who also provided some reasons why this may be so:

... there is a figure of 37% of the Aboriginal population are Aboriginal people living with disabilities, however that figure also acknowledges that this figure may in fact be a conservative one given that it does not include psychological disabilities. One of the most basic reasons why data on prevalence continues to be unreliable is that many Aboriginal and Torres Strait Islander people with disabilities do not in fact identify as people with disabilities. This occurs for a range of reasons including:

- Why would you identify as a person with disability when you already experience discrimination based on your Aboriginality? i.e. why take on another negative label?
- In traditional language there was no comparable word to disability which suggests that disability may have been accepted as part of the human experience.
- Or in some communities particularly communities that continue to practice a more traditional lifestyle disability may be viewed as a consequence of 'married wrong way.' That is many Aboriginal people with disabilities and their parents and family members experience stigma related to a kind of 'bad karma' view of disability.
- A predominance of the medical model of disability has had a profoundly negative impact on the lives of many Aboriginal and Torres Strait Islander people with disabilities. Much of the focus on contemporary Indigenous Australia relates to the Closing the Gap campaign. This campaign whilst essential often focuses heavily on primary health interventions. This does not address the whole of life needs of Aboriginal and Torres Strait Islander people with disabilities. An example of this includes recognition, rightfully of the high prevalence of hearing impairment amongst young Aboriginal children and a concerted campaign to address this. What tends to happen however is that many Aboriginal children are getting their hearing impairment treated however their accompanying learning disability which has occurred because of extended

⁷⁰⁸ Submission 72, p 8

⁷⁰⁹ Submission 34, NSW HMMS State Council, p 1

periods without proper hearing does not get addressed? This results in only part of the job being done, that is a medical intervention has taken place but a 'social model of disability' intervention around the more long term related impairment has not.⁷¹⁰

- 9.155** Professor Julie Byles, President, NSW Division of the Australian Association of Gerontology, highlighted the importance of research in providing a strong evidence base for service provision, including the use of linked data:

We would like to make a strong recommendation regarding the value and importance of research for providing an evidence base for service provision, for evaluating the equity, effectiveness and efficiency of services, and for planning for future service needs. We argue that such research needs to involve a number of disciplines and research approaches including research using administrative and linked data. For example, recent projects using Home and Community Care data have provided information on barriers to access and effective models of care for older men ... and opportunities for the health promotion and disease prevention for people receiving HACC services.⁷¹¹

- 9.156** The Committee also received evidence that funded organisations are required to input data into multiple systems. The Anglicare Sydney submission also explained that organisations do not receive feedback once the data has been provided:

Each government funded program has its own reporting requirements and separate database system. This requires data entry at the service end but provides minimal reporting back to the services or the return of such data. It is generally not possible to access the program data once it has been entered in either the State or Federal Government databases, and so a system of double entry of data is required - which is extremely time consuming and inefficient for Not-for-Profits.⁷¹²

- 9.157** Anglicare Sydney believes that a significant amount of data is captured by the government and that it is not used adequately to report back to the sector on its performance:

Currently a significant amount of data is being captured by governments in various databases for various programs across the country. However there appears to be no intention to consolidate and analyse this data for high level reporting back to the sector on performance and outcomes. There is a consistent focus by government on inputs into the programs but very little reporting of outputs or outcomes back to the sector. Benchmarking and regular reviews of performance in key funding areas would be possible if such global data analysis was carried out.⁷¹³

- 9.158** Anglicare recommend that "[t]he current data capture system for ADHC-funded programs be reviewed, with the aim of providing maximum data access to services for their own reporting and internal evaluation purposes."⁷¹⁴

⁷¹⁰ Submission 97, Aboriginal Disability Network, p 3

⁷¹¹ Submission 37, NSW Division of the Australian Association of Gerontology, p 1

⁷¹² Submission 66, Anglicare, Diocese of Sydney, p 14

⁷¹³ Submission 66, p 14

⁷¹⁴ Submission 66, p 14

- 9.159** Mr Moore stated that there is a need 'to take a more deliberate and considered approach to creating a robust evidence base for disability services', suggesting a consolidated national approach may be appropriate:

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.⁷¹⁵

- 9.160** The significant issue of infrequent data collection is being addressed by ADHC through working with ABS and the Australian Institute of Health and Welfare (AIHW) to improve other relevant statistical data collections:

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.⁷¹⁶

Committee comment

- 9.161** The Committee acknowledges the difficulties faced by ADHC regarding the infrequent collection of disability sector data and acknowledges the work that ADHC is doing to make good use of other relevant statistical data collections. The Committee understands that this makes it difficult for ADHC to plan for the needs of people with disability in NSW and to adequately plan for phase two of Stronger Together.
- 9.162** The Committee agrees with Mr Moore, that a survey of service users, carers and their families should be completed every three years to improve ADHC's understanding of the population that is receiving a service, the level of unmet need and any other relevant issues that are not captured through other means.

Recommendation 49

That the Minister for Disability Services conduct a survey of all service users, carers and their families who receive services from ADHC and funded organisations every three years to improve ADHC's understanding of issues in the disability service system.

That the results of the survey and ADHC's response to the results are published within six months after completion of the survey.

⁷¹⁵ Submission 31, p 61

⁷¹⁶ Submission 31, p 64

Licensed boarding houses

9.163 The Committee heard that boarding houses are an accommodation option for people with a disability. A boarding house must be licensed by ADHC if they contain two or more people with a disability. Across the State, there are about 50 or 60 licensed boarding houses with approximately 800 residents. Boarding houses vary in size. For example, a boarding house on the Central Coast has over 100 residents, while in Newcastle there is one with four and another with 11.⁷¹⁷

9.164 Licensed boarding houses are monitored by licensing officers employed by ADHC, and are visited by Official Community Visitors. In contrast, unlicensed boarding houses have neither of these safeguards, and if they have more than two residents with a disability, may be operating illegally. Ms Armstrong, Official Community Visitor, shared with the Committee her concerns about those persons with a disability who reside in an unlicensed boarding house, which are not monitored by ADHC:

The identification of people with disabilities living in boarding houses is a matter of concern for community visitors. Because boarding houses are licensed under the *Youth and Community Services Act* they are monitored by licensing officers employed by ADHC, and community visitors visit licensed boarding houses. Community visitors do not visit other boarding houses or rooming houses that are not licensed.⁷¹⁸

9.165 Boarding houses are regulated under the *Youth and Community Services Act 1973*. The Committee heard evidence that this Act is very old and in need of reform. In particular, Ms Sands, Executive Director, People with Disability, expressed concern that the rights and care of boarding house residents needs to be improved. She provided examples where residents have been over-medicated and subject to punitive and overbearing rules:

... because the boarding house sector is not covered by the Disability Services Standards or the Disability Services Act, it is governed by the Youth and Community Services Act, which is a very old Act and, as you are probably aware, there has been a process of reform, but it has been stagnating over the last 10 years. We are very concerned that that Act has not been modernised to concentrate on the rights of residents, so I suppose a lot of our work with residents is looking at their basic rights to be able to have choice about what they do and where they go. There are incidences of people in boarding houses who are forced to take the annual holiday that all residents take, where there is a lot of over-medication or medication distributed inappropriately; where the whole of their disability pension or 80 per cent of it may be going to support their lodgings and food with very little left over; there are a lot of punitive measures to perhaps control what is called challenging behaviour which might be taking cigarettes from people or only distributing them at certain times.⁷¹⁹

9.166 Ms Armstrong also expressed concern about the lower level of services provided to persons with a disability just because they reside in a boarding house. In comparison, persons living in a funded group home have a much greater right to access of disability services:

⁷¹⁷ Ms Armstrong, Evidence, 27 September 2010, p 46

⁷¹⁸ Ms Armstrong, Evidence, 27 September 2010, p 46

⁷¹⁹ Ms Therese Sands, Executive Director, People with Disability Inc, Evidence, 3 September 2010, pp 33-34

The argument is more about equity. A person with a disability living in a group home has a right to receive X services. A person with a disability living in a boarding house does not have that same right, because the operators of that boarding house are not required to deliver services in accordance with the *Disability Services Act*. That is it in a nutshell; it is about equity.

... Persons in a group home would usually have a day program for four days a week and then they would have a day at home. A person with a disability living in a licensed boarding house can leave that boarding house and go for a walk, but there is no onus on the proprietor to assist that person in organising a day program.⁷²⁰

- 9.167** The Committee also received evidence that service providers are referring people with disability to unlicensed boarding houses because the alternative is to live on the street. For instance, Ms Armstrong explained to the Committee:

All I know from my working in the community is that people with disabilities are often driven to take accommodation in these facilities because ... they find it difficult to get anything else. Through our work we are aware that there are agencies and community-based services that continue to refer people with a disability to unlicensed boarding houses because the alternative is the street.⁷²¹

Committee comment

- 9.168** The Committee is concerned about the level of care provided to persons with a disability in both licensed and unlicensed boarding houses. It is evident to the Committee that boarding house residents are some of the most vulnerable and marginalized in society.
- 9.169** The Committee is particularly concerned that persons with disability are being referred to unlicensed boarding houses, simply because no other option is available.

Recommendation 50

That the Minister for Disability Services ensure that people with disability who reside in boarding houses receive person-centred planning and that the services provided to people who reside in boarding houses comply with the NSW Disability Service Standards.

-
- 9.170** The Committee believes that an increased focus on the inspection and monitoring of licensed boarding houses is appropriate, and that there needs to be a formal mechanism for people to report boarding houses that are operating illegally.

⁷²⁰ Ms Armstrong, Evidence, 27 September 2010, p 49

⁷²¹ Ms Armstrong, Evidence, 27 September 2010, p 47

Chapter 10 Carers

This chapter examines the role of carers and their contribution to the disability services sector. Carers play a crucial role in the lives of people with disability. The informal networks of support provided by family and friends relieve a great deal of pressure from the formal support system. During the Inquiry it became evident that there are number of distinct issues facing carers, including the provision of respite and supported accommodation services, person-centred service delivery and futures planning services. This chapter also examines the stress placed on family relationships when caring for a person with disability and explores the specific needs of older carers, culturally and linguistically diverse (CALD) and Aboriginal carers.

The issues raised by carers are significant and illustrate the broader concerns in the disability services sector which are examined in all chapters. As such, this chapter does not make any recommendations, rather the recommendations concerning these issues can be found throughout the report.

The role of paid carers is specifically examined in Chapter 11.

Role of carers

10.1 There are approximately 750,000 carers in NSW.⁷²² Carers NSW, the peak organisation for carers in the State, defined a carer as "... any individual who provides unpaid care and support to a family member or friend who has a disability, mental illness, drug and alcohol dependencies, chronic condition, terminal illness or who is frail."⁷²³ Carers NSW continued that "carers come from all walks of life, cultural backgrounds and age groups. For many caring is a 24 hour job that is often emotionally, physically and financially stressful."⁷²⁴

10.2 The Committee received a lot of evidence from carers, who revealed their feelings of love, dedication and at times, desperation, as they face their caring duties. The author of Submission 71 shared her story of caring for her daughter:

... [my daughter] requires 24/7 specialized care, & we have to guard her health from environmental elements (Wind, Rain, debris like sand, hair ETC from being inhaled through her Trachie and into her lungs, as well as safeguarding her from catching cold and flu as best as we can). Even Bathing/showering her is risky as she could accidently splash/inhale water down her trachie.

Basically I adore my child, and as hard as it is to have given up my life & career, & other relationships and interests, and as complex as her health is, I'm happily devoted to her life and well-being (for both my children).⁷²⁵

10.3 The author of Submission 88 described her experience of caring for her husband who is a complete C4/C5 quadriplegic:

⁷²² Submission 33, Carers NSW, p 2

⁷²³ Submission 33, p 1

⁷²⁴ Submission 33, p 1

⁷²⁵ Submission 71, Name suppressed, p 1

... I am constantly struggling with all that is required of looking after him, our seven year old daughter, running a household, looking after the house, working part time, and in a constant state of panic of "we don't have enough money to survive!!!"⁷²⁶

- 10.4** Ms Jennifer Rollo OAM, carer to David, reflected on her determination to assist her son to receive essential services, and the impact on her family of her being her son's carer:

I have also been forced to become a lobbyist and a fundraiser for disability and disability health services, writing endless submissions to government inquiries, attending meetings with service providers and other parent groups, and attending round tables to advise governments about policy, leaving less time for my family and making my role as carer to my son more strained. I have no doubt that this has contributed significantly to my marriage of nearly 3 decades ending - like so many other marriages when there is a child with a disability.⁷²⁷

- 10.5** Carers play a critical role in the lives of people with disability. Informal networks of support have significant financial and social impacts on people with disability and the wider community. Mr Dougie Herd, Executive Officer of the Disability Council of NSW, reflected on the significance of carers to the disability sector, stressing that the system would fail without them:

The system could not work without the informal network of support. It is that straightforward. The lives of many people with disability, not all, are made tolerable and possible because of the support they get from family members, friends, neighbours and others. It is usually women, usually mothers or wives or sisters, who put in hours that would probably be illegal if they were being paid for them and under terms that probably would not meet the occupational health and safety requirements that non-government staff are required to meet when they go into somebody's house.⁷²⁸

Recognition of carers

- 10.6** The Government applauded the work of carers and acknowledged the significant contribution they play in the lives of their loved ones. Mr Jim Moore, Director General of Ageing, Disability and Home Care supported Mr Herd's assessment of the role of carers, and particularly the unquantifiable non-financial benefits of carers:

... the thing that is much more important in understanding the role of carers is not just that they are saving us money but the difference in the life of the person with the disability that they make. The person with a disability is now going to live a long life, is going to need to have people who are not unduly burdened by people who are able to help them build their life in the community. The more we have people continuing in those roles in whatever level they can manage, the better the social outcomes we will get. That is the one that the financial analysis misses time and again; it is not just about numbers in this case.⁷²⁹

⁷²⁶ Submission 88, Name suppressed, p 1

⁷²⁷ Submission 38, Ms Jennifer Rollo OAM, p 1

⁷²⁸ Mr Dougie Herd, Executive Officer, Disability Council of NSW, Evidence, 9 August 2010, p 31

⁷²⁹ Mr Jim Moore, Chief Executive, ADHC, Evidence, 27 September, p 6

- 10.7** The Government's 2007 *Carers Action Plan 2007-2012* praised carers and their role in the community. In the Forward, the former Premier, Morris Iemma MP, also gave high praise to carers and the role they play in the community, stating that "[m]ore than one in ten members of the NSW community are carers - dedicated citizens making an unsung yet indispensable contribution to our social fabric."⁷³⁰
- 10.8** In recent years the NSW Government has taken significant steps to support and recognise the important role carers play in the community although evidence received through the Inquiry suggested that there is still a long way to go. In its submission ADHC affirmed its commitment to ensuring carers are respected and valued through improving services and supports as set out in *Stronger Together* and the *NSW Carers Action Plan 2007-2012*:
- [ADHC is] 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.⁷³¹
- 10.9** The *NSW Carers Action Plan 2007-2012* sets out five priorities for action that are fundamental to improving the quality of life for carers and the individuals that they care for.⁷³² Carers NSW praised the plan saying it signalled that the government recognised carers' issues crossed a range of government agencies.⁷³³
- 10.10** Another initiative to assist carers is the Companion Card NSW. Individuals with a significant or permanent disability who require attendant care for the rest of their lives are eligible to receive the card which enables free admission to certain community activities and events to attendant carers supporting people with disability.⁷³⁴
- 10.11** Additionally, ADHC has established the Local Carer Awards Program in 2010. These awards recognise the outstanding contributions made by local carers and carer groups.⁷³⁵
- 10.12** The Shadow Minister for Ageing and Disability Services introduced a Private Members Bill titled the *Carers Recognition Bill 2010* to Parliament on 12 March 2010.⁷³⁶
- 10.13** In April 2010 members of the NSW Parliament passed the *Carers (Recognition) Act NSW* (2010). This Bill seeks to acknowledge, protect and promote the rights of carers. The objects of the Bill are:

⁷³⁰ NSW Health, *NSW Carers Action Plan 2007-2012, 2007*, p 1

⁷³¹ Submission 31, Ageing, Disability and Home Care, p 25

⁷³² NSW Health, *NSW Carers Action Plan 2007-2012, 2007*, p 9

⁷³³ Ms Elena Katrakis, Chief Executive Officer, Carers NSW, Evidence, 9 August 2010, p 52

⁷³⁴ Submission 31, p 23

⁷³⁵ Hon P Primrose MLC, Minister for Ageing, Disability and Home Care, 'Awards for outstanding local carers', *Media Release*, 20 October 2010

⁷³⁶ *NSWPD (Legislative Council)*, 12 March 2010, p 21378

- to enact a Carers Charter to recognise the role and contribution of carers to our community and to the people they care for, and
- to increase the awareness of the valuable contribution that carers make to our community.⁷³⁷

10.14 Schedule 1 of the *Carers (Recognition) Act 2010* (NSW) provides the NSW Carers Charter:

- (a) The valuable social and economic contribution that carers make to the community and the persons for whom they care should be recognised and supported.
- (b) Carers' health and wellbeing are to be given due consideration.
- (c) The views and needs of carers and the views, needs and best interests of the persons for whom they care must be taken into account in the assessment, planning, delivery and review of services provided to persons who are cared for.
- (d) Carers should be referred to, and made aware of, appropriate services to assist carers in their caring role. Such referrals should be made after an assessment of the needs of carers or as part of the assessment or provision of services to the person being cared for.
- (e) The relationship between carers and the persons for whom they care should be respected.
- (f) Carers are to be acknowledged and recognised as having their own individual needs within and beyond their caring role. This acknowledgement and recognition is to take into consideration Aboriginal or Torres Strait Islander culture, age, disability, religion, socio-economic status, cultural differences, gender identification and place of residence.
- (g) Children and young people who are carers have the same rights as all children and young people.
- (h) Children and young people who are carers face additional difficulties and burdens and should be supported in overcoming these difficulties and burdens.
- (i) Carers should have the same rights, choices and opportunities as other Australians.
- (j) Carers' choices in their caring role should be supported and recognised, including the recognition of carers in the assessment, planning, delivery and review of services that impact on carers and their role as carers.
- (k) The additional difficulties faced by remote and rurally based carers caused by isolation should be recognised and acknowledged.
- (l) Support for carers should be timely, responsive, appropriate and accessible.
- (m) Carers' unique knowledge and experience should be acknowledged and recognised.⁷³⁸

⁷³⁷ Parliament of NSW, Carers (Recognition) Bill 2010, (accessed 22 October 2010) <<http://bulletin/prod/parlament/nswbills.nsf/V3BillsHome>>

⁷³⁸ *Carers (Recognition) Act 2010* (NSW), schedule 1

- 10.15** During the "Agreed to in Principle" speech, the Hon Carmel Tebutt MP, Minister for Health was effusive in her praise for carers:

There are 750,000 carers in NSW. That is more than one in every ten of us. Carers are mothers and daughters, fathers and sons, nieces, nephews, aunts and uncles, grandparents. They are people who know someone who is disabled, old and frail, or suffering from an illness, and they take the very human decision to provide them with personal care, support and assistance. These are people who care about someone else. Because they are often not paid for what they do, their contribution to our society does not register in economic statistics or analyses of national wellbeing. But without them our society simply would not work the way it does. They are the often unsung and unseen heroes of our community. They make an enormous contribution and they deserve our respect, support and recognition.⁷³⁹

- 10.16** NSW Department of Health (NSW Health) informed the Committee that in July 2010 the Premier allocated responsibility for the Act to ADHC and transferred policy responsibility for carers from NSW Health to ADHC.⁷⁴⁰ This will include the *NSW Carers Action Plan 2007-2012*, the evaluation plan for the Carers Action Plan, the statewide NGO Carer Grants Program and peak funding for Carers NSW.⁷⁴¹

- 10.17** In April 2009 the Federal Government released *Who Cares ...? Report on the inquiry into better support for carers* (herein known as *Who Cares...?*). The report investigated how the Government could improve its support to unpaid carers. The Committee made 50 recommendations. The primary recommendation sought to secure immediate financial relief for carers by increasing the base rate of income support for carers and has called for means testing thresholds to be reviewed.⁷⁴² In its Government Response to the report, the Commonwealth Government agreed to this recommendation and increased the Carer Payment:

The Commonwealth Government has implemented this recommendation through the 2009–10 Budget Secure and Sustainable Pension Reform package.

This package provided an increase in pension rates from 20 September 2009. The increase in the rate of pensions, which includes Carer Payment, was \$32.50 per week for full rate singles and \$10.15 per week for couples combined.

In addition to the rise in the rate of Carer Payment, the Commonwealth Government introduced a new, permanent Carer Supplement of \$600 per year for Carer Payment recipients, and an additional \$600 per year for Carer Allowance recipients for each eligible person in their care.⁷⁴³

⁷³⁹ *NSWPD (Legislative Assembly)*, 21 April 2010, p 22028

⁷⁴⁰ Answers to questions taken on notice during evidence, Dr Richard Matthews, Deputy Director-General, Strategic Development, NSW Health, 27 September 2010, p 3

⁷⁴¹ Answers to questions taken on notice during evidence, Dr Matthews, 27 September 2010, p 3

⁷⁴² Ms Annette Ellis MP, Chair, Standing Committee on Family, Community, Housing and Youth, Urgent assistance recommended for carers, *Media Release*, 1 May 2010, p 1, (accessed 7 October 2010) < <http://www.aph.gov.au/house/committee/fchy/carers/media/media16.pdf> >

⁷⁴³ Government response, *Who Cares ...? Report on the inquiry into better support for carers*, 29 October 2010, p 21

- 10.18** The Commonwealth Government has also instigated a number of policy changes that impact on carers, such as the National Disability Agreement. The National Disability Agreement is discussed in Chapter 2.

Supported accommodation

- 10.19** The availability of supported accommodation was a pressing concern raised by carers during the Inquiry. Carers NSW contend that despite the government's work to increase the number of supported accommodation places there continues to be significant unmet need for accommodation choices for people with disability.⁷⁴⁴ Supported accommodation placements offer people with disability an opportunity to live away from their family in a supported environment that adequately meets their care needs.
- 10.20** In its joint submission the Physical Disability Council of NSW (PCDN) and Council on the Ageing NSW (COTA) noted that the apparent shortage of placement options was identified by Working Carers in its report *No place for our loved ones to go*. The report stated that "last year [2008] there were 1700 requests from carers already in crisis seeking supported accommodation for their loved one with a disability. Only 112 places were available."⁷⁴⁵
- 10.21** Inquiry participants echoed the need for more supported accommodation. Carers, such as Ms Bernadette Marshall, expressed feelings of despondency as they sought to secure suitable accommodation for their loved ones.⁷⁴⁶ Lyn, an older carer, described families being "ignored or tossed from pillar to post" before being able to receive a supported accommodation placement.⁷⁴⁷ Issues concerning supported accommodation and Committee recommendations can be found in Chapter 5 and Chapter 6.
- 10.22** Difficulties securing supported accommodation placements were vividly illustrated by Ms Christine Regan, Senior Policy Officer, NCOSS, who shared the story of a carer who was hospitalised before her son could be offered a placement:

I know of one woman who could not get equipment into her house in order to have her son, who had very high support needs, seated and into bed. This was only about three years ago. She used to put a sleeping bag on the floor and she fed him on the floor until her own shoulders gave out and she had to go into hospital. Only at that point was she offered supported accommodation for her son, when she had completely broken down.⁷⁴⁸

- 10.23** A number of carers referred to the system as being in crisis and called for the Government to act swiftly. The author of Submission No. 110, carer to her son, said that "the most

⁷⁴⁴ Ms Katrakis, Evidence 9 September 2010, p 47

⁷⁴⁵ Submission 51, Ms Ruth Robinson Chief Executive Officer, Physical Disability Council of NSW and Ms Anne-Marie Elias, Policy and Communications Manager, Council on the Ageing NSW, p 4, quoting, *Working Carers* (2009) <http://www.workingcarers.org.au/carers-stories/1051-no-place-for-our-loved-ones-to-go>

⁷⁴⁶ Submission 13a, Ms Bernadette Moloney, p 2

⁷⁴⁷ Submission 29, Lyn, p 3

⁷⁴⁸ Ms Christine Regan, Senior Policy Officer, Council of Social Service of NSW, Evidence, 9 August 2010, p 62

CRITICAL AND PRESSING problem amongst the Services funded by ADHC is the EXTREME SHORTAGE OF SUPPORTED ACCOMMODATION and the absence of any planning around it"[emphasis as per original].⁷⁴⁹ The author of Submission No. 82 had similar concerns, stating "access to supported accommodation continues to be by crisis only... Supported accommodation needs to be seen as a top priority by Governments and a right for people who have a disability."⁷⁵⁰

- 10.24** A number of carers called for improved future planning of services to assist families make arrangements for a time when they can no longer care for their loved one.⁷⁵¹ The ability to plan and secure supported accommodation would ease some of the burden of caring, particularly for older carers, and is examined in Chapter 10.
- 10.25** The case study below highlights the overwhelming desire of a carer to find a supported accommodation placement for her son, brought before the Committee during its Public Forum.

Case study 11 - Ms Janice Marshall⁷⁵²

My name is Janice Marshall and I am the mother of Daniel, my 22-year-old son, who has autism, suffers from extreme anxiety, has bizarre behaviours, is very destructive and has an intellectual disability. He lives at home with us. I would like to address one of the most critical problems facing ADHC... the acute shortage of supported accommodation for our adult children with disabilities...

To solve this problem I propose the following 3 solutions:

1. Families should have the right to future planning for an organised and timely transition for their loved one into an appropriate accommodation setting, with quality services and a degree of family control... This will relieve families of a burden of stress, improve their mental and physical health, encourage them to be greater partners in the process, and reduce total costs.
2. Individualised funding packages would allow families to be involved in deciding on how their loved one will be best accommodated. They are the people who best know and understand the person with a disability and should help choose appropriate service providers...
3. Many families may be prepared to provide equity in some form to their loved one's accommodation solution, either in the form of a physical home, funding contribution or informal supports to help in the day-to-day care by means of friends, family or community members, if ADHC would be more flexible and allow families more control over the type and quality of care. This would all reduce cost to ADHC and spread funding over more families...

I come from a privileged background of having had a university education and a successful business career in the investment industry but nothing—nothing—prepares you for the stress and trauma of living with autism every day for 22 years. It has taken a mighty toll on our family. My husband was diagnosed with Parkinson's disease four years ago at the age of 51—an illness which, if not caused by stress, certainly is made much worse by ongoing stress. Our 20-year-old daughter suffers from an anxiety disorder, which has certainly been made worse by our son and which has almost claimed her life. After years and years of therapy with us, our son, Daniel, also would like to live away from us. He has had enough of us. There are families worse than us, and one family in our group has relinquished care only this week, with all the emotional trauma and guilt which comes with it.

⁷⁴⁹ Submission 110, Name suppressed, p 1

⁷⁵⁰ Submission 82, Name suppressed, p 1

⁷⁵¹ Submission 110, p 1

⁷⁵² Ms Janice Marshall, Public Forum, 30 September, pp 10-11

- 10.26** Some carers have undertaken innovative approaches to encourage ADHC to create more supported accommodation facilities. The Committee heard of a group of parent carers who have created a lobby group to secure supported accommodation in the Ryde Area. The Ryde Area Supported Accommodation for Intellectually Disabled hopes to gain funding to build five cluster homes to support the needs of their loved ones.⁷⁵³
- 10.27** ADHC acknowledged that there is unmet need for supported accommodation placements however there was some debate as to the actual number of people with disability requiring assistance. The Australian Institute of Health and Welfare has reported that the number of people with unmet need for supported accommodation in NSW is approximately 10,000.⁷⁵⁴ Mr Moore, challenged this statistic:
- If we look at our registers of requests for supported accommodation where people can ask, we will list them and that is the list we draw on to fill vacancies. We have about 750 people at the moment who are saying, were they to be asked, they could accept a place immediately. We have another thousand who would say they would like a place sometime in the future. It is still a long way to go from there to get to 10,000.⁷⁵⁵
- 10.28** ADHC has taken steps to improve supported accommodation options since the introduction of *Stronger Together*. There have been hundreds of additional supported accommodation places allocated since 2006.⁷⁵⁶
- 10.29** The issues raised by carers regarding unmet need for supported accommodation are consistent with the wider debate raised by other Inquiry participants. For more information about unmet for supported accommodation see Chapter 5 and Chapter 6.
- 10.30** Carers were concerned about the practices of certain supported accommodation facilities that their family members currently reside in. The Committee heard of poorly trained staff and unsuitable placements. For example, Carolyn Mason, mother and carer to Amy, told of poor management and unprofessional behaviour of staff at her daughter's group home.⁷⁵⁷
- 10.31** The families of a 51 year old woman with Down Syndrome and an older man with Down Syndrome were devastated that a young, non-verbal autistic male with obsessive compulsive tendencies had been placed in their loved ones' supported accommodation facility. Ms Valerie Noone, sister to the 51 year old woman, said she feared for her sister's safety since the new house member had been introduced.⁷⁵⁸ The author of Submission 43, brother to the older man, said the inappropriate placement impacted negatively on the quality of life of all of the members and staff of the home.⁷⁵⁹
- 10.32** Another example of poor placement choice was described by the author of Submission 109, carer to her daughter with complex medical issues. The carer was distressed that a man was

⁷⁵³ Submission 38, p 2

⁷⁵⁴ Submission 31, p 47

⁷⁵⁵ Mr Moore, Evidence, 9 August 2010, p 6

⁷⁵⁶ Submission 31, p 34

⁷⁵⁷ Submission 14, Ms Carolyn Mason, p 5

⁷⁵⁸ Ms Valerie Noone, Public Forum, 30 September 2010, p 2

⁷⁵⁹ Submission 43, Name suppressed, p 2

placed in her daughter's group home. Her daughter had previously been sexually assaulted by another man and became anxious and fearful about another male joining the home.⁷⁶⁰

Respite

10.33 During the Inquiry carers shared their experiences of accessing respite services. While certain stakeholders were happy with the services they received, others discussed problems such as unsuitable services and unmet need.

10.34 ADHC defines respite as "... planned short-term and time-limited breaks for families and other unpaid care givers of children with a developmental delay and adults with an intellectual disability in order to support and maintain the primary care-giving relationship."⁷⁶¹ There are four types of ADHC provided or funded respite activity:

- centre-based (general and specialist)
- home-based
- host Family
- community-based.

10.35 The Committee received a number of positive stories about carers experience with out-of-home respite. Most families told the Committee that without respite they would be unable to cope with caring for their family member. In her submission Ms Estelle Shields explained that she was grateful for the ADHC provided respite services she received for her son, however at times she has encountered difficulties:

... ADHC runs an excellent respite facility in my local area, with experienced, caring and long term staff who have come to know their clients and families well. I can tell you that almost everything that has made my life worth living in the past ten to fifteen years has happened because my son has been in respite. There have been other times when blocked beds have precluded his attendance at respite and all plans have had to be put on hold. Not only does respite give me a break, but it gives my son a social experience and prepares him for the inevitable move out of home.⁷⁶²

10.36 Ms Rollo told the Committee she had positive experiences accessing respite for her son at the Estia Foundation in Gladesville, an ADHC funded facility:

They have embraced our family and saved my sanity. David has been able to learn to let others care for him which is very important should he ever achieve supported accommodation, and will certainly be needed if/when I should suddenly die and he is left without my care. More importantly he is given the opportunity of being with his peers. He loves staying at the respite house.

⁷⁶⁰ Submission 109, Name suppressed, p 3

⁷⁶¹ Department of Human Services, Ageing, Disability and Home Care, Respite, (accessed 13 October 2010) < <http://www.dadhc.nsw.gov.au/dadhc/People+with+a+disability/Respite.htm> >

⁷⁶² Submission 15, Ms Estelle Shields, p 4

From my point of view I have a chance to break away from the 9am to 3pm routine that dominates my existence, for a few days every month to 6 weeks.⁷⁶³

- 10.37** Not all families are able to access out-of-home respite. Ms Debbie Robertson, carer to Brett, told the Committee that because of her son's severe intellectual disability and behaviour he currently receives in-home respite and that this impacts on her caring duties:

... We have had several attempts over the years to access ADHC respite. However, there was never a suitable place for him where he would be kept safe. No service met Brett's needs in terms of him absconding...

This has meant that we have been unable to have much-needed breaks away from the caring role, and this has taken an enormous toll on our health as individuals and as a family. At present, we receive five hours a month in home respite, and that is as far as the respite goes.⁷⁶⁴

- 10.38** Ms Robertson continued that she hoped there may be an opportunity for Brett to access out-of-home respite in the future:

At the moment we are in the process: it seems after 20-odd years—Brett is now 29 years old—that we might hopefully have found a respite unit, which is in Blacktown, that is suitable for Brett. But we are in the process now of just going through getting him eased into being away from home. He is now 29 and, because of unsuitable respite, he is not accustomed to being away from home.⁷⁶⁵

- 10.39** Some carers also shared negative experiences accessing out-of-home respite for their loved ones. Ms Moloney told of her unfortunate experience using an ADHC provided respite service for her son:

We were referred to an ADHC centre based respite house and received about 2 nights respite per six week period. I think we used it 2 or 3 times. I never saw the same person twice. Charley was a toddler with an intellectual age of less than 9 months. I hated dropping him off with complete strangers every single time. It goes against all maternal instincts - but I was desperate. Finally my older son, who must have been 6 or 7 years old at the time said to me one day as we were driving away "Don't leave Char there Mum, go back and get him". I don't think I did go back, but we have never used an ADHC managed service since then.⁷⁶⁶

- 10.40** Alternatively, Ms Malonoy had positive experiences using church-based respite.⁷⁶⁷

- 10.41** The Committee heard that there were concerns about the behaviour of clients and staff in certain respite facilities. Mr Reg Mason, carer and father to Amy, informed the Committee of an incident involving alleged improper conduct by a respite client towards his daughter. Mr Mason expressed anxiety about an older man with an intellectual disability having an inappropriate romantic relationship with his daughter while she was visited an ADHC funded

⁷⁶³ Submission 38, pp 2-3

⁷⁶⁴ Ms Debbie Robertson, Public Forum, 30 September 2010, p 23

⁷⁶⁵ Ms Robertson, Public Forum, 30 September 2010, p 23

⁷⁶⁶ Submission 13a, p 1

⁷⁶⁷ Submission 13a, p 1

respite centre. Mr Mason believed that the respite centre staff's decision to not act on the matter was irresponsible and cavalier.⁷⁶⁸

- 10.42** During the Inquiry, as with unmet need for other services, the issue of unmet need for respite was discussed by carers. Carers NSW reported that in its consultation with carers, almost all carers said that they wanted more respite.⁷⁶⁹ The Association for Children with a Disability NSW (ACD NSW) had a similar complaint and noted that "[m]any families claim that there is just not enough respite available and of the respite models that are available they are not flexible enough to allow the family to tailor the service to the child's individual needs."⁷⁷⁰
- 10.43** In an answer to question on notice, Mr Moore told the Committee that the Government is working towards addressing issues of respite provision. Since the introduction of *Stronger Together* an additional 5,036 respite places made available.⁷⁷¹
- 10.44** The provision and delivery of respite services can cause tension between the rights of carers and the rights of people with disability. There was some debate as to whether the way in which respite is provided causes a conflict of interest between carers and care recipients. Mr Herd explained this argument and its grounding in the United Nations Convention on the Rights of Persons with Disabilities:

I think respite should be an outcome, not a place you go to. We have created day-centre-based respite facilities only because we have created a tension between people with disability and those that care for them. You do not need centre-based respite if you have provided a network of support around people. Here is where the tension comes in that I think we will have to look at in future. If it is true that the United Nations Convention on the Rights of Persons with Disabilities says that people with disability have rights as citizens, then removing them from their home to give someone else a break is a breach of the convention. We will have to look at that tension in reality in the future, but I know what the reality is.⁷⁷²

- 10.45** Ms Ruth Robinson, Executive Officer, Physical Disability Council of NSW, also noted the potential conflict of interest in the provision of respite:

Respite is a complicated thing but a rather fabulous thing. It provides an opportunity potentially for the person who is the recipient of care to have an interesting and worthwhile experience, and it provides an opportunity for those people who are their care providers to do other things in their life and recharge their batteries.

Unfortunately, when you are looking at the provision of respite it becomes a question of: Whose needs are you going to meet? Are you going to meet the needs of the carer and just pop the person somewhere or anywhere to get that break, or are you going to be focusing on the person with the disability?⁷⁷³

⁷⁶⁸ Submission 49, Mr Reg Mason, pp 2-3

⁷⁶⁹ Submission 33, p 4

⁷⁷⁰ Submission 96, Association for Children with a Disability NSW, p 1

⁷⁷¹ Answers to questions taken on notice during evidence, Mr Moore, 9 August 2010, p 12

⁷⁷² Mr Herd, Evidence, 9 August 2010, p 31

⁷⁷³ Ms Ruth Robinson, Executive Officer, Physical Disability Council of NSW, Evidence, 3 September, p 23

Committee comment

- 10.46** The Committee acknowledges the love and dedication shown by the carers who appeared before it. The Committee admires their devotion to their children and partners and respects their commitment to caring for their loved ones. The Committee recognises that the work carers do is essential to the functioning of the disability services sector.
- 10.47** The Committee recognises carers' frustration at the apparent lack of suitable supported accommodation and respite options. ADHC has noted that this is an important issue and is working towards its goals as outlined in *Stronger Together*. It is expected that the Government will continue to improve these services after the introduction of *Stronger Together II*. The Committee's recommendations addressing issues in the delivery of supported accommodation and respite can be found in Chapter 5 and Chapter 6.
- 10.48** The Committee notes that there can be a conflict of interest in the provision of respite between carers and care recipients. Respite should serve the interests of both groups equally. The Committee understands that it is difficult to find the appropriate balance because the needs of both groups are important, however it is expected that ADHC and funded organisations work towards this goal in the future provision of these services.

Person-centred service provision

- 10.49** Throughout the Inquiry, the Committee was told of the merits of moving towards person-centred service provision, including greater financial control. Carers called for the Government to reconfigure its approach to service provision, including the way it distributes funds. In recent years ADHC has moved towards person-centred planning, which seeks to ensure the person with disability is at the centre of planning considerations.⁷⁷⁴ There was debate as to whether this move has significantly altered the way in which clients receive services and supports.
- 10.50** Carers NSW noted that despite key government policies, including *Stronger Together*, promoting 'person-centred' approach to service provision it was not the reality of carers.⁷⁷⁵ The author of Submission 88, carer to her husband, offered an example of this predicament:

For example, if I need to race off for work, and [my husband] is taking our daughter to school (he's in a power chair), we might both need to leave the house by 9am. This means the carer also has to leave the house then, although there is still 30 mins left of their shift which is mopping up in the bathroom after him, dealing with overnight drainage bottles etc, and finishing all that is required on a morning shift... Very annoying!⁷⁷⁶

- 10.51** A central tenet of person-centred planning is the flexible use of resources, including individualised funding for certain programs. Individualised funding can be seen as a means for further encouraging "choice" for carers and people with disability.⁷⁷⁷ ADHC advised the

⁷⁷⁴ Submission 31, p 70

⁷⁷⁵ Submission 33, p 5

⁷⁷⁶ Submission 88, p 2

⁷⁷⁷ Submission 33, p 13

Committee that the agency has introduced a number of programs that have individualised support options, including

- 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.⁷⁷⁸

10.52 A number of carers told the Committee that they would like to have greater financial control over the services and supports they access on behalf of the person they care for. The author of Submission 110, carer to her son, reasoned that families often know the person with disability best and therefore should be able to choose which service providers they would like to use.⁷⁷⁹

10.53 Ms Mason believed that if she had been offered individualised funding she would have greater control over which service providers her daughter used and the flexibility to alter their assistance as her circumstances changed.⁷⁸⁰

10.54 Carers NSW was supportive of client-centred service provision and individualised funding however warned that there are potential problems with such moves:

.... giving carers more control over the services they use is important for increasing their choices and quality of life. It is essential, however, that any shift towards a person-centred approach, where the carer is at the core of decision-making about their lives, avoids creating more work for the carer and does not leave them to navigate the complex service system on their own.

10.55 There was also some apprehension about the introduction of individualised funding and the payment for tasks that family carers had traditionally performed without remuneration. Ms Robinson explained her concerns:

... there is a great concern that having an unpaid care provider within a family situation can sometimes damage rather dramatically the nature of the relationships between those family members and there is a strong concern and a strong call for funding or individualised funding to be made available to the person with the disability, the person who is the care recipient, so that other services can be purchased so that the relationship is not damaged. For example, if you are a gentleman and your wife is providing a lot of the personal care stuff, it changes the nature of your husband and wife relationship. It changes the nature of parent and children relationships, especially as they get older.⁷⁸¹

⁷⁷⁸ Submission 31, p 71

⁷⁷⁹ Submission 110, p 1

⁷⁸⁰ Submission 14, p 26

⁷⁸¹ Ms Robinson, Evidence, 3 September 2010, p 23

- 10.56** Ms Christine Reagan, Senior Policy Officer of the Council of Social Service of NSW (NCOSS), countered this argument, claiming that experience demonstrates that such problems exist in the current system and are handled reasonably well.⁷⁸²
- 10.57** ADHC has made provisions to overcome concerns about hiring family members as paid carers. Certain programs have support intermediaries that can assist people with disability in the employment of family members. For example, Carers NSW currently provides support to older parent carers on the Mid-North Coast through the *My plan, my choice: Individualised (Packaged) Support Participatory Action Research Strategy*.⁷⁸³ Carers in the program are provided support packages of \$20,000-\$45,000 and are assisted in their decision-making by a support planner (an ADHC case worker) and a Support Intermediary (from Carers NSW).⁷⁸⁴
- 10.58** Ms Elena Katrakis, Chief Executive Officer of Carers NSW, explained that as support intermediaries her organisation assists in the navigation of issues involving the employment of family members:

Often families employ other family members as part of the self-directed care packages. That also means you are taking what was an informal support of Billy coming to mow the lawns but then paying Billy to mow the lawns. Then he is no longer is part of the informal support network; he is part of the formal support network. That changes the dynamics and all of those things. When a family is employing another family member there can be huge issues with that. With "my plan, my choice" we are that support intermediary and we carry that risk for the family. We work with an employment agency. We do not employ the family member directly but we employ them through an employment agency. If there is a risk or something goes wrong and Billy does not work out you have an employment agency there so you still have some safeguards around that. That model again is one component or example of a model. That is why that model is a bit different, because it takes that burden off that choice and the carer making that choice for themselves. That will work for some, but with others there is that protection as well.⁷⁸⁵

- 10.59** Ms Katrakis noted that using an employment agency ensures insurance issues are also taken care of.⁷⁸⁶

Committee comment

- 10.60** The Committee recognises that carers would like ADHC to provide more person-centred services to assist people with disability and their families. This was a common issue raised by many participants in the Inquiry. Person-centred service provision rightly places the person with disability at the centre of all planning decisions. This process allows for more flexible and responsive programs that cater to the specific needs of individuals. The importance of individualised funding options to the development of client-centred services cannot be underestimated. Individualised funding allows people with disability and their carers to be more involved in decision-making processes and encourages creative and dynamic service provision.

⁷⁸² Ms Regan, Evidence, 9 August 2010, p 65

⁷⁸³ Answers to questions taken on notice during evidence, Ms Katrakis, 27 August 2010, p 5

⁷⁸⁴ Answers to questions taken on notice during evidence, Ms Katrakis, 27 August 2010, p 5

⁷⁸⁵ Ms Katrakis, Evidence, 9 August 2010, p 54

⁷⁸⁶ Ms Katrakis, Evidence, 9 August 2010, p 54

- 10.61** The Committee notes that the Government discusses the provision of person-centred services throughout its policies and procedures. It is therefore disappointing that the experience of carers does not reflect this stance.
- 10.62** The Committee accepts that there are concerns regarding the introduction of payment for tasks traditionally completed for free by carers may disrupt family relationships. On the balance of evidence received during the Inquiry, the benefits of individualised funding outweigh the unlikely occurrence of such measures causing a major rupture in family dynamics. ADHC has implemented a number of safety nets, such as providing support intermediaries in the *my plan, my choice: Individualised (Packaged) Support Participatory Action Research Strategy*, to help minimise such issues.
- 10.63** The issues of person-centred services are broader than those raised by carers. The Committee has made recommendations in relation to these issues in Chapter 4 to Chapter 9.

Access to future planning services

- 10.64** A number of Inquiry participants expressed frustration at the lack of government-provided future planning of services. The need for these services was most acutely felt by older carers, who often have great anxiety about what will happen to their loved one when they pass away. Ms Carol Berry, Executive Director of the NSW Council on Intellectual Disability, said that the lack of future planning provisions characterised the crisis-driven nature of the disability service system.⁷⁸⁷
- 10.65** The current and impending surge of unmet need for supported accommodation options further complicates this problem. Anglicare argued that lack of available supported accommodation significantly compounds the crisis-driven nature of the system:
- While transition planning is a critical component of ANGLICARE's Ageing Parent Carer Support Coordination program, a key element in the success of such planning is the availability of suitable and sustainable supported accommodation options for people with a disability. Currently there is a significant gap in the provision of such accommodation which would allow both ageing parent carers and their adult children with a disability to be co-located in the same or adjoining facilities.⁷⁸⁸
- 10.66** An example of the current approach to future planning was described by Ms Beverley Gollan, 75 years of age and carer to her 47 year old son. Ms Gollan was distressed that ADHC had not provided her with confirmation that her son will have a group home placement when she becomes ill or dies.⁷⁸⁹
- 10.67** The issue was highly emotive for some Inquiry participants. Ms Robertson reflected on her desire to ensure her son's future is secure:

⁷⁸⁷ Ms Carol Berry, Executive Director, NSW Council on Intellectual Disability, Evidence, 26 August 2010, p 19

⁷⁸⁸ Submission 66, Mr Peter Kell, Chief Executive Officer, Anglicare Diocese of Sydney, p 15

⁷⁸⁹ Submission 3, Ms Beverley Gollan, p 1

As a parent and a carer I do not feel that I should want my son to pass away before I do because of lack of services. Why should I? I know there are a lot of other parents and carers who feel the same way. Why should we?⁷⁹⁰

10.68 To overcome these difficulties, carers sought greater access to future planning services and called for the Government to increase supported accommodation placements. As previously noted, Ms Marshall said that families felt stressed and their health suffers when they do not have access to future planning services.⁷⁹¹

10.69 The author of Submission 110 also highlighted the pressing need for families to be able to plan to transition their children to supported accommodation:

If families knew they could plan for the future, then ironically many would actually care for their family member for longer, as they know there is an acceptable future solution. This would also simultaneously relieve stress and pressure from the family carers and significantly improve their quality of life and mental health. This would reduce costs to govt for services to the carers in addition to helping families enormously.⁷⁹²

10.70 Lyn, an older carer, also expressed dismay at the lack of future planning provisions and uncertainty in securing a supported accommodation placement for son.⁷⁹³

10.71 Care recipients are also concerned about the lack of future planning. The PDCN conducted a survey of people over 50 years-of-age with disability and found that their greatest fear was who would care for their children once their current carer can no longer able to do so.⁷⁹⁴

10.72 It was recommended that the provision of high-quality supported accommodation and access to free or low cost legal advice to allow some degree on futures planning would assist carers to make decisions about the future of their loved ones.⁷⁹⁵ Northcott Disability Services supported additional funding for future planning services and sought to ensure that these services access carers at younger ages, to help them start planning for the future earlier.⁷⁹⁶

10.73 The Committee was informed that ADHC is currently engaged in a Futures Planning project to assist older carers.⁷⁹⁷ It is hoped that this project will encourage ADHC to increase its services in this area.

⁷⁹⁰ Ms Robertson, Public Forum, 30 September 2010, p 24

⁷⁹¹ Ms Marshall, Public Forum, 30 September 2010, p 21

⁷⁹² Submission 110, p 1

⁷⁹³ Submission 29, p 3

⁷⁹⁴ Ms Robinson, Evidence, 3 September 2010, p 28

⁷⁹⁵ Ms Margaret Bowen, Chief Executive Officer, Disability Trust, Evidence, 3 September 2010, p 58 and Ms Anne-Marie Elias, Policy and Communications Manager, Council On The Ageing, Evidence, 3 September 2010, p 29

⁷⁹⁶ Submission 70, Ms Liz Forsyth, Manager, Service Department and Government Relations, Northcott Disability Services, p 5

⁷⁹⁷ Answers to additional questions on notice, Mr Moore, 9 August 2010, p 17

Committee comment

- 10.74** The Committee considers the lack of suitable future planning services as unacceptable. Not being able to access these services places unnecessary burden on all carers and is most acutely felt by older carers. The Committee commends the provision of a dedicated future planning service to assist older carers and notes that ADHC is currently engaged in a Futures Planning project. The Committee expects that the outcome of this project will encourage the delivery of extensive futures planning services for older carers.
- 10.75** The Committee's recommendations on planning are provided in Chapter 4.

Communication and navigating the disability service sector

- 10.76** Inquiry stakeholders felt that ADHC does not effectively communicate with carers. Poor communication can lead to confusion and distress for carers and people with disability. *Who Cares ...?* identified access to information about supports, services and assistance as one of the main challenges faced by carers.⁷⁹⁸

- 10.77** Ms Robinson told a story of carer who recently came into contact with ADHC and was given incorrect information:

... this morning [I had a phone call] ... from a person in relation to her mum, and her mum was about 48 and she had a physical disability that she acquired during her life. Her dad had been the carer for this person but dad had suddenly died so she rang the department. Someone told her she should ring the department. She rang the department to see if she could get some support in helping to support her and care for her mum during this intervening period while they figure out what their options are, and they were told, "No, your mother wasn't born with a disability so therefore we won't provide care". That is not exactly correct but it highlights that sometimes having one spot where you go to for information is fine but that information needs to be right.⁷⁹⁹

- 10.78** Clear communication and access points can assist carers to navigate the increasingly complex disability service sector. The Committee heard reports of carers becoming frustrated because of poor communication with ADHC and service providers. For example, Ms Jackie Dufty, carer to her partner, told the Committee she had great difficulty organising Home Care for her partner when they moved from Canada to NSW.⁸⁰⁰

- 10.79** Ms Amelia Starr, Senior Policy Officer, Disability Council of NSW, said that she was alarmed to hear parents say that they are exhausted by the system:

It is still very alarming and very hard to hear parents saying, "I have an extraordinary son or daughter with a disability. I know I am a good parent but I am extraordinarily exhausted with the system." Whether it is getting into the system, whether it is servicing the system, whether it is getting the right services, whether it is about being able to navigate linking to another system, there still seems to be a level of overlay that

⁷⁹⁸ Submission 33, p 8

⁷⁹⁹ Ms Robinson, Evidence, 3 September, p 30

⁸⁰⁰ Ms Jackie Dufty, Public Forum, 27 September 2010, p 13

parents and people caring for people with disabilities find just too hard to get through.⁸⁰¹

- 10.80** In its submission Carers NSW noted that poor communication resulted in carers having unrealistic expectations of services leads to poor futures planning.⁸⁰² Ms Katrakis highlighted that unrealistic expectations, particularly for supported accommodation services, is especially concerning for older carers.⁸⁰³
- 10.81** The Committee heard that ADHC needed to develop and disseminate more targeted information for CALD and Aboriginal carers. While ADHC has come some way in addressing the needs of these groups it was thought further action should be taken.
- 10.82** It has been suggested that ADHC's provision of information to carers could be greatly improved and the agency is working towards this goal. An ADHC Directorate is currently developing good practice guidelines to assist staff on effective communication and how to build effective productive relationships with families.⁸⁰⁴

Committee comment

- 10.83** The Committee understands the frustration of carers as they attempt to navigate the complex web that is the disability services sector. Their task is further complicated by poor communication and information provision by ADHC and funded organisations. ADHC and funded organisations should aim to provide clear, easy-to-understand information. The issues arising from the complexity of the disability services sector are not restricted to carers. The Committee's recommendations are included in Chapter 4 and Chapter 5.

Complaints handling and grievance mechanisms

- 10.84** Inquiry participants expressed frustration towards ADHC and funded organisations complaints handling and grievance mechanisms. Common frustrations included that clients were not aware of the appropriate processes and that issues were not thoroughly investigated.
- 10.85** Complaints handling is considered in more detail in Chapter 9. This section raises some specific issues raised by carers.
- 10.86** The author of Submission 56, carer to a person with very high support needs, questioned the comprehensiveness of ADHC's complaints handling procedures. The author referred to ADHC's complaints handling mechanisms as a 'joke' and was disappointed with the way his complaint was investigated.⁸⁰⁵
- 10.87** Carers NSW told the Committee that the increased availability of NGO-provided services and supports can compound confusion about which complaints handling and grievance

⁸⁰¹ Ms Amelia Starr, Senior Policy Officer, Disability Council of NSW, Evidence, 9 August 2010, p 29

⁸⁰² Submission 33, p 9

⁸⁰³ Ms Katrakis, Evidence, 9 August 2010, p 47

⁸⁰⁴ Submission 31, p 91

⁸⁰⁵ Submission 56, Name suppressed, p 5

mechanisms a carer should access.⁸⁰⁶ Ms Mason shared her harrowing experience complaining about the services provided by an ADHC-funded supported accommodation facility.⁸⁰⁷ Ms Mason was scathing of ADHC's complaints handling and grievance mechanisms:

ADHC's current policy and procedures and mechanism for complaint handling and grievances are totally flawed. It is of major concern that ADHC does not have the power to directly investigate the very services it chooses to fund. Both ADHC and non-government service providers are allowed to conduct their own internal investigations. Complaints can be directed to the NSW Ombudsman, who does not appear to have the legislative power, funding or resources to conduct a thorough police-style investigation into serious issues such as breaches of the NSW disability service standards, the use of restricted practices and non-compliance with practices, procedures and guidelines which govern these issues.⁸⁰⁸

- 10.88** ADHC recognised that its complaints handling processes are insufficient. Mr Moore told the Committee that "I do not think that we do well enough with complaints handling. I do not think that we get near as many complaints through our formal complaints mechanism as we would want."⁸⁰⁹ Mr Moore was clear that when making a complaint, clients are expected to first approach their service provider, if the client does not consider that the complaint has been properly investigated they can approach ADHC.⁸¹⁰

Committee comment

- 10.89** The Committee appreciate that carers find ADHC provided and funded service complaints processes and grievance mechanisms inadequate. This situation is disappointing as clients should expect to have their concerns thoroughly investigated and a resolution determined in a timely manner. The issues concerning the complaints processes and grievance mechanisms of ADHC and funded organisations are not restricted to carers. The Committee's recommendations are included in Chapter 9.

Impact on family relationships

- 10.90** The Committee heard that family relationships can become fraught when under the constant pressure of caring for a person with disability. Inquiry participants clearly elucidated their love and compassion for their family members but explained that there are extensive stressors on their relationships.
- 10.91** Parents told the Committee about the difficulties of caring for their child with disability. Their experiences highlight the strain that their partnerships and relationships with other children can be exposed to.
- 10.92** The case study below provides an example of the impact of being a person's carer on family relationships, brought before the Committee during its Public Forum.

⁸⁰⁶ Ms Katrakis, Evidence, 9 August 2010, p 55

⁸⁰⁷ Ms Carolyn Mason, Public Forum, 30 September 2010, p 16

⁸⁰⁸ Ms Mason, Public Forum, 30 September 2010, p 16

⁸⁰⁹ Mr Moore, Evidence, 9 August 2010, p 18

⁸¹⁰ Mr Moore, Evidence, 9 August 2010, p 18

Case study 12 - Ms Sayde Sarkis⁸¹¹

I am 32 years old and married with two young girls aged five and three. I am my younger daughter's primary carer. Her name is Charlize.. it is important for me to be very open and honest about what life has been like for me, my husband, our children, relatives, friends—friends who are not friends anymore because they do not understand our life and everything that comes with it. Charlize was diagnosed with several medical conditions and she has been left disabled as a result.

... Charlize was born with floppy airways, laryngomalacia and tracheomalacia as well, so she has been left with a tracheostomy... she was in ICU for four to five months... our life just went upside down from there. By nature I always saw that my glass was always half full, no matter how tricky it all got. To this day that is still how I see my world, even though it feels like our house was the only house that the tsunami hit and it feels like everything is tipped upside down.

We do not really recognise our surroundings or our feelings; we just know we feel very challenged in every single way. I do have to pose the question: what does support really mean to families facing disability with a loved one? ... How did it every get to feel that our family got so disconnected from society in terms of equality of rights, the right to a good quality of life or the right for our disabled daughter to receive even the basic therapies needed daily to help condition her whole body, the right to obtain special seating, bedding, transport, never mind her starting school or anything else other children get the chance....

When Charlize was 2½ years old I had a breakdown. I have not slept for 2½ years; I would sleep for maybe an hour and then her alarm would beep and I was up again. She is very dependent...

I have a five-year-old daughter as well who is healthy and she needs me just as much as Charlize does, if not more. She was only 20 months old when Charlize went into hospital. That year I felt like I had honestly lost both my children. My five-year-old just two days ago said to me, "Mummy, my heart is beating really fast. Can you feel my chest?" That, to me, is anxiety. I am not quite sure but I am definitely going to explore that.

10.93 The physical and emotional toll that caring can take on families can be devastating. As noted previously, Ms Marshall said that caring for her son has had negative repercussions on the health her family.⁸¹²

10.94 Ms Anne-Marie Elias, Policy and Communications Manager of COTA, told the Committee that couples who have a child with disability are more likely to separate than couples who do not.⁸¹³ Ms Elias further supported this assertion with statistics from the Australian Institute of Health and Welfare:

... In 1998, 99% of children with a disability aged 0-14 years lived in households. Of these children, 1,900 (or 72%) lived in a couple-parent family, and 83,700 (28%) lived in a single parent family. Bradbury et al. (2001), using the same data, estimated the disability rate for children aged 5-14 years in single-parent families to be almost double that found in couple families (7.3% compared to 3.8% respectively). This result

⁸¹¹ Ms Sayde Sarkis, Public Forum, 30 September 2010, pp 20-23

⁸¹² Ms Marshall, Public Forum, 30 September 2010, p 23

⁸¹³ Ms Elias, Evidence, 3 September 2010, p 29

suggests that 30.6% of children with a disability live in single-parent families, compared with an estimated 18.1% of children without a disability.⁸¹⁴

- 10.95** Ms Sharryn Llewellyn, Regional Manager of The Benevolent Society, offered similar anecdotal evidence of family breakups and general ill-health of carers.⁸¹⁵
- 10.96** The Committee also received evidence from carers and care recipients about the strain their marriage/life partnership can at times come under. The following case study from a participant in the Public Forum is an example of those strains.

Case study 13 - Ms Jackie Dufty⁸¹⁶

I am the partner of a person with a spinal cord injury at C5 level which renders him a quadriplegic. We have moved back to Australia from Canada on July 4 of this year. Before moving, with the assistance of Dan's parents who are living in Australia, we attempted to contact and set up home care... We found this process initially very difficult. Through many phone calls we were directed to and contacted ADHC with regards to setting up care for when we arrived. We were told that they would not send out any paperwork until we were in the country and we needed to meet with them to assess the specific needs. This requirement is unacceptable because the paperwork and assessment take time, leaving my partner without care when we initially arrived in this country.

We were able, however, to get respite organised for a three-week interim period. Respite said that they could promise us an hour a day. My partner's care involves close to five hours per day seven days a week. Three of these hours are involved with bowel care, which when we attempted to try to get more hours we were told that we would have to suck it up and do it ourselves. As the man who spoke earlier regarding the relationship with his spouse, it does not constitute a very good marriage when you are dealing with faecal issues with your spouse.

I feel that government agencies, ADHC included, lack interdepartmental communication and cooperation to provide an integrated approach to providing client care. Dan had to go into hospital. When he was ready to be discharged we learnt that respite care was no longer available. The hospital discharge planners, nurses and social work department said that he would have to go into a long-term aged care facility until the money was allocated from ADHC to set up home care. Dan has been out of hospital mentally well. Putting him into a long-term aged facility would not constitute a proper mental wellbeing. It would actually regress the situation, since he has been out of hospital since 1 April 2009. At that point we were told that we should have filled out the paperwork before returning to Australia. It is just a kind of nasty circle....

On a home care front, I feel government-funded home care agencies suffer from a lack of adequate funding and integration of services, affecting the quality of care they are able to provide. It is apparent to me that the quality of care that is being provided by home care agencies is lacking because there is not enough money being allocated to care agencies to provide the service...

⁸¹⁴ Answers to questions taken on notice during evidence, Ms Elias, 3 September 2010, p 1, quoting Australian Institute of Health and Welfare (AIHW) 2004, *Children with disabilities in Australia*, AIHW cat. no. DIS 38. Canberra: AIHW

⁸¹⁵ Ms Sharryn Llewellyn, Regional Programs Manager, Southern Sydney, The Benevolent Society, Evidence, 26 August 2010, p 26

⁸¹⁶ Ms Dufty, Public Forum, 30 September 2010, pp 13-14

It was stated many times by different home care workers that they did not feel comfortable with the level of training on the job. We had a home care agent perform a bowel routine who was not trained in the procedure and tore my partner's bowel wall.

As a side note on transportation, we live in a population pocket on the Central Coast which leaves us relatively isolated due to a lack of public transportation. There are very few accessible buses. The train stations are not fully accessible, as at some stations there is a ramp only on one side. So we can get on but we are unable to get off. We have to travel 20 minutes more down the line, then get back on the train to come back to where we live. As a young couple we like to go out and do things. That has put a little rift in us getting out and being a normal couple.

10.97 The author of Submission 88 told of the pressures her family have faced since her husband became a complete quadriplegic:

My husband has always worked full time, and in the years leading up to his accident was self-employed. I am no longer able to [a] work full time job due to the care which he needs, and caring for our seven year old daughter... It angers and frustrates me that we are good hard working people who are now struggling to stay afloat and pay our bills.

... I am banging my head against a brick wall – and quite frankly, I'm exhausted.⁸¹⁷

10.98 Mr Antony Varrall was concerned that his disability placed a burden on his wife:

... I am acutely aware of the fact that I am unable to help my wife like any normal husband and that I am somewhat of a burden to her, which does create a strain on the marriage. To preserve our happy marriage I have to be very careful to spread the workload between my friends, my wife, the family, Home Care and other people I pay for assistance. When I do not get that help, obviously I get very frustrated waiting and repeatedly asking, and the people who are helping me get fed up attending to my never-ending needs, et cetera.⁸¹⁸

10.99 Inquiry participants argued that the disability services sector needs to create and uphold a support system that does not exacerbate pressures on family relationships. Mr Herd explained the current system does not allow for normal family functioning:

We need to build a system of supporting people to have natural family relationships, which means I live with my partner and she assists me with some things and I assist her with other things. People with disability contribute to family life as well as receive from family caregivers. We need to not create familial caring as a ghetto. We need to try to make sure that people with a disability can live autonomous, independent lives so that family members can live independent, autonomous lives.⁸¹⁹

10.100 Mr Herd hoped that the findings of the current Productivity Commission inquiry into disability care and support would alleviate stress on families.⁸²⁰

⁸¹⁷ Submission 88, p 4

⁸¹⁸ Mr Antony Varrall, Public Forum, 30 September 2010, p 15

⁸¹⁹ Mr Herd, Evidence, 9 August 2010, p 31

⁸²⁰ Mr Herd, Evidence, 9 August 2010, p 31

Child relinquishment

- 10.101** The Committee received evidence of families being faced with the difficult decision to relinquish care of their child. While some families were threatened or forced to surrender care because of complaints to the Guardianship Tribunal, others told of relinquishing care as the final means to receive supported accommodation.
- 10.102** The Committee heard from one young family that had been threatened that they would have to relinquish care of their daughter to the Department of Community Services (DoCS). The author of Submission 71 was warned that her daughter could be removed from her home and her care subject to an inquiry by the Guardianship Tribunal.⁸²¹ The resulting DoCS investigation proved fruitless and her daughter was not removed from the home, however the experience was traumatic for all involved.⁸²²
- 10.103** Ms Mason spoke of the anguish her family suffered when ADHC referred the care of her daughter to the Guardianship Tribunal. Ms Mason claimed that the case against her was built on insufficient evidence and the Guardianship Tribunal allowed her to retain custody of their daughter.⁸²³ Ms Mason said of the experience:
- I hope that no other families are treated so inhumanly and put through the same fear, trauma, stress and sleepless nights that I have endured, not knowing whether or not I would be purposely removed from my daughter's life.⁸²⁴
- 10.104** Some carers relinquish care of their loved one with disability because they feel they can longer provide adequate care. Abandoning their child is seen as the final option available to ensure they receive support. Ms Robinson acknowledged that this was a long standing problem and although ADHC had come some way in addressing it people continue to feel compelled to abandon their child as a last resort.⁸²⁵
- 10.105** The issue can become particularly pressing for older carers who are unsure of who will care for their son/daughter when they are no longer able to do so. Ms Moloney referred to the situation as the 'The DOCS Dump' and said she had heartbreaking stories of families having to leave their child at respite because they could no longer cope and had no hope of securing supported accommodation.⁸²⁶
- 10.106** The following case study is from a submission author who has relinquished care of her son.

⁸²¹ Submission 71, p 1

⁸²² Submission 71, p 1

⁸²³ Ms Mason, Public Forum, 30 September 2010, p 16

⁸²⁴ Ms Mason, Public Forum, 30 September 2010, p 16

⁸²⁵ Ms Robinson, Evidence, 3 September 2010, p 26

⁸²⁶ Submission 13a, p 2

Case study 14 - Lyn⁸²⁷

Families of people with disabilities in desperate need of support are ignored or tossed from pillar to post. If only we knew that there was some provision for our precious children, if we knew that there was suitable supported accommodation for them when we can no longer care, then we would be able to continue to care for as long as possible.

As things stand, there is almost no provision of care for our sons and daughters; provision is minimal and almost nonexistent, the 'places' that they talk of are given to others...

So what can we do? We are left with one option; we are told that we must relinquish our children to the care of the state. This is the only way we will find supported accommodation for them. This is not always suitable accommodation either. The Advocacy groups tell us to do this and if we don't follow their directive, they say sorry we can no longer help you and they walk away. This is the way it is for us.

The system is crisis driven. Not planned in an orderly fashion giving consideration to the families or their sons and daughters with disabilities. The results are heartbreaking and devastating to say the least. This usually happens when a parent, often the mother dies. The person with disabilities will then lose everything: Their family, their home, their friends, their workplace and their community. This will happen in one foul swoop as they will be whisked away to a respite unit and possibly moved around for a period of time and then, when a group home is eventually found, it will surely be a long way from everything and everybody that they have known and trusted throughout their lives. The sad thing is that ADHC will have known of these situations for years. If only we could plan and ensure our children our housed and safe - close to home and their existing networks. If we could do this before we die? This is what we want. This is what or children deserve.

I have relinquished care of my son. I did this to save his life. I had no other choice.

People are in fact dying for lack of care. Families are desperate; their lives are horrendous as they battle just to get through another day. Please do not continue to close your eyes and ears, let us speak, let us tell you how many of us there are...

Committee comment

10.107 The Committee understands the concerns carers have about the pressure their role places on their family. The strain on carers was evident during the Inquiry. All Inquiry participants were ardent in their love for the care recipient, be it their child or partner, however it was apparent that caring is an all-encompassing activity that inevitably causes other relationships to somewhat fall by the wayside.

10.108 The Committee also acknowledges the significant challenges caring places on traditional partnerships. Having a partner take care of intimate personal needs unquestionably places unnecessary additional strain on relationships. It was sad to hear Inquiry participants describe themselves as a burden to their loved ones. All carers and care recipients wished to maintain their relationships, their request was to lighten and share their load through the provision of more services. The Committee would like to see ADHC extend services to people with disability and their carers to alleviate some of these pressures. Recommendations aimed at addressing carers concerns about service delivery are included in Chapter 4 and Chapter 5.

⁸²⁷ Submission 29, pp 4-5

10.109 The Committee recognises the terrible difficulty carers face when they consider the possibility of relinquishing care of their child. This decision is not made lightly and a service system that drives people to such a choice is unacceptable. To support carers, particularly older carers, it is imperative to provide adequate future planning services and supported accommodation options. Recommendations aimed at addressing carers concerns about service delivery are included in Chapter 4 and Chapter 5.

Older carers

10.110 Inquiry stakeholders raised concerns about the particular needs of older carers. It was widely accepted that the ageing population will have a significant impact on the provision of disability services. An older carer is defined as an older person (aged over 60) who provides unpaid care and support to a family member or relative.⁸²⁸ Older carers requested greater access to future planning services and voiced apprehension about the financial contribution they continued to make to their son/daughter with disability.

10.111 In 2003 the Australian Bureau of Statistics reported that over 35 per cent of carers were aged over 65 and that 29 per cent of informal carers were between the ages of 35-54.⁸²⁹ The recent Auditor-General's report on respite services stated that "... ageing carers present a growing challenge for government as their capacity to provide care diminishes over time. At least 13 per cent of carers in NSW, and more than 20 per cent in the Hunter and Southern regions, are over 65 years old".⁸³⁰

10.112 It was said that ADHC is facing a potential "tsunami" of middle-aged sons and daughters of ageing carers who are dying.⁸³¹ In its submission the NSW Division of the Australian Association of Gerontology cautioned of the additional pressures the ageing population will place on the health care system:

We note the mismatch between the increasing need for ageing and disability services and the available funding for these services. Inflation, increase in pay rates and other cost increases have further eroded the ability of - these services to meet the increasing demand for them, with consequences for service quality and timeliness. With increasing numbers of older people, a lack of quality and timely services will also increase pressure on the state funded health system.⁸³²

10.113 Ms Emily Caska, State Policy Coordinator, National Disability Services NSW, also warned that the Government needed to tackle these problems soon as the ageing population will have significant consequences on the role of informal care networks:

... effective resource allocation and service planning is vital given the growing demand pressures on the system, due in large part to changing demographic trends,

⁸²⁸ Answers to additional questions on notice, Ms Katrakis, 27 August 2010, p 3

⁸²⁹ Submission 51, p 4, quoting Australian Bureau of Statistics (2003) Disability, Ageing and Carers: Summary of Findings

⁸³⁰ Submission 51, p 4, quoting Auditor-General's report performance audit (2010) *Access to Overnight Centre-Based Disability Respite*, p 10

⁸³¹ Submission 15, p 2

⁸³² Submission 37, NSW Division of the Australian Association of Gerontology, p 1

improvements in medical technology prolonging life and ageing carers, leading to a decline in informal support networks.⁸³³

- 10.114** The Committee was informed that older carers have specific needs. Carers NSW stated that caring for a loved one, often with very little or no formal support, has a significant impact on the social, emotional, physical and financial wellbeing of older carers.⁸³⁴ Also, as carers face age-related issues their caring responsibilities do not necessarily diminish nor do they receive additional supports.⁸³⁵
- 10.115** As previously discussed, older carers were dismayed at the lack of suitable future planning services available. Service planning was seen as a means to ensuring older carers could plan for the transition of their loved one into a supported accommodation facility.
- 10.116** Aged carers were apprehensive about the financial pressure associated with their responsibilities. The authors of Submission 7, aged 77 and 79 who assist in the care of their 50-year-old daughter with disability, raised concerns about the expectation that they continue to financially support their daughter:

At present [our daughter] needs daily assistance with the many aspects of living independently. We, her aged parents (77 & 79) have to help her with shopping, medical, dental and money matters. She purchases some of the other necessary services at rates of \$27 per hour weekdays and up to \$53.60 per hour at weekends. Such a situation is plainly not sustainable.

To date, our plans for our daughter's independent future have been blocked due to our inability to obtain an appropriate care package...⁸³⁶

- 10.117** Issues associated with older carers from culturally and linguistically diverse (CALD) backgrounds were brought to the Committee's attention. COTA highlighted the plight of older CALD carers who have largely dealt with their child's disability of their own and now struggle to do so.⁸³⁷ Ms Elias used the example of the Italian community to illustrate this predicament:

There are huge numbers of Italian older people who are caring for children with disability... who have never interacted with the care system. They are quite a handful for anybody to take on. Some of the counselling and support the parents receive is the importance of assisting those kids to be as independent as possible because then that provides greater options of who can actually care for them in the event that the parents go.⁸³⁸

- 10.118** There were concerns about whether a grandparent caring for a grandson/granddaughter with disability has access to appropriate services. Ms Elias told the Committee that most grandparent carers do not receive respite and that her organisation finds it difficult to direct

⁸³³ Submission 32, Ms Emily Caska, State Policy Coordinator, National Disability Services, NSW, p 10

⁸³⁴ Answers to additional questions on notice, Ms Katrakis, 27 August 2010, p 3

⁸³⁵ Answers to additional questions on notice, Ms Katrakis, 27 August 2010, p 3

⁸³⁶ Submission 7, Name suppressed, p 1

⁸³⁷ Ms Elias, Evidence, 3 September 2010, pp 23-24

⁸³⁸ Ms Elias, Evidence, 3 September 2010, p 29

grandparent carers to suitable services.⁸³⁹ Ms Elias further argued that grandparent carers, particularly those from CALD backgrounds, require additional supports.⁸⁴⁰

10.119 In an effort to address the short-term needs of older carers it was recommended that they be offered more intensive in-home supports.⁸⁴¹ This action could however cause a conflict of interest between the needs of an ageing carer and the primary care recipient. Ms Margaret Bowen, Chief Executive Officer of the Disability Trust, referred to the possibility of older carers becoming dependent on the services that are provided to their son/daughter with disability:⁸⁴²

10.120 Ms Penelope Desazures, Executive Manager Community and Residential Services, Respite and Care Solutions at the Disability Trust, explained that her organisation provides services to a number of families where ageing carers have become dependent on the services that a supposed to be for their loved one:

They [aged carers] are looking typically at personal care support and respite support to bridge that gap from when they realise that they cannot cope on their own, but they are not ready to have their son or daughter move to a group home...we have a lot of situations where we are providing support to a 55-year-old person with a disability and to their 89-year-old mother who has dementia so that dad can go out and have two hours break in the middle of the week. There are quite different needs between the son and the mother, but you need to bridge those and try to work around that as well.⁸⁴³

10.121 As noted previously, long-term policy solutions included that the provision of high-quality supported accommodation and access to free or low cost legal advice to allow some degree on futures planning.⁸⁴⁴

10.122 ADHC acknowledged that the cohort of older carers will grow as the population of people with disability ages thus it needs to ensure appropriate services are available.⁸⁴⁵ Mr Moore told the Committee he recognised that there would be substantially increased demand for funding in this area as people with disability and their carers are living longer.⁸⁴⁶

10.123 Mr Moore provided the Committee with details of a number of strategies that ADHC has employed that focus on early intervention and long-term planning for older carers and their son/daughter with disability, including:

- case management services for ageing parents aged 60 years and over, and 45 years and over for Aboriginal carers;
- a Futures Planning project;

⁸³⁹ Ms Elias, Evidence, 3 September 2010, p 25

⁸⁴⁰ Ms Elias, Evidence, 3 September 2010, p 29

⁸⁴¹ Ms Margaret Bowen, Chief Executive Officer, Disability Trust, Evidence, 3 September 2010, p 58

⁸⁴² Ms Bowen, Evidence, 3 September 2010, p 58

⁸⁴³ Ms Penelope Desmazures, Executive Manager Community and Residential Services, Respite and Care Solutions, The Disability Trust, Evidence, 3 September 2010, p 58

⁸⁴⁴ Ms Bowen, Evidence, 3 September 2010, p 58 and Ms Elias, Evidence, 3 September 2010, p 29

⁸⁴⁵ Answers to additional questions on notice, Mr Moore, 9 August 2010, p 17

⁸⁴⁶ Mr Moore, Evidence, 9 August 2010, p 17

- supported accommodation models to meet the needs of people with disability who are ageing; and,
- Day Program initiatives targeting people with disability who are beyond middle age.⁸⁴⁷

10.124 ADHC also provides the Respite for Ageing Carers program and used funds from the Commonwealth-funded Disability Assistance Packages to allocate additional services to ageing carers.⁸⁴⁸

10.125 The Committee heard from two funded organisations about older carer programs. The Benevolent Society offers an aged carer program in southern Sydney. The program provides \$7,500 to each aged client and allows them to choose how they wish to allocate their money, within certain parameters, for example they can access respite services, receive personal care, and/or use community transport.⁸⁴⁹ Ms Llwynn said that that program had been successful because aged carers felt a genuine sense of involvement and inclusion in decision-making process.⁸⁵⁰

10.126 Carers NSW is a provider of the Support Coordination Program for Older Parent Carers, an ADHC-funded program, that aims to identify and engage 'hidden' older carers and assist families to build and strengthen social supports.⁸⁵¹ Carers NSW provides the program in South East Sydney, Orana/Far West and on the Mid North Coast. The organisation also provides an Aboriginal stream of this program.

Committee comment

10.127 The Committee recognises the significant contribution older carers play in the lives of people with disability and acknowledges their concerns about access to futures planning services and supported accommodation places, as well as apprehension over their ability to provide continued financial assistance to their loved ones.

10.128 The Committee is concerned that the Government has not put in place sufficient resources to assist older carers, particularly as it is anticipated that there will be a boom in this demographic in coming years. Although ADHC currently provides a range of programs targeting older carers it is alarming to note that a number of older carers, especially those from CALD backgrounds, are not effectively engaged with the formal support system.

10.129 The Committee considers it appropriate to extend in-home support services to older carers. Although there are concerns that such measures will impact negatively on the services provided to the primary care recipient, it may be possible to ensure the needs of both groups are met. The Committee suggests that ADHC investigate the viability of increasing the level of intensive in-home supports to older carers.

⁸⁴⁷ Answers to additional questions on notice, Mr Moore, 9 August 2010, p 18

⁸⁴⁸ Answers to additional questions on notice, Mr Moore, 9 August 2010, p 18

⁸⁴⁹ Ms Sharryn Llwynn, Regional Program Manager, Southern Sydney, The Benevolent Society, Evidence, 26 August 2010, pp 26-27

⁸⁵⁰ Ms Llwynn, Evidence, 26 August 2010, pp 26-27

⁸⁵¹ Answers to additional questions on notice, Ms Katrakis, 27 August 2010, p 4

Culturally and Linguistically Diverse (CALD) carers

10.130 Inquiry participants were apprehensive about the ability of the Government to identify and promote the needs of carers from CALD backgrounds. It has been estimated that 25 per cent of all carers in NSW are from CALD backgrounds.⁸⁵² In its submission Carers NSW stated that it had previously conducted a research project with Down Syndrome NSW and identified unique issues faced by this group including:

- cultural concepts of disability, illness, ageing are often different from mainstream Australian perception;
- language and communication barriers;
- stigmatisation of people with disability or illness; and,
- isolation from family supports.⁸⁵³

10.131 The Committee was told that the word “carer” is often not able to be translated into other languages. Ms Diana Qian, Executive Director of the Multicultural Disability Advocacy Association (MDAA), explained that the confusion over the concept of a "carer" discouraged people from accessing services:

... the word "carer" is problematic in multicultural communities. Again, it is not universal. Often family members who provide care will see that as part and parcel of being a mother, wife, husband, partner, brother or sister; it is part of being in a family support relationship. They do not necessarily identify themselves as a carer or even want to adopt that label.

If you structure a service system based on the expectation that people need to adopt a label before they become eligible for service then you exclude a range of people. If someone fronts up for services and they say they are a carer they will automatically be channelled into a range of carer support services. If they do not do that they might be excluded.⁸⁵⁴

10.132 The idea of “respite” can also be difficult to explain to CALD carers. Ms Liz Forsyth, Manager of Service Development and Government Relations for Northcott Disability Services, informed the Committee that the idea of respite being a break from the person with disability can be troublesome for certain groups:

Traditionally that [respite] is about the carer actually separated from the person they are caring for in order to give them a break. For some communities and cultures that is not having a break and actually separating them from that person is not a helpful way.⁸⁵⁵

⁸⁵² Multicultural Disability Advocacy Association and Carers NSW, *Working with Cultural Competence: Carers and the NSW Action Plan*, accessed 12 October 2010 <http://www.carersnsw.asn.au/storage/pdfs/conf2009/concurrent_sessions/Friday-Session%207/CulturalCompetence_May2009.pdf>

⁸⁵³ Submission 33, p 12

⁸⁵⁴ Ms Diana Qian, Executive Director, Multicultural Disability Advocacy Association, Evidence, 26 August 2010, pp 47-48

⁸⁵⁵ Ms Liz Forsyth, Manager, Service Development and Government Relations, Northcott Disability Services, Evidence, 26 August 2010, p 55

- 10.133** The stigma associated with disability within some cultural groups can cause further problems for people with disability and their carers. For example, Northcott Disability Services provided anecdotal evidence of a Vietnamese family that attempted to keep their child's disability a secret and were reluctant to access services.⁸⁵⁶
- 10.134** Inquiry participants offered a number of ideas to assist ADHC to communicate with CALD carers. The MDAA was adamant that before the government examines the role of carers in CALD communities it needs to scrutinise how the system can best support people with disability:
- If you are looking at supporting carers in those communities you first need to look at how the system can best support people with a disability. Only when they are supported can the word "carer" become redundant. They can have a meaningful family relationship with a person with a disability. They can be who they are—mother, wife or whatever—rather than purely basing their relationship on caring.⁸⁵⁷
- 10.135** This argument was supported by Carers NSW, who encouraged ADHC to first identify how carers and care recipients engage with the system and then create and fund a service system that adequately supports their needs.⁸⁵⁸ The MDAA also noted that service providers should build trust with clients to ensure they are comfortable accessing their supports.⁸⁵⁹
- 10.136** The Committee was informed that the NSW Government is committed to addressing the needs of people with disability and their carers from CALD backgrounds. ADHC recognised that there are a number of barriers to accessing its culturally diverse client base and has therefore implemented a flexible, innovative and responsive approach to service provision.⁸⁶⁰
- 10.137** ADHC developed an action agenda, *Valuing and Managing Diversity: Cultural Diversity Strategic Framework 2010-2012*, to better equip itself and funded organisations to meet the needs of clients from CALD backgrounds. The action agenda aligns with *Better Together* and *Stronger Together* and integrates cultural diversity into ADHC's core business.⁸⁶¹
- 10.138** Since 2006 ADHC has implemented a number of CALD specific projects that aim to address the needs of people with disability and their carers. These programs include:
- the CALD Innovative Accommodation Support Initiative;
 - funding to explore the meaning on 44 commonly used English terms in the disability sector and to develop fact sheets in 14 languages;
 - funding to create a DVD, in eight languages, about preparing a child with disability for school; and,
 - funding to develop an information kit, 'Raising Kids Together', that was translated into five languages.

⁸⁵⁶ Ms Anita Fisher, Senior Manager, Northcott Disability Services, Evidence, 26 August 2010, p 55

⁸⁵⁷ Ms Qian, Evidence, 26 August 2010, p 48

⁸⁵⁸ Ms Katrakis, Evidence, 9 August 2010, p 52

⁸⁵⁹ Ms Qian, Evidence, 26 August 2010, p 48

⁸⁶⁰ Submission 31, p 79

⁸⁶¹ Answers to additional questions on notice, Mr Moore, 9 August 2010, p 26

Aboriginal carers

- 10.139** Aboriginal carers are confronted with similar barriers to service provision as CALD carers. The Committee was told that Aboriginal carers found it difficult to access services due to different cultural understandings of disability-related terms, mistrust of government institutions, and lack access to services in regional areas. The Aboriginal Disability Network (ADN) asserted that it is important to recognise Aboriginal experiences of dispossession, removal of children and discrimination when discussing issues of interaction with the government.⁸⁶²
- 10.140** An obstacle to ADHC's provision of services to Aboriginal carers is that certain Indigenous communities do not experience disability in the same manner as mainstream society. The ADN noted that in some traditional languages the word "disability" cannot be translated, while in other communities there can be a stigma surrounding a 'bad karma' view of disability.⁸⁶³ Also, parents and carers are reluctant to seek help because they fear being judged as bad parents.⁸⁶⁴
- 10.141** Various Inquiry participants noted that indigenous communities often have issues with the idea of respite. Mr Damian Griffis, Executive Officer of the Aboriginal Disability Network, explained that Aboriginal carers are often hesitant to use centre-based respite services:
- Many carers the ADN meet express concern or a deep reluctance to use respite services. This is because it may conjure connotations to old days of forced removal. The notion of having the person you care for taken away to a respite centre sits uncomfortably with many Aboriginal carers. Furthermore the idea of a centre based approach to respite may also be viewed as being culturally inappropriate by some Aboriginal carers. In addition the respite centre itself may be some distance away from home, even possibly in a different town or region which will also cause reluctance.⁸⁶⁵
- 10.142** Ms Forsyth said that she had encountered similar issues when working with Aboriginal families.⁸⁶⁶ Also, Ms Anita Fisher, Senior Manager, Client Programs for Northcott Disability Services, referred to the fact that the term "respite" cannot be translated into indigenous languages.⁸⁶⁷
- 10.143** Another concern was the lack of available services outside metropolitan and major regional centres. Out-of-home respite can be located quite a distance from people with disability, so they are separated from their carers, extended families and communities. Mr Griffis suggested that the Government support Aboriginal carers through the use of in-home or community-based respite services to discourage the practice of taking people away from their communities.⁸⁶⁸

⁸⁶² Submission 97, Aboriginal Disability Network, p 2

⁸⁶³ Submission 97, p 3

⁸⁶⁴ Mr Damian Griffis, Executive Officer, Aboriginal Disability Network, Evidence, 27 September 2010, p 36

⁸⁶⁵ Answers to questions taken on notice during evidence, Mr Griffis, 27 September 2010, p 2

⁸⁶⁶ Ms Forsyth, Evidence, 26 August 2010, p 55

⁸⁶⁷ Ms Fisher, Evidence, 26 August 2010, p 55

⁸⁶⁸ Answers to questions taken on notice during evidence, Mr Griffis, 12 October, 2010, p 2

10.144 The ADN called for greater recognition of extended family and community members who provide respite. It was suggested that community groups who provide respite should be receive subsidies and greater resources to assist in their endeavors.⁸⁶⁹

10.145 The provision of services to Aboriginal people can be further complicated because carers and other family members may also have a disability. Mr Griffis said that "the ADN regularly meets with carers who have disability, often acquired through the demands of being a primary carer. Furthermore it is not uncommon for the ADN to meet families that have several members with disability."⁸⁷⁰

10.146 As previously discussed, it is necessary to consider how cultural groups, such as Aboriginal carers, engage with the current service system before developing additional programs and supports. Programs need to be suitably flexible and dynamic to meet the needs of Aboriginal carers. Ms Katrakis explained that different approaches to service provision are required depending on circumstances:

Responding to culturally diverse carers is very difficult ... you really need to look at how those services are identifying carers and [how] care recipients are engaging... part of the answer [is], having information in relevant languages ... but it is about getting into the communities and really working with those communities ... [i]t is about looking at what that service mix might be. Sometimes a brochure or an Aboriginal-looking brochure about how to get services is not enough; it needs to be more at the coalface and to have appropriately trained and responsive services on the ground.⁸⁷¹

10.147 Carers NSW has taken a number of steps to address barriers to support for Aboriginal carers. These initiatives include:

- providing an Aboriginal stream of the Support Coordination Program for Older Parent Carers;
- consulting with older Aboriginal carers to create a training DVD as part of the Aboriginal Carers Health and Wellbeing Training Program; and,
- revising the Koori Yarning Resource Manual, a guide for service providers on how to work with Aboriginal carers in a culturally appropriate way.⁸⁷²

10.148 Ms Katrakis described the Aboriginal component of the Support Coordination Program for Older Parent Carers as a success.⁸⁷³ Ms Katrakis noted that the program received half the funding of the generic component, employed Aboriginal and non-Aboriginal staff, and worked with communities and service providers to the best outcomes for carers.⁸⁷⁴ The ADN praised Carers NSW for its efforts to support Aboriginal carers.⁸⁷⁵

⁸⁶⁹ Answers to questions taken on notice during evidence, Mr Griffis, 12 October, 2010, p 2

⁸⁷⁰ Answers to questions taken on notice during evidence, Mr Griffis, 12 October, 2010, p 2

⁸⁷¹ Ms Katrakis, Evidence, 9 August 2010, p 52

⁸⁷² Answers to additional questions taken on notice, Ms Katrakis, 27 August 2010, p 4

⁸⁷³ Ms Katrakis, Evidence, 9 August 2010, p 53

⁸⁷⁴ Ms Katrakis, Evidence, 9 August 2010, p 53

⁸⁷⁵ Answers to questions taken on notice during evidence, Mr Griffis, 12 October, 2010, p 2

Committee Comment

- 10.149** The Committee notes the concerns of Inquiry participants about the specific, often unmet needs of CALD and Aboriginal carers. These groups play a significant role in the lives of people with disability and are entitled to the same level of services and supports as mainstream carers. The Committee acknowledges that there are often difficulties reaching these groups because of cultural differences, however the Government should continue to make a concerted effort to reach out and support CALD and Aboriginal carers.
- 10.150** The Committee accepts that the Government needs to evaluate the way in which people from CALD backgrounds and/or Aboriginal people engage with the disability service system before it makes further decisions regarding carers from these groups. For recommendations concerning communication and information dissemination to people from CALD backgrounds and Aboriginal people see Chapter 4 and Chapter 5.

Chapter 11 Disability services staffing

This Chapter examines issues regarding disability services staff who are paid for or funded by Ageing, Disability and Home Care (ADHC). Issues such as attracting staff to the carer profession, as well as staff training, retention and pay, are canvassed.

The number of staff

11.1 In 2010/11 ADHC 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.⁸⁷⁶ The Committee acknowledges that the agency is one of the largest human services organisations in NSW, and that its sheer size indicates a significant commitment to disability services by the NSW Government.

11.2 Mr Jim Moore, Chief Executive of ADHC, outlined to the Committee some of the staffing characteristics of the organisation:

ADHC has a workforce of around 14,000 people. The vast majority of those work as care workers in a group home network we run where we have over 2,500 clients being helped by about 3,500 staff.

We have a Home Care Service of NSW, which is a statutory authority that effectively is integrated into the agency. It has 4,500 staff. We have a set of large residential services. We have got about another 2,500 nurses in it. We also have a therapy case management workforce of around 8,000.⁸⁷⁷

11.3 ADHC also funds around 900 local government and non government organisations to provide similar services across NSW. There is no clear data to indicate how many people work in the sector in these organisations. Nevertheless, it is evident to the Committee that the disability and ageing sector is a significant employer in the State.

11.4 The Committee heard that the management of the disability staff workforce is a huge task, especially when a care organisation is endeavouring to provide a flexible service. For example, Ms Bowen of the Disability Trust told the Committee:

Last year the Trust delivered 83,188 hours of respite and in-home care, but that was delivered in 27,628 episodes of care using about 200 staff over different durations of shifts, over different shift penalties. What that means is that the rostering, financial management, human resources and workforce development is incredibly complicated. That is a new thing. In the old days, funded services just opened their doors and said, "This is what you will receive". The management of those sorts of systems is not complex. Delivering flexible service systems is incredibly complex.⁸⁷⁸

⁸⁷⁶ Submission 31, Mr Jim Moore, Chief Executive, ADHC, p 6

⁸⁷⁷ Mr Moore, Evidence, 9 August 2010, p 5

⁸⁷⁸ Ms Margaret Bowen, Chief Executive Officer, The Disability Trust, Evidence, 3 September 2010, p 55

The importance of good staff

- 11.5** The Committee understands that having a family member in need of support can be a highly emotional and physically exhausting experience. Hence the importance of well trained, professional, caring staff cannot be over emphasised. Ms Epstein-Frisch, of Family Advocacy, explained to the Committee that sometimes carers do not understand the huge influence they can have on a person's and their family's life:

Families often report that difficulties arise when their family member with a disability is supported by staff who are not attuned to the person. Many services seem reluctant to acknowledge the impact of the knowledge, skills and qualities of staff on the person being supported.

When staff are not attuned to the needs and communication of the person with a disability, difficulties can arise and can be expressed as OHS concerns. As a result, the person with disability is then penalised by restriction in service or opportunities. Families want services to acknowledge when difficulties arise as a result of factors in staff. Families stress that the person with disability should not be blamed and penalised for these staff failings.⁸⁷⁹

- 11.6** The Committee is also aware that people appreciate support that is run well with caring staff. For instance, in her submission Ms Shields shared with the Committee her experience with respite care for her son, and the implicit value of caring, long term staff:

There is one service that I would not give up and that is centre-based respite ... Now, however, ADHC runs an excellent respite facility in my local area, with experienced, caring and long term staff who have come to know their clients and families. I can tell you that almost everything that has made my life worth living in the past ten to fifteen years has happened because my son has been in respite.⁸⁸⁰

- 11.7** Similarly, Mr Antony Varrall recounted to the Committee his experience with a home care provider, and the important service that it provides:

On the positive side, we have been most appreciative of our home care provider, which has always done its best to provide high-quality carers on the days and at the times that we requested. There has never been a problem on the rare occasions we have requested that it provide a different carer due to our unhappiness, for some reason or another, with the carer that it has provided. Home care is a wonderful and extremely important service, without which many disabled people like me could not survive in a home situation.⁸⁸¹

- 11.8** The author of Submission 40 also praised her care workers and said that most had been lovely with a genuine desire and ability to help.⁸⁸²

- 11.9** Ms Bernadette Moloney commended the carer system at the Kingsdene Special School and Residential Services, where three or four clients are assigned one carer.⁸⁸³ Ms Moloney also

⁸⁷⁹ Submission 23, Family Advocacy, p 2

⁸⁸⁰ Submission 15, Ms Estelle Shields, p 5

⁸⁸¹ Mr Antony Varrall, Public Forum, 30 September 2010, p 5

⁸⁸² Submission 40, Name suppressed, p 1

⁸⁸³ Ms Bernadette Moloney, Public Forum, 30 September 2010, p 18

praised her son's former care workers at the St Anthony's respite service for their high-quality care.⁸⁸⁴

11.10 The author of Submission 43 extolled the behavior of the care workers as his brother's group home. The author noted that he witnessed and admired the staff's professional attention to detail and love in delivering quality care.⁸⁸⁵

11.11 Mr Killeen has been a Home Care service user for the last 22 years, and explained to the Committee that some of the staff had been helping him for 18 years. He explained further:

I have been using Home Care, for personal care, for some 22 years now. Some workers have been with me for 18 years ... I would not survive in the community without Home Care's personal care support service and other programs in Sydney that run this essential service. I find that the people who come to me are fairly well trained and do their job. I am not saying that everything is perfect. I am not saying that there is not an initial hiccup in the service, where sometimes someone does not turn up. The coordination might not have rostered someone on, or something like that. But overall, I find it reasonably good. That is my perspective. It provides services to lots of people.⁸⁸⁶

11.12 Mr Moore explained to the Committee that an independent survey had found positive results in regard to customer feedback:

But I put alongside that that the Home Care Service of NSW does make a virtue of being the HACC provider who steps into the space where no-one else will go. That often includes late-night, out-of-hours servicing. I also think that, as an organisation that has 4,500 staff and is a \$200 million a year operation, not everything will go perfectly. But the Home Care Service does an independently conducted biennial consumer customer satisfaction survey. The results for the last one are just in, and it attracts a 95 per cent satisfaction rate. So, yes, I know there are some things that have not gone well, but there has now been a long history of Home Care being in the mid to upper levels in terms of client satisfaction.⁸⁸⁷

Committee comment

11.13 The Committee recognises the high value that people with disability and their families place on carer staff that are highly professional, experienced and caring. The Committee appreciates and acknowledges the many thousands of hard working, caring employees who work in the ageing and disability support sector. The positive comments that persons with a disability and their families had towards their carers were often the only positive comments that were received by the Committee.

11.14 The Committee is aware that ADHC has recently introduced Local Carers Awards, for carers who have made an outstanding contribution to caring for someone.⁸⁸⁸ The Committee

⁸⁸⁴ Submission 13a, Ms Bernadette Moloney, p 1

⁸⁸⁵ Submission 43, Name suppressed, p 2

⁸⁸⁶ Mr Greg Killeen, Senior Policy Officer, Spinal Cord Injuries Australia, Evidence, 26 August 2010, p 34

⁸⁸⁷ Mr Moore, Evidence, 27 September 2010, p 4

⁸⁸⁸ ADHC, *Awards for outstanding Local Carers, Media Release*, 20 October 2010, (accessed 21 October 2010) <www.dadhc.nsw.gov.au/dadhc/Media+Releases/20101020+Localcarers.htm>

considers that it would be worthwhile for ADHC to establish a similar cross-sector employee recognition program, so that clients can nominate an exceptional employee for appropriate recognition.

Attracting and Retaining Staff

11.15 The first part of this Chapter highlighted the large number of employees in the care sector. Nevertheless, the Committee also heard a considerable amount of evidence that attracting and retaining staff is a significant issue. Reasons given include:

- poor pay
- difficult or unpleasant work
- lack of career pathways
- inadequate training.

11.16 This section of the Chapter discusses the difficulty in attracting workers to the sector, and then retaining them once they are there.

Attracting staff

11.17 Warringah Council explained to the Committee that in its experience, attracting and retaining passionate, dedicated workers is a common issue across service providers:

Attracting and retaining passionate, quality dedicated workers to the disability sector are common issues for service providers which impact on their service outcomes. Skilled, strategic management staff are also difficult to attract and retain and greatly impact on the development of services ...⁸⁸⁹

11.18 Similarly, Ms Hewitt of Futures Alliance and Uniting Care Disability, explained to the Committee that, as a service provider, it was finding it increasingly difficult to recruit staff. She observed that attracting people to the profession, especially young people fresh out of school, was problematic:

We as service providers find it increasingly difficult to recruit staff into positions. I think there is both the issue of the types of salaries and conditions that people are provided as well as the very nature of the kind of work that we are asking people to do, particularly when you get a cohort of younger people who are coming out expecting that they are going to work in nice clean jobs, that they are going to travel a lot and things like that, and that is not the lot of somebody who is a paid carer. Those are the kinds of things that we as service providers we are constantly facing, how to both reward our staff in the way that we need to, but attract good staff to those kind of positions, and attract staff who are fit and healthy enough themselves. It is often women who have raised their children who feel the desire to become a carer, which is

⁸⁸⁹ Submission 108, Ms Louise Bannerman, Disability Development Officer, Warringah Council, p 4

wonderful, but they are often the people who are not physically in a position to do some of the work that we are requiring them to do.⁸⁹⁰

11.19 Mr Kell of Anglicare also referred to the difficulties in attracting and retaining staff:

It is becoming increasingly difficult to find appropriately skilled and qualified staff for aged care and disability support programs and to properly remunerate such staff.⁸⁹¹

11.20 National Disability Services (NDS) is the national industry association for disability services, representing over 650 not-for-profit organisations. Its submission highlighted the need for a skilled expanding workforce, and estimated that there will be a need to fill 38,000 vacancies in the sector in the five years to 2014:

In light of the growth experienced under the first five years of *Stronger Together*, one of the key lessons learned was the need for a skilled, dedicated and expanding workforce to deliver high quality services that achieve quality outcomes for people with a disability, their families and carers in NSW. The ever growing demand for services and movements within and out of the sector (resulting from retirement, change and churn), only compound this need.

In 2009-10, in its carriage of the Workforce Recruitment Project, NDS undertook a disability and home and community care workforce projection exercise.... That exercise identified a need to fill 38,000 vacancies in the 5 years to 2014 across frontline support and professional roles, as well roles in facilities and transport, administration and management.⁸⁹²

11.21 Mr Moore outlined to the Committee that there is a labour shortage, which has been particularly acute in the disability care sector:

... we need to solve the issue of where the workforce is going to come from and how we are going to get the right skill and quality of workers. In 2007 we were witnessing a significant labour shortage within the specialist disability system. We know that specialist disability services are not generally the sector of choice for employees and that there are a lot of employees, prospective employees, who choose care work but they tend to choose care work in the aged care sector rather than in the specialist disability service sector.⁸⁹³

11.22 Dr More, Manager, Workforce Initiative, National Disability Services, explained to the Committee that there is a lack of understanding in the community about what working in the disability and ageing support sector involves:

We found very quickly that the sector does not have the visibility, that it does not have the understanding of what work in the sector involves, and that there are career pathways and career opportunities within it, and multiple careers. So, we needed to develop an initiative to open up and shift perceptions that were blocking people joining the sector. Most fundamentally, that can be summarised as people believing

⁸⁹⁰ Ms Jo-Anne Hewitt, Chairperson, Futures Alliance, and Director, Uniting Care Disability, Evidence, 3 September 2010, p 49

⁸⁹¹ Submission 66, Anglicare, Diocese of Sydney, p 19

⁸⁹² Submission 32, National Disability Services, NSW, p 38

⁸⁹³ Mr Moore, Evidence, 9 August 2010, p 4

that the work done here is not professional, it is done by volunteers, and that it used to be done by people who are saints ...⁸⁹⁴

11.23 Another complicating factor in terms of staff recruitment is the physically demanding nature of the work. Some care workers are expected to complete strenuous tasks. The author of Submission 106 called for all care workers to have a regular medical examinations and functional assessments to make sure they are capable of carrying out their roles.⁸⁹⁵

11.24 The often physically demanding nature of care work also has implications for the occupational health and safety of workers in the profession.

11.25 Anglicare identified that not only was an increase in the base pay rate required to attract staff, the industry needed more defined career pathways:

Increased funding is required in order to raise the base wage rate in order to attract the appropriate people with skills into the sector. Attracting qualified personnel is reflected in the remuneration offered and as such Government must increase funding accordingly. To operate to best practice standards, Not-for-Profits must seek to be Employers of Choice and to do this must offer better conditions, opportunities and reasonable, comparable pay rates. This will encourage younger qualified people to see aged care and disability support as a real career option.⁸⁹⁶

11.26 With its long experience in providing care, Anglicare raised the following considerations about attracting and retaining staff to the profession:

- Providing defined career pathways, particularly for young workers entering the sector. This cohort could be attracted by training opportunities that would provide a career pathway.
- Many people coming into the aged care workforce and disability support are mature staff and perhaps entering a second or third career.
- Recognition of overseas qualifications - can support be offered until they are accredited and giving opportunities to work their way through the care system?
- Tapping cohorts of potential employees, such as women with young children.
- Providing more flexible working hours and child care support.⁸⁹⁷

The workforce recruitment strategy

11.27 In its submission ADHC outlined a program to attract staff to the sector, known as the Workforce Recruitment Strategy. It explained that the purpose of the strategy is 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 strategy has received the following funding allocations:

⁸⁹⁴ Dr Kate More, Manager, Workforce Initiative, National Disability Services, Evidence, 9 August 2010, p 39

⁸⁹⁵ Submission 106, Name suppressed, p 1

⁸⁹⁶ Submission 66, p 19

⁸⁹⁷ Submission 66, p 19

- \$3.3 million, one year (2008 – 2009)
- \$1.0 million, one year (2009 – 2010)
- \$4.273 million, two years (2010 - 2012)⁸⁹⁸

11.28 ADHC explained that the strategy is targeted at three primary groups within the community: parents returning to work; education leavers; and career changers. There are two sub projects in the strategy – carecareers and project ABLE. Both of these projects are explained in the following sections.

The Carecareers program

11.29 Carecareers is an internet based recruitment initiative with an associated fully staffed Careers Centre. It has been established to help job seekers and hiring managers in the community care and disability sector to meet their recruitment needs. The program is funded by ADHC and implemented by National Disability Services. Dr More explained to the Committee that the underlying rationale for the Carecareers program was to attract potential employees to the sector:

So the biggest job before we even tried to create training opportunities and skilling a workforce that we attract into the sector is to get them to see it as desirable in the first place. That is fundamentally, in a nutshell, what carecareers has been about. But in terms of implementation, it has also allowed us an opportunity to understand the pressure points that organisations experience in terms of recruitment and attraction and retention, and to respond to those and provide some very skilled recruitment expertise directly into organisations that are moving to attract people. It is also allowing us to have direct relationships with respect to candidates.⁸⁹⁹

11.30 In its submission NDS further elaborated on carecareers and the number of people who have participated in the website:

carecareers has achieved significant early success. In just 6 months, it has attracted over 160,000 individuals to its recruitment portal, 5000+ job applications and more than 3000 suitable candidates into its talent pool. It has also secured the participation of 99% of the sector's employers, advertised more than 1300 jobs, and generated recognition and a supportive community for those already working in the sector.⁹⁰⁰

Project ABLE

11.31 Project ABLE is another program funded by ADHC and implemented by NDS. It is a work placement program, providing an opportunity for secondary school students and allied health tertiary students to be placed with a service provider and gain experience in the field. As part of the program secondary school students will be able to obtain a Certificate III in either

⁸⁹⁸ Submission 31, p 96

⁸⁹⁹ Dr More, Evidence, 9 August 2010, p 39

⁹⁰⁰ Submission 32, National Disability Services, NSW, p 38

Disability or Community Services, and tertiary students will gain a three month paid position.⁹⁰¹

- 11.32** ADHC reports that to date, 320 secondary students from 26 schools (public and private) have enrolled in the program, and that four disability and community care organisations have signed on to host students. ADHC also notes that the project ABLE concept is transferable to other key areas of workforce interest, such as Aboriginal and Torres Strait Islanders and Culturally and Linguistically Diverse populations, and that plans are in development for these two project components in 2010-12.⁹⁰²

Committee comment

- 11.33** It became evident to the Committee that there are a multitude of reasons why care providers are experiencing difficulty in recruiting staff. These included rates of pay, working conditions and a lack of career structure. The next section of this Chapter focuses on workforce retention.
- 11.34** The Committee supports the good work of the Workforce Recruitment Strategy, and notes that proactive recruitment work by ADHC and non-government service providers will assist in attracting people to the profession. The Committee further notes that funding for this program is not allocated after 2012, and recommends that six months prior to the end of current funding, the strategy is reviewed with a view to extending it for a further two years.

Recommendation 51

That six months before the end of funding of the Workforce Recruitment Strategy, ADHC, with the assistance of stakeholders, review the strategy in consultation with stakeholders, with a view to extending it for a further two years.

The retention of staff

- 11.35** The Committee also heard evidence that not only are service providers finding it difficult to recruit staff, keeping them in the profession is a challenge.
- 11.36** The Physical Disability Council and Council on the Ageing together submitted that workers are leaving the community sector due to low wages, and that there is a lack of younger people entering the industry. They submitted to the Committee:

It is a fact that workers are leaving the community sector due to low wages and being redeployed in other industries. There is a lack of younger people entering into the community service industry due to poor remuneration and a lack of an appropriate career path. As the population ages there it follows that there will be fewer volunteers available and this will directly impact on organisations' ability to deliver services, especially Meals on Wheels and Community Transport, whose volunteer force are ageing. If this reducing number of volunteers is not addressed, services will close and

⁹⁰¹ National Disability Services, *News – A call to recruit younger skilled workers – Project ABLE launches*, 23 March 2010, (accessed 15 October 2010) <www.nds.org.au/news/article/627>

⁹⁰² Submission 31, p 96

ADHC will have to become the major service provider in the State as not for profit will become unsustainable without workers and volunteers.⁹⁰³

- 11.37** Similarly, NDS noted that greater consideration is needed to be given to workforce planning, retention, training and mobility:

NDS contends that the sector's ability to attract and retain a skilled workforce is also dependent on an extension of training, a focus on staff retention and development, the existence of multiple career pathways, ongoing strategic workforce planning and competitive remuneration. The sector's ability to secure an appropriately skilled workforce also depends on the capacity of employers to make their recruitment more efficient, compelling and competitive in relation to the open market. NDS promotes the continued investment in talent attraction and recruitment via *carecareers* but also recommends greater consideration be given to workforce planning, retention, training and mobility.⁹⁰⁴

- 11.38** The Association for Children With a Disability reported that the high turnover of care workers is detrimental to the health of children with disability. The Association noted that with a high carer turnover, families face a 'revolving door' of different paid carers. Not only is this detrimental to the child, it does not allow for the paid carers to ever build a rapport with the child or a sense that the paid carer is contributing to the child's development in the long term.⁹⁰⁵

- 11.39** This 'revolving door' of carers can also be stressful for the families involved. Submission 13 shared their frustration of having a continual turnover of case managers:

As my son nears the end of school years, I have been reintroduced to the saga of the ADHC caseworker. Since the beginning of this year I have attended 3 meetings with ADHC representatives and I am yet to see the same person twice. On separate occasions I have spoken to 3 different people who have introduced themselves as my son's new caseworker. I have spent 2 hours with one of these caseworkers providing a profile of my sons needs post school. I have never spoken to the same person twice. ... ADHC seems to play a continual game of musical chairs and it is near impossible to have more than 2 conversations with one person before they have moved on and a new person has taken over their position....⁹⁰⁶

- 11.40** The Benevolent Society explained to the Committee that it had managed to reduce its staff turnover from 25 per cent to around 14 per cent over a two year period:

In terms of turnover we are looking mostly at coordination level and case management level staff. Our most recent staff survey told us that we have reduced our turnover from around 25 per cent to about 14 per cent over a two-year period, which we are quite pleased with. We have volunteers in our direct service delivery and again we support them quite closely. We have a couple of positions within our head office, so to speak, that support volunteer recruitment and at the local level we work closely

⁹⁰³ Submission 51, Physical Disability Council of NSW and Council on the Ageing NSW, p 10

⁹⁰⁴ Submission 32, p 38

⁹⁰⁵ Submission 96, Association for Children With a Disability NSW, p 22

⁹⁰⁶ Submission 13, Ms Moloney, p1

not only with the volunteers themselves but also with the Home and Community Care volunteer programs in our region.⁹⁰⁷

Committee comment

- 11.41** The Committee is concerned about the high turnover of staff, and acknowledges the distress that this can cause for clients. The Committee recommends that ADHC convene a cross sector working party to develop a workforce retention strategy.
-

Recommendation 52

That ADHC convene a cross sector working party to develop a workforce retention strategy. This strategy should include, but not be limited to, issues of:

- career pathways
- professional development
- working conditions
- appropriate remuneration levels.

That the strategy, including recommendations and actions, is published on ADHC's website.

Differing pay rates between government and non-government providers

- 11.42** ADHC provides funding for non-government organisations to deliver care services and also is a direct service provider itself. The Committee received evidence that carers employed by ADHC receive a higher rate of pay compared to staff doing the same work but employed by a non government provider. Mr Moore suggested that non-government employees get paid a salary some 20 to 25 per cent less than their government carer counterparts.⁹⁰⁸
- 11.43** Non-government service provider Northcott Disability Services explained to the Committee this pay equity difference has created a barrier to employing staff:

In the disability system, ADHC is both the funding body and a provider of some direct services, for example: centre based respite, case management, therapy. However, nongovernment organisations (NGOs) are often funded at a lower rate than ADHC services for providing the same service. As a result of this, staff working in NGOs received lower rates of pay than those working in ADHC services. This can serve as a barrier to attracting skilled staff to the NGO sector. As such, Northcott supports consistency in levels of funding for government and NGO provided services. Alternatively, ADHC could cease to provide those services which are able to be provided more efficiently and effectively by the NGO sector, and use the savings realised to increase services.⁹⁰⁹

⁹⁰⁷ Ms Sharryn Llewellyn, Regional Programs Manager, The Benevolent Society, Evidence, 26 August 2010 p 30

⁹⁰⁸ Mr Moore, Evidence, 9 August 2010, p 8

⁹⁰⁹ Submission 70, Northcott Disability Services, p 5

- 11.44** Mr Maher told the Committee that the wage disparity between the two sectors has meant that wages are simply too low to attract people to the industry:

The obvious difference is that the wages that are paid to people working in ADHC-operated services are significantly higher than those for people who are working in ADHC-funded services. ...But in our sector, the average wage is, I understand, about 60 per cent of the national average wage for people working as carers in the disability sector in NSW. That is just too low, and we do struggle to attract people to the sector.⁹¹⁰

- 11.45** Mr Le Breton, Chief Executive Officer, Disability Enterprises Leura, told the Committee that his staff are paid less than ADHC staff, and that they deserve pay equity:

I believe our staff deserve more. I am not saying that the DADHC staff deserve less. This is an issue nationally about the disparity between the current award that is being paid to people within the SACS award. ... Generally speaking, across this whole industry the pay is very, very meagre.⁹¹¹

- 11.46** The Committee heard that there is currently a pay equity case about these different levels of pay before Fair Work Australia. Mr Moore explained to the Committee:

In the non-government sector there is a pay equity case that is now in front of the Fair Pay Commission [now called Fair Work Australia]. That pay equity case is, on the way it has been put, likely to see a very substantial increase in wages. As part of the preparation for that there is a collaborative effort among the sector players—the employers, the unions and the funders like the Government—to try to understand the exact nature of the totality of the workforce so that we can then begin to understand what the financial and other consequences of that workforce would be and what the pay equity case would be. Also, we can begin to think about how we can respond to that rather than simply as an issue of an increase in wages.⁹¹²

- 11.47** Mr Maher explained that National Disability Services is fully supporting the pay equity case. However, he noted that it will have to be funded:

We generally work under the *Social and Community Services Award*, which is one of the awards that will be covered by this pay equity case that is being taken before Fair Work Australia. We are fully supporting that: we are united. I have to say everyone is united in that on the basis that when it comes in it is going to have to be funded.⁹¹³

- 11.48** In regard to salary levels Mr Moore summarised for the Committee the findings of the Productivity Commission 2009 inquiry into the not-for-profit sector. In essence, wages in the not-for-profit sector, which employs a significant number of ageing and disability carers, will have to increase:

⁹¹⁰ Mr Patrick Maher, Chief Operating Officer and State Manager, National Disability Services, Evidence, 9 August 2010, p 39

⁹¹¹ Mr John Le Breton, Chief Executive Officer, Disability Enterprises, Evidence, 30 September 2010, p 10

⁹¹² Mr Moore, Evidence, 9 August 2010, p 8

⁹¹³ Mr Maher, Evidence, 9 August 2010, p 39

But the thing that I always thought was the most informative piece of advice in terms of judgements around this is that the Productivity Commission has only once in its lifespan, so I am advised, said that there should be an increase in workers' wages, and that was in the not-for-profit report that it brought down last year. It had a really simple argument, a pure economics argument. It is what leads you to say: There is something substantial in this, that the not-for-profit sector is the second largest contributor to the Australian economy. It must grow. Its wages will not allow it to grow; therefore its wages have to go up.⁹¹⁴

Committee comment

- 11.49** The Committee supports the principle of equal pay for delivering the same service, no matter whether a carer is an employee of ADHC or a non-government provider. The Committee understands that the successful outcome of the pay equity case before Fair Work Australia will have funding implications, which will need to be addressed by the NSW Government.

Professional development of staff

- 11.50** The importance of properly trained carer staff was a theme included in many submissions to the Committee. However, the Committee received limited submissions on this issue from professional carers, so it has been difficult to determine the perspective of employees in regard to the amount and suitability of training provided to them.

- 11.51** Carers are entitled to professional development and training opportunities to expand and develop their skills. Mr French, of the NSW Disability Discrimination Legal Centre Inc, explained to the Committee that under the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), there is a general obligation to promote the training of staff working with persons with a disability. Mr French noted that the capacity of ADHC in the professional development area needs to be strengthened:

Under Article 4(l)(i) of the UNCRPD, parties have a general obligation to promote the training of professionals and staff working with persons with disability.... It is obvious from the issues we highlight above that ADHC currently lacks capacity to effectively implement a human rights based approach to policy development and service delivery for persons with disability. Consequently, we believe the next phase of Stronger Together ought to incorporate a suite of measures that will build the capacity of ADHC and its staff to recognise and effectively implement a human rights based approach to policy, programme and service development. This would include comprehensive professional development for all staff in UNCRPD rights and related issues that is calibrated with work roles, as well as the development of specific policy tools that will assist staff to ensure that practice is consistent with UNCRPD rights.⁹¹⁵

- 11.52** Ms Llewellyn explained that the Benevolent Society had a strong commitment to the professional development of its staff. She also discussed that some of the smaller carer organisations find the ADHC funded training programs very positive:

I think our organisation is in quite a privileged position because we do have resources that would call on in terms of research internally and we also have a very strong

⁹¹⁴ Mr Moore, Evidence, 9 August 2010, p 8

⁹¹⁵ Submission 20, NSW Disability Discrimination Legal Centre Incorporated, p 12

commitment towards learning and development for our staff, whether that is paid or unpaid. We really are quite clear that everyone in our organisation has access to training and that we have qualification levels that we expect to see and if we do not have those qualification levels we support people to obtain those. So for an organisation of our size with that culture and commitment around that work it works well for us. Where we have smaller organisations locally who need that extra support ADHC does fund through the HACC program some very positive training programs for volunteers and for paid staff—those are offered at no cost actually for HACC-funded services. They are extremely effective because they are able to bring in experts around particular training areas that people identify with in the region.⁹¹⁶

- 11.53** The level training of Home Care workers was questioned by certain Inquiry stakeholders. The Committee heard of clients being injured because of poorly trained staff. The author of Submission 69, a C5-6 complete quadriplegic, said he had experienced untrained carers which had resulted in unfortunate consequences:

I have had untrained carers being rostered into my high needs care (not very often but it should not happen at all). In some cases I have had carers changing routines because of their own inability or "nursing" an injury to try to retain the position which personally suited them. One such instance led to me developing a pressure area due to the inability of the carer using a hoist sling properly. I might add this was the first pressure area I had ever had in over 46 years.⁹¹⁷

- 11.54** Ms Jackie Dufty, carer to her husband, stated that Home Care workers often said that they felt uncomfortable with the level of on the job training.⁹¹⁸ Furthermore, Ms Dufty told the Committee that an untrained care worker tore Ms Dufty's husband's bowel wall while performing a bowel procedure.⁹¹⁹

- 11.55** A long-time client of Home Care observed that on the job training requirements appear to have diminished in recent times. Mr Adam Johnston, a Home Care service user, said he assisted in training his new care workers:

It is also to my advantage that I am verbal and can give any new staff "on the job" training as required. Previously, this training was done by a second staff member who had experience with a client. However, in the last year or so, my personal observation is that this practice has not always been followed. Again, while the lack of an experienced staff member to train a recruit is not a major problem in my case, it could be confronting and problematic for a new carer and client alike, particularly if the latter has difficulty articulating their needs.⁹²⁰

- 11.56** The author of Submission 106, a former Home Care worker, noted that care workers need increased training and monitoring to ensure the best outcomes for clients.⁹²¹

⁹¹⁶ Ms Llewellyn, Evidence, 26 August 2010 p 28

⁹¹⁷ Submission 69, Name suppressed, p 1

⁹¹⁸ Ms Jackie Dufty, Public Forum, 30 September 2010, p 13

⁹¹⁹ Ms Dufty, Public Forum, 27 September 2010, p 13

⁹²⁰ Submission 104, Mr Adam Johnston, p 2

⁹²¹ Submission 106, p 1

- 11.57** Whilst Ms Smidt of the Disability Advocacy Information Centre noted that ADHC are providing opportunities for staff to be trained to deliver better quality services, the Committee heard from ADHC itself that more could be done.⁹²² Mr Moore observed:

The Home Care Service of NSW has some ability to train staff and better within its funding.

... I think that across the board within the HACC system and the specialist disability system, and beyond, but across those two, the need to invest more in staff skills is very evident.⁹²³

- 11.58** Mr Moore also explained that some of the ADHC operated services, such as the Home Care Service, are likely to do more staff training than the smaller non-government providers. He told the Committee that an important way forward is to share skill development with the non-government sector:

... because the Home Care Service is big, because of the natural way in which big organisations operate compared with a lot of smaller ones, we would probably do a bit more [staff training] than the non-government sector. We certainly know in the disability side of our business that the conversation with the NGO representatives is how we will be able to better share resources on skill development so that we can pull ourselves all up together, so to speak.⁹²⁴

- 11.59** The Committee heard that the non-government sector agrees with this shared skill development approach. For instance, NDS submitted that it would like to see a shared training regime between the whole of ADHC and the non-government sector:

... consistency in access to shared training and resources between ADHC-operated and funded organisations would be beneficial. NDS would like to see a general principle put in place that allows for shared training and resources where relevant across the whole of ADHC and the NGO sector. This would be best administered by each region but should be strongly communicated and transparently monitored by central office on the basis of partnership moving forward.⁹²⁵

Committee comment

- 11.60** There are many facets to employee job satisfaction. Obviously pay and remuneration is important, but a career path supported by training and professional development opportunities is also important. It is evident to the Committee that a renewed commitment on the training and development of staff would be welcomed in both the government and non-government provider sector. In particular, the Committee supports joint and regional professional development involving both the government and non-government providers.
- 11.61** The Committee is concerned about the level of training for Home Care workers. Stories of clients being injured by poorly-trained, ill-equipped staff are unacceptable. The Committee

⁹²² Submission 57, Disability Information Advocacy Service, p 4

⁹²³ Mr Moore, Evidence, 9 August 2010, p 5

⁹²⁴ Mr Moore, Evidence, 9 August 2010, p 5

⁹²⁵ Submission 32, p 11

recommends that the Home Care Service of NSW undertake an evaluation of training levels for all care workers.

Recommendation 53

That the Home Care Service of NSW undertake an evaluation of training levels of all care workers, which identifies training gaps and how these will be addressed.

Recommendation 54

That ADHC coordinate and share training programs and opportunities with both their own staff and that of non-government service providers in each of the six ADHC regions.

Rude and abusive staff

- 11.62** Earlier in this Chapter the importance of good carer staff was highlighted. The opposite of this is of course that bad staff can have a devastating effect on clients and their families. The Committee heard evidence that carers can be rude, offensive and belittle their clients.
- 11.63** The relationship between poor quality staff and compliance with the NSW Disability Services Standards is examined in Chapter 9.
- 11.64** The Committee held a Public Forum for people to share first hand some of the problems they face when confronted with staff who are not caring. For example, Ms Mason told the Committee about her personal experience with ADHC staff:

My personal experience in dealing with DADHC staff allows me to formally state I found them to be totally unprofessional in their contact and dealings with me. They were totally biased against me and my family, colluded and conspired together with staff of the service provider, and also in my opinion had a close and too familiar relationship with our advocate from one of this country's leading advocacy groups for people with disabilities who are supposed to act independently.⁹²⁶

- 11.65** Ms Sarkis shared with the Committee her concerns about ADHC, referring to some departmental staff as 'cold-hearted souls':

I know I might be sounding ungrateful or even disrespectful of the Department of Ageing, Disability and Home Care but maybe they should be respecting us first. Personally, I have come across many cold-hearted souls from ADHC and I am very sorry but I am actually being very nice when I mention what I am saying. Most of the individuals working there should honestly look around them and remember what their department actually stands for. It really does not feel like they have any connection to humanity. There is no compassion; maybe there are a few but maybe they have their own barriers too and it feels as though you cannot really get any truth out of anybody that I have ever had to deal with.

⁹²⁶ Ms Carolyn Mason, Public Forum, 30 September 2010, p 17

... I just need to be very honest about some of the things that have been said to me personally, whether they be face-to-face, over the phone or just in passing. Many times I have been left shaken and sobbing after telephone conversations and/or meetings. One sentence that was said to me by my supposedly understanding and compassionate case manager, who was also a mother herself, were the cold words—and honestly to this day it still sends a cold shiver down my spine—"It must be so hard, so difficult for you being her mum, sitting there watching and waiting for Charlize to die". Honestly, they are the exact words; I will never forget. I was so shocked and so angry at the same time that I could not muster up any reply.⁹²⁷

- 11.66** The inappropriate use of words by an ADHC staff member was identified at the Public Forum by Mr Joseph Harrison. He stated:

I know of one ADHC staff in a senior position who still refers to people with intellectual disability as "morons", arguing this is an acceptable medical diagnosis . That person was originally from a rural agency but was working in head office in a senior role when we met in 2000. Noone within ADHC thought to address the matters as "she is entitled to her private beliefs" is the argument that I often heard. However, as a representative of ADHC addressing people with disability and their families and carers, and the non-government sector, her attitude has caused some disquiet and concern.⁹²⁸

- 11.67** Mr Moore indicated to the Committee that he understood the angst and distress that poor staff can cause. He noted the importance of various value statements and codes of conduct that ADHC staff must adhere to. However, Mr Moore also explained to the Committee that, whilst it is never acceptable for a staff member to behave badly towards their clients, sometime there are very trying circumstances that need to be worked through, and this can sometimes explain, but not excuse, aberrant behaviour:

You cannot be in everybody's house alongside every staff member. As I said, there are 4,500 staff members. But we have various value statements, codes of conduct, and branch management supervision arrangements, where we would be dealing with appropriate ways of dealing with clients. Again, I am not saying that about the specific examples there, and I am not trying to in any way denigrate the person who is making the comments there. It is never acceptable for a staff member to behave like that. At the same time, it is a matter of one human being dealing with another human being, and situations can get difficult from both sides at times and there are very trying circumstances that our staff have to work through. While I am not trying to excuse behaviour like that, I can explain it sometimes.⁹²⁹

Committee comment

- 11.68** The Committee acknowledges the outstanding work of the majority of ADHC care workers. The work of these individuals allows people with disability to participate more fully in community life and offers respite for carers. The difficulties in supervising some 4,500 staff, caring for persons in their client's homes under minimal supervision, are noted. The Committee believes that this is why attracting and retaining the right people to the profession in the first place is so important.

⁹²⁷ Ms Sayde Sarkis, Public Forum, 30 September 2010, p 21

⁹²⁸ Mr Joseph Harrison, Public Forum, 30 September 2010, p 19

⁹²⁹ Mr Moore, Evidence, 27 September 2010, p 5

- 11.69** However, the Committee acknowledges that it received evidence of some carer staff who are rude, abusive and neglect their clients. This is clearly unacceptable. The Committee strongly believes that both ADHC and the non-government service provider sector need to strengthen their reporting and accountability mechanisms, so that clients can report inappropriate staff behaviour and have confidence that their concerns will be dealt with promptly and appropriately. Recommendations to improve accountability mechanisms are contained in Chapter 9.

The special problems in regional and remote areas

- 11.70** This Chapter has canvassed many staffing issues in relation to ageing and disability care. It became apparent to the Committee that many of these issues are compounded in regional and remote areas. For example, Mrs Vicki Happ, a mother of a child with Down's syndrome, lives in Far Western NSW, with a two hour drive to the largest regional centre of Dubbo. She explained to the Committee the effect of this relative isolation:

ADHC Case Workers/Managers have large areas to cover often with little or no experience in dealing with the diversity and complexity of families and the problems they face therefore there is a significant staff turnover. Our family has had 5 case workers in my sons first 7 years of life, some of that time the position was vacant, and some of the workers only lasted months...

There has been reoccurring problems with ADHC availability of Therapists. I have found ADHC services overall to be inconsistent, with some inexperienced therapists, who leave to get married (our last Occupational Therapist, we have not seen an OT from ADHC since), have babies (our previous Speech therapist who twice went out on maternity leave, both times the position was not filled in her absence) or just leave because of the enormous workload and large area they service.⁹³⁰

- 11.71** Similarly, Mrs Narelle Hughes, a mother of an adult disabled daughter, told the Committee that having lived in both coastal and rural NSW, services in regional areas are not as good:

Having lived in both coastal and rural NSW as well as Sydney, my experience has been that services are lacking in all areas. Many of the service providers funded by ADHC have a commitment to their clients but are so overstretched due to lack of funding that they are unable to individualise programs. ...

The situation in regional areas is even worse, with the lack of allied health professionals and case managers employed directly by ADHC.⁹³¹

- 11.72** Ms Margaret Bowen, the Chief Executive Officer of service provider Disability Trust, recounted to the Committee some of the difficulties in finding staff to work in remote and regional areas:

It is a quality and skill issue and it is a cost issue. We work with some people who live in very small towns. Finding and training staff in those environments is very difficult. If we cannot find staff that are available in a town of three or four hundred people or we have utilised, exhausted that community, we have really got to pay travel for

⁹³⁰ Submission 1, Mrs Vicki Happ, p1

⁹³¹ Submission 26, Mrs Narelle Hughes, p 1

people to come an hour down the road or half an hour down the road, because people just will not drive for an hour to work and drive home for an hour. There is no way of doing that other than to provide an incentive, and that is not something that funding covers traditionally.⁹³²

- 11.73** ADHC is administratively divided into six regions. These are Metropolitan South, Metropolitan North, Hunter, Northern, Southern and Western. National Disability Services explained to the Committee that the equitable delivery of services across these six regions is a continual issue:

Equity, consistency, transparency and portability across ADHC's six regional areas continues to be an issue reported to NDS frequently by non-government disability service providers. Frequent turnover of ADHC regional staff makes continuity and relationship building difficult for non-government organisations. Regional interpretations of central policies and procedures often vary greatly and it is often only through sector feedback to NDS that these issues are identified. Streamlined, systemic approaches must be put in place to ensure greater consistency and equity across all regions in terms of procurement of services, engagement with NGOs, regional planning, communications and consultations, contract management, information provision and client referral processes.⁹³³

- 11.74** The Physical Disability Council and Council on the Ageing together submitted that, whilst obtaining and retaining skilled workers and volunteers is difficult, it is even more problematic in rural and remote areas.⁹³⁴
- 11.75** Northcott Disability Services explained to the Committee that there are additional costs in providing services in rural and regional areas, and that this should be recognised when funding is allocated. Northcott outlined some of the problems of service delivery in regional and rural areas:

There are additional costs associated with providing services in regional and rural areas, including: Large areas for service coverage resulting in increased travel, accommodation and infrastructure costs for service delivery. This also impacts upon ability to meet service outputs as more time is spent on travel (indirect time) in order to deliver the same number of hours of service (outputs). Difficulty in recruitment of qualified staff – due to smaller pool of suitable workers and competition with other services. This can often mean employing less qualified staff who have additional training needs to meet the requirements of role. As a state-wide provider of disability services, Northcott sees the need for a review of the funding distributed for services covering regional and rural areas. Northcott also supports that additional funding (in the form of higher unit costs) should be built into funding models for service delivery in regional and rural areas, to allow for the additional cost to provide service.⁹³⁵

Recommendation 5: Regional and rural services receive levels of funding based on higher unit costs.

⁹³² Ms Bowen, Evidence, 3 September 2010, p 59

⁹³³ Submission 32, p 14

⁹³⁴ Submission 51, p 10

⁹³⁵ Submission 70, p 5

Committee comment

- 11.76** The Committee recognises the extra difficult circumstances that both ageing and disability service providers and the service users face in rural and remote communities. Problems of distance, recruitment of suitable people and provision of training are all issues compounded by living away from major cities.
- 11.77** The Committee received evidence that the provision of services is more expensive in rural and remote areas, and that higher per unit funding should be allocated to service providers in these areas. The Committee considers that ADHC should investigate these concerns, with a view to increasing the funding for services in rural and regional areas, if appropriate.

Recommendation 55

That the Minister for Disability Services investigate the cost of providing ageing and disability services in metropolitan and rural areas of NSW, with a view to increasing the funding allocation to ensure equity of service provision in rural areas, if required.

Appendix 1 Submissions

No	Author
1	Mrs Vicki Happ
2	Miss Renee Goossens
3	Ms Beverley Gollan
4	Name suppressed
5	Name suppressed
6	Name suppressed
6a	Name suppressed
7	Name suppressed
8	Name suppressed
9	Mr Gary Blaschke OAM (Disabled Surfers Association of Australia Inc.)
10	Name suppressed
11	Name suppressed
12	Name suppressed
12a	Name suppressed
13	Ms Bernadette Moloney
13a	Ms Bernadette Moloney
14	Ms Carolyn Mason
15	Ms Estelle Shields
16	Confidential
17	Confidential
18	Ms Kate Melhopt (South East Neighbourhood Centre)
19	Confidential
20	Mr Phillip French (NSW Disability Discrimination Legal Centre Inc)
21	Mr Max Bosotti (ParaQuad, Paraplegic and Quadriplegic Association of NSW)
22	Mrs Joyce Bellchambers (DARE to CARE)
23	Ms Belinda Epstein-Frisch (Family Advocacy)
24	Mr Mark Grierson (Disability Advocacy NSW)
25	Ms Sancha Donald (AccessibleARTS/Arts + Disability NSW)
26	Mrs Narelle Hughes
27	Name suppressed
28	Ms Ruth Ley (Blue Mountains Home Modification and Maintenance Service)

No	Author
29	Lyn
30	Ms Christine Regan (Council of Social Service of NSW (NCOSS))
31	Mr Jim Moore (Ageing, Disability and Home Care (ADHC))
32	Ms Emily Caska (National Disability Services, NSW)
33	Ms Elena Katrakis (Carers NSW)
34	Ms Stacey Sheppard-Smith (NSW Home Modification and Maintenance Services State Council)
35	Ms Carol Ireland (Epilepsy Action Australia)
36	Mr Martin Boers
37	Professor Julie Byles (NSW Division of the Australian Association of Gerontology)
38	Ms Jennifer Rollo OAM
39	Ms Carol Berry (NSW Council for Intellectual Disability)
40	Name suppressed
41	Ms Roz Armstrong (Official Community Visitors Scheme)
42	Mr Greg Killeen
42a	Mr Greg Killeen
43	Name suppressed
44	Name suppressed
45	Ms Sondra Wibberley (Association for Blind Citizens of NSW Inc)
46	Ms Jenny Barron (Attendant Care Industry Association of NSW Inc)
47	Name suppressed
48	A/Professor Rosemary Leonard (Social Justice and Social Change Research Group, University of Western Sydney)
49	Mr Reg Mason
50	Name suppressed
51	Ms Ruth Robinson and Ms Anne-Marie Elias (Physical Disability Council of NSW and Council on the Ageing NSW)
52	Mrs Diana Palmer (IDEAS NSW)
53	Mr Mark Sheehan (Allowance Incorporated)
54	Mr Graham Opie (Motor Neurone Disease Association of NSW)
55	Name suppressed
56	Name suppressed
57	Ms Susan Smidt (Disability Information Advocacy Service)
58	Ms Jocelyn Selwood (Fragile X Association)

No	Author
59	Mr Frank Francis (Sunnyfield Independence)
60	Ms Sue Crane (Vision Australia)
61	Mr Martin Lavery (The Lorna Hodginson Sunshine Home)
62	Mrs Jo-Anne Hewitt (Futures Alliance)
63	Mr Malcolm Schyvens (Guardianship Tribunal)
64	Mr Michael Coutts-Trotter (NSW Department of Education and Training)
65	Professor Debora Picone (Department of Health)
66	Mr Peter Kell (Anglicare, Diocese of Sydney)
67	Mr Sean Lomas and Mr Greg Killeen (Spinal Cord Injuries Australia)
68	Mr John Berryman (Royal Institute for Deaf and Blind Children)
69	Name Suppressed
70	Ms Liz Forsyth (Northcott Disability Services)
71	Name suppressed
72	Mr Noel Baum (Local Government and Shires Association of NSW)
73	Name suppressed
74	Name suppressed
75	Name suppressed
76	Mr Mark Trevaskis (Best Buddies Australia)
77	Mrs Yolanda Encina (Fairfield City Council and Fairfield Seniors Network)
78	Professor James Middleton (State Spinal Cord Injury Service)
79	Mr Barrie Styles
80	The Shepherd Centre
81	Ms Julie Hourigan-Ruse (Homeless Persons' Legal Service)
82	Name suppressed
83	Confidential
84	Early Childhood Intervention Australia (NSW Chapter) Inc.
85	Ms Jillian McDonnell (The Aged Care Rights Service (TARS))
86	Mr John Paul Carr
86a	Mr John Paul Carr
86b	Mr John Paul Carr
87	Mr Ian Williams (Williams & Co, Solicitors and Barristers)
88	Name suppressed
89	Mr Gerard Crewdson
90	Mr Sharon Everson (The Deaf Society of NSW)

No	Author
91	Ms Therese Sands (People with Disability Australia Incorporated (PWD))
92	Confidential
93	Ms Janne Bidenko
94	Dr Robert Leitner (Association of Doctors in Developmental Disability (ADIDD))
95	Associate Professor Eileen Baldry (University of NSW)
96	Ms Katrina Clark (Association for Children with a Disability NSW (ACD NSW))
97	Mr Damian Griffis (Aboriginal Disability Network)
98	Ms Sarah Fogg (The Benevolent Society)
99	Name suppressed
100	Mr Bruce Barbour (NSW Ombudsmans Office)
100a	Mr Bruce Barbour (NSW Ombudsmans Office)
101	Ms Adeline Hodgkinson (NSW Agency for Clinical Innovation - Brain Injury Rehabilitation Directorate)
102	Ms Mary Dallow (Maitland City Council)
103	Mrs Denise Redmond (Nardy House Inc)
104	Mr Adam Johnston
105	Name suppressed
106	Name suppressed
107	Ms Margaret Bowen (The Disability Trust)
108	Miss Louise Bannerman (Warringah Council)
109	Name suppressed
110	Name suppressed
111	Name suppressed
111a	Name suppressed
112	Mr Michael Hart

Appendix 2 Witnesses

Date	Name	Position and Organisation
Monday 9 August 2010 Jubilee Room, Parliament House	Mr Jim Moore	Chief Executive, Ageing, Disability and Home Care
	Ms Ethel McAlpine	Deputy Director General, Ageing, Disability and Home Care
	Ms Lauren Murray	Deputy Director General, Ageing, Disability and Home Care
	Ms Marie New	Regional Director, Hunter Region, Ageing, Disability and Home Care
	Mr Ron McCallum	Chair, Disability Council of NSW
	Ms Amelia Starr	Senior Policy Officer, Disability Council of NSW
	Mr Douglas Herd	Executive Officer, Disability Council of NSW
	Mr Patrick Maher	Chief Operating Officer and State Manager, National Disability Services, NSW
	Mr Gordon Duff	State Manager Policy and Projects, National Disability Services, NSW
	Ms Emily Caska	State Policy Coordinator, National Disability Services, NSW
	Dr Kate More	Manager Workforce Initiative, National Disability Services, NSW
	Ms Elena Katrakis	Chief Executive Officer, Carers NSW
	Ms Samantha Edmonds	Deputy Director Policy and Communications, Council of Social Service of NSW
	Ms Christine Regan	Senior Policy Officer, Council of Social Service of NSW
Thursday 26 August 2010 Jubilee Room, Parliament House	Ms Eileen Baldry	Associate Professor, School of Social Sciences and International Studies, University of NSW
	Ms Carol Berry	Executive Director, NSW Council for Intellectual Disability
	Ms Barbara Squires	Regional Manager, The Benevolent Society
	Ms Karen Lee	Senior Manager, Practice Development, The Benevolent Society
	Ms Sharryn Llewellyn	Regional Programs Manager, Southern Sydney, The Benevolent

Date	Name	Position and Organisation
	Mr Greg Killeen	Society Senior Policy Officer, Spinal Cord Injuries Australia
	Mr Sean Lomas	Policy and Advocacy Manager, Spinal Cord Injuries Australia
	Ms Diana Qain	Executive Director, Multicultural Disability Advocacy Association
	Ms Kerry Stubbs	Chief Executive Officer, Northcott Disability Services
	Ms Liz Forsyth	Manager, Service Development and Government Relations, Northcott Disability Services
	Ms Anita Fisher	Senior Manager, Northcott Disability Services
Friday 3 September 2010 Jubilee Room, Parliament House	Mr Max Bosotti	Chief Executive Officer, ParaQuad NSW
	Ms Tonina Harvey	General Manager, Community Services, ParaQuad NSW
	Ms Stacey Sheppard-Smith	Executive Officer, NSW Home Modification and Maintenance Services State Council
	Ms Shalla Thomas	Chairperson, NSW Home Modification and Maintenance Services State Council and Service Manager, Coffs Harbour, Home Modification and Maintenance Services, and the Service Manager for the mid North Coast Home Modification Scheme
	Mr Steve Malvern	Vice Chairperson, NSW Home Modification and Maintenance Services State Council and Project Manager, NSW Statewide Level 3 Project
	Ms Ruth Ley	Secretary, NSW Home Modification and Maintenance Services State Council and Service Coordinator/Builder Blue Mountains Home Modification and Maintenance Services
	Ms Ruth Robinson	Executive Officer, Physical Disability Council of NSW
	Ms Anne-Marie Elias	Policy and Communications Manager, Council on the Ageing NSW
	Ms Therese Sands	Executive Director, People with Disability Australia

Date	Name	Position and Organisation
	Ms Denise Beckwith	Acting Manager, Individual Advocacy, People with Disability Australia
	Ms Jo-Anne Hewitt	Futures Alliance member and Director, UnitingCare Disability
	Mr Paul Sadler	Futures Alliance member and Chief Executive Officer, Presbyterian Aged Care NSW
	Mr Mike Blaszczyk	Futures Alliance member and General Manager, McCall Gardens Community Limited
	Ms Margaret Bowen	Chief Executive Officer, The Disability Trust
	Ms Penelope Desmazures	Executive Manager, Respite Community Services and Residential Services, The Disability Trust
Monday 27 September 2010 Jubilee Room, Parliament House	Dr Robert Leitner	Chairperson, Association of Doctors in Development Disability
	Dr Vivian Bayl	Executive Committee, Association of Doctors in Development Disability
	A/Prof Julian Troller	Executive Committee, Association of Doctors in Development Disability
	A/Prof Allan Sturgess	Executive Committee, Association of Doctors in Development Disability
	Dr Helen Somerville	Executive Committee, Association of Doctors in Development Disability
	Mr Jim Moore	Chief Executive, Ageing, Disability and Home Care
	Ms Lauren Murray	Deputy Director General, Ageing, Disability and Home Care
	Mr Tom Cowen	Acting Chief Executive Officer, The Aged Care rights Service
	Mrs Margaret Small	Acting Principal Solicitor, The Aged Care rights Service
	Ms Jillian McDonnell	Education Officer and Advocate, The Aged Care Rights Service
	Dr Richard Matthews	Deputy Director-General, Strategic Development, NSW Department of Health
	Ms Cathrine Lynch	Director, Primary Health and Community Partnerships, NSW

Date	Name	Position and Organisation
	Mr Damian Griffis	Department of Health Executive Officer, Aboriginal Disability Network
	Ms Roz Armstrong	Consultation Committee Representative, Official Community Visitors Scheme
	Mr Colin Allen	Director of Services, The Deaf Society of NSW
	Mr Stephen Nicholson	Manager, Consumer and Community Services, The Deaf Society of NSW
Thursday 30 September 2010 Jubilee Room, Parliament House	Mr John Le Breton	Chief Executive Officer, Disability Enterprises
Thursday 30 September 2010 Jubilee Room, Parliament House Public Forum	Mrs Valerie Noone Mrs Judy Brosas Mr Antony Varrall Ms Bernadette Moloney and Charley Armstrong Mr Joseph Harrison Ms Janice Marshall Ms Debbie Robertson Miss Jackie Dufty Mr Barrie Styles Ms Carolyn Mason Mr Greg Killeen Mr Marc Kay Ms Sayde Sarkis	

Appendix 3 Tabled documents

1. Monday 9 August 2010

Public Hearing, Jubilee Room, Parliament House

- Ms Christine Regan, Senior Policy Officer Council of Social Service of NSW (NCOSS) tendered the following documents, NSW Aboriginal Community Care Gathering Committee, *Leading Our Way In Community Care, Policy Position*, April 2007 and Futures Alliance, *Blue Print for People with Disability who are Ageing*.

2. Thursday 26 August 2010

Public Hearing, Jubilee Room, Parliament House

- Ms Diana Qian, Executive Director, Multicultural Disability Advocacy Association, tendered the following document, Multicultural Disability Advocacy Association, *Less Talk More Action*, 2003.

3. Friday 3 September 2010

Public Hearing, Jubilee Room, Parliament House

- Ms Stacey Sheppard-Smith, Executive Officer, NSW Home Modification and Maintenance (HMMS) State Council, tendered correspondence between HMMS State Council, Ageing, Disability and Home Care and the NSW Department of Health.
- Ms Therese Sands, Executive Director, People With Disability, tendered the following document, E-Bulletin, *Issue 50: Living Independently and Being Included in the Community*, People With Disability, February 2009
- Mr Mike Blaszczyk, Futures Alliance member and also appearing as CEO, McCall Gardens, tendered the following document, ADHC/Price Waterhouse Cooper statistics on people ageing with disability.
- Ms Margaret Bowen, Chief Executive Officer, Disability Trust, tendered the following documents, Annual Report and brochures, the Disability Trust, 2008-2009.

4. Monday 27 September 2010

Public Hearing, Jubilee Room, Parliament House

- Mr Robert Leitner, Chairperson, Association of Doctors in Developmental Disability, tendered the following document, 'Summary of Key Issues for Parliamentary Inquiry', Association of Doctors in Developmental Disability.
- Mr Tom Cowen, Acting Chief Executive Officer, The Aged Care Rights Service, tendered the following documents, 'The Aged-Care Rights Service (TARS), including Older Persons' Legal Service Annual Report 2008-2009 and an information package containing a variety of brochures and information sheets.
- Mr Colin Allen, Director of Services, The Deaf Society of NSW, tendered the following, a document containing the text of his opening statement and an information package, containing a variety of brochures and information sheets.

5. Thursday 30 September 2010

Public Hearing, Jubilee Room, Parliament House

- Mr John Le Breton, Chief Executive Officer, Disability Enterprises, tendered the following, Family Advocacy, Presenting the Evidence, Deinstitutionalisation: A Review of Literature, June 2007 and Greystanes Disability Services DVD, 'A place to call home: talking about devolution', 2010.

Appendix 4 Answers to questions on notice

The Committee received answers to questions on notice from:

- Aboriginal Disability Network
- Associate Professor Eileen Baldry, School of Social Sciences and International Studies, University of NSW
- Association of Doctors in Developmental Disability (ADIDD)
- Blue Mountains Home Modification and Maintenance Service
- Carers NSW
- Council of Social Service of NSW (NCOSS)
- Council on the Ageing, NSW
- Department of Ageing Disability and Home Care (ADHC)
- Futures Alliance
- National Disability Services, NSW
- NSW Department of Health
- Northcott Disability Services
- NSW Council for Intellectual Disability
- NSW Home Modification and Maintenance Services (HMMS) State Council
- Official Community Visitors Scheme
- ParaQuad, Paraplegic and Quadriplegic Association of NSW
- Physical Disability Council of NSW
- People with Disability Australia Incorporated (PWD)
- Spinal Cord Injuries Australia
- The Aged Care Rights Service (TARS)
- The Deaf Society of NSW
- The Disability Trust.

Appendix 5 Disability Service Standards, Principles and Applications of principles

Disability Service Standards

1. **STANDARD SERVICE ACCESS**
Each consumer seeking a service has access to a service on the basis of relative need and available resources.
2. **INDIVIDUAL NEEDS**
Each person with a disability receives a service which is designed to meet, in the least restrictive way, his or her individual needs and personal goals.
3. **DECISION MAKING AND CHOICE**
Each person with a disability has the opportunity to participate as fully as possible in making decisions about the events and activities of his or her daily life in relation to the services he or she receives
4. **PRIVACY, DIGNITY AND CONFIDENTIALITY**
Each consumer's right to privacy, dignity and confidentiality in all aspects of his or her life is recognised and respected.
5. **PARTICIPATION AND INTEGRATION**
Each person with a disability is supported and encouraged to participate and be involved in the life of the community.
6. **VALUED STATUS**
Each person with a disability has the opportunity to develop and maintain skills and to participate in activities that enable him or her to achieve valued roles in the community.
7. **COMPLAINTS AND DISPUTES**
Each consumer is free to raise and have resolved, any complaints or disputes he or she may have regarding the agency or the service
8. **SERVICE MANAGEMENT**
Each service adopts sound management practices which maximise outcomes for consumers.
9. **FAMILY RELATIONSHIPS**
Each person with a disability receives a service which recognises the importance of preserving family relationships, informal social networks and is sensitive to their cultural and linguistic environments.
10. **RIGHTS AND FREEDOM FROM ABUSE**
The agency ensures the legal and human rights of people with a disability are upheld in relation to the prevention of sexual, physical and emotional abuse within the service.

1. Schedule 1 Principles and Applications of principles (NSW Disability Services Act 1993)

1 Principles

Persons with disabilities have the same basic human rights as other members of Australian society. They also have the rights needed to ensure that their specific needs are met. Their rights, which apply irrespective of the nature, origin, type or degree of disability, include the following:

- a) persons with disabilities are individuals who have the inherent right to respect for their human worth and dignity,
- b) persons with disabilities have the right to live in and be part of the community,
- c) persons with disabilities have the right to realise their individual capacities for physical, social, emotional and intellectual development,
- d) persons with disabilities have the same rights as other members of Australian society to services which will support their attaining a reasonable quality of life,
- e) persons with disabilities have the right to choose their own lifestyle and to have access to information, provided in a manner appropriate to their disability and cultural background, necessary to allow informed choice,
- f) persons with disabilities have the same right as other members of Australian society to participate in the decisions which affect their lives,
- g) persons with disabilities receiving services have the same right as other members of Australian society to receive those services in a manner which results in the least restriction of their rights and opportunities,
- h) persons with disabilities have the right to pursue any grievance in relation to services without fear of the services being discontinued or recrimination from service providers,
- i) persons with disabilities have the right to protection from neglect, abuse and exploitation.

2 Application of principles

Services and programs of services must apply the principles set out in clause 1. In particular, they must be designed and administered so as to achieve the following:

- a) to have as their focus the achievement of positive outcomes for persons with disabilities, such as increased independence, employment opportunities and integration into the community,
- b) to contribute to ensuring that the conditions of everyday life of persons with disabilities are the same as, or as close as possible to, norms and patterns which are valued in the general community,
- c) to form part of local co-ordinated service systems and other services generally available to members of the community, wherever possible,
- d) to meet the individual needs and goals of the persons with disabilities receiving services,
- e) to meet the needs of persons with disabilities who experience an additional disadvantage as a result of their gender, ethnic origin or Aboriginality,
- f) to promote recognition of the competence of, and enhance the image of, persons with disabilities,

- g) to promote the participation of persons with disabilities in the life of the local community through maximum physical and social integration in that community,
- h) to ensure that no single organisation providing services exercises control over all or most aspects of the life of a person with disabilities,
- i) to ensure that organisations providing services (whether specifically to persons with disabilities or generally to members of the community) are accountable to persons with disabilities who use them, the advocates of those persons, the State and the community generally for the provision of information from which the quality of those services can be judged,
- j) to provide opportunities for persons with disabilities to reach goals and enjoy lifestyles which are valued by the community generally and are appropriate to their chronological age,
- k) to ensure that persons with disabilities participate in the decisions that affect their lives,
- l) to ensure that persons with disabilities have access to advocacy support where necessary to ensure adequate participation in decision-making about the services they receive,
- m) to recognise the importance of preserving the family relationships and the cultural and linguistic environments of persons with disabilities,
- n) to ensure that appropriate avenues exist for persons with disabilities to raise and have resolved any grievances about services, and to ensure that a person raising any such grievance does not suffer any reprisal,
- o) to provide persons with disabilities with, and encourage them to make use of, avenues for participating in the planning and operation of services and programs which they receive and to provide opportunities for consultation in relation to the development of major policy and program changes,
- p) to respect the rights of persons with disabilities to privacy and confidentiality.

Appendix 6 Minutes

Minutes No. 46

Thursday 24 June 2010

Members Lounge, Parliament House at 4.27 pm

1. Members present

Mr Ian West *Chair*

Mr Trevor Khan *Deputy Chair*

Mr Greg Donnelly

Ms Marie Ficarra

Dr John Kaye

Ms Helen Westwood

2. Confirmation of previous minutes

Resolved, on the motion of Mr Kaye: That Draft minutes No. 45 be confirmed.

3. Inquiry into the provision of services by the Department of Ageing, Disability and Home Care

The Chair tabled terms of reference received from the House on 23 June 2010 for an inquiry into the quality, effectiveness and delivery of services provided or funded by the Department of Ageing, Disability and Home Care.

Time line for inquiry

Resolved, on the motion of Mr Donnelly: That the Committee adopt the following time line, subject to any changes necessary and determined by the Chair in consultation with the Committee:

Thur 24 June 2010	Terms of reference referred
Fri 25 June 2010	Inquiry announced via press release
Wed 7 July 2010	Inquiry and call for submissions advertised
Mon 5 July 2010	Stakeholder letters sent
Fri 6 August 2010	Closing date for submissions
See item 3.5	Hearings
See item 3.5	Report deliberative
Thurs 30 September 2010	Tabling.

Press release

Resolved, on the motion of Ms Ficarra: That a press release announcing the commencement of the inquiry and the call for submissions be distributed to media outlets throughout NSW to coincide with the call for submissions.

Advertising inquiry and call for submissions

Resolved, on the motion of Mr Kaye: That the closing date for submissions be 6 August 2010.

Resolved, on the motion of Mr Kaye: That the Inquiry and the call for submissions be advertised in The Sydney Morning Herald and The Daily Telegraph and any other appropriate publications as determined by the Secretariat in consultation with the Chair.

Invitations to stakeholders to make a submission

Resolved, on the motion of Mr Khan: That the Committee write to stakeholders identified by the Secretariat in consultation with the Committee informing them of the Inquiry and inviting them to make a submission.

Resolved, on the motion of Mr Kaye: That Members notify the Secretariat of any stakeholders they wish to be invited by COB Thursday 1 July 2010.

Hearings and report deliberative

Resolved, on the motion of Mr Kaye: That the following dates be set aside by the Committee for public hearings: Monday 9, Tuesday 10, Monday 16, and Tuesday 17 August 2010, and that the report deliberative be held on Monday 27 September 2010.

4. General business

Resolved, on the motion of Ms Westwood: That the Secretariat organise and promote the services of an Auslan interpreter for the four inquiry hearings.

5. Adjournment

The Committee adjourned at 4.40 pm, *sine die*.

Beverly Duffy

Clerk to the Committee

Minutes No. 47

Monday 9 August 2010

Jubilee Room, Parliament House at 9.07 am

1. Members present

Mr Ian West *Chair*

Mr Trevor Khan *Deputy Chair*

Mr Greg Donnelly

Ms Marie Ficarra

Dr John Kaye

Ms Helen Westwood

2. Confirmation of previous minutes

Resolved, on the motion of Ms Ficarra: That Draft minutes No. 46 be confirmed.

3. Correspondence

The Committee noted the following items of correspondence received:

- 5 August 2010 – From Professor Alan Hayes, Director, Australian Institute of Family Studies, declining invitation to make a submission to the Inquiry and attaching the following publications:
 - Edwards B., Higgins, D.J., Gray, M., Zmijewski, N., and Kingston, M. (2008). *The nature and impact of caring for family members with a disability in Australia*. (AIFS Research Report No. 16). Melbourne: Australian Institute of Family Studies and Department of Families, Housing, Community Services and Indigenous Affairs.
 - *Family Matters No. 78*
 - Edwards B., Higgins, D.J., (2009). *Is caring a health hazard? The mental health and vitality of carers of a person with a disability in Australia*. Medical Journal of Australia. 190(7), S61-S65
 - Edwards B., Gray, M., Baxter, J., and Hunter, B. (2009). *The tyranny of distance? Carers in regional and remote areas of Australia*. Commissioned report, Carers Australia.

4. Submissions***Public submissions***

Resolved, on the motion of Ms Ficarra: That according to section 4 of the *Parliamentary Papers (Supplementary Provisions) Act 1975* and Standing Order 223(1), the Committee authorise the publication of Submission Nos 2, 3, 9, 15, 18, 20- 25, 28, 30- 33.

Public submissions and appendices fully confidential

Resolved, on the motion of Dr Kaye: That according to section 4 of the *Parliamentary Papers (Supplementary Provisions) Act 1975* and Standing Order 223(1), the Committee authorise the publication of Submission No 26 with appendices kept fully confidential

Partially confidential submissions – name suppressed

Resolved, on the motion of Ms Westwood: That according to section 4 of the *Parliamentary Papers (Supplementary Provisions) Act 1975* and Standing Order 223(1), the Committee authorise the partial publication of Submission Nos 4, 6, 11, 12, 13, with names suppressed.

Partially confidential submissions – other identifying details suppressed

Resolved, on the motion of Ms Ficarra: That according to section 4 of the Parliamentary Papers (Supplementary Provisions) Act 1975 and Standing Order 223(1), the Committee authorise the partial publication of Submission No 1 with identifying details suppressed.

Partially confidential submissions – name and other identifying details suppressed

Resolved, on the motion of Dr Kaye: That according to section 4 of the *Parliamentary Papers (Supplementary Provisions) Act 1975* and Standing Order 223(1), the Committee authorise the partial publication of Submission Nos 7, 8, 27, 29, with names and identifying details suppressed.

Partially confidential submissions – name, other identifying details and appendices suppressed

Resolved, on the motion of Ms Westwood: That according to section 4 of the *Parliamentary Papers (Supplementary Provisions) Act 1975* and Standing Order 223(1), the Committee authorise the partial publication of Submission Nos 5, 10, 14, with names, identifying details and appendices suppressed.

Fully confidential submissions – at the request of the author

Resolved, on the motion of Mr Donnelly: That, according to section 4 of the Parliamentary Papers (Supplementary Provisions) Act 1975 and standing order 223(1), the Committee keep the following submissions fully confidential: Nos 16, 17.

Submission containing adverse mention

Mr Khan moved: That according to section 4 of the Parliamentary Papers (Supplementary Provisions) Act 1975 and Standing Order 223(1), the Committee authorise the partial publication of Submission No 19.

Question put and negatived.

Resolved, on the motion of Ms Westwood: That, according to section 4 of the Parliamentary Papers (Supplementary Provisions) Act 1975 and standing order 223(1), the Committee keep Submission No 19 fully confidential and that the Secretariat write to the author advising him of the appropriate grievance mechanisms for his concerns.

5. Ongoing acceptance of submissions and supplementary submissions

Resolved, on the motion of Mr Khan: That the Committee continue to accept submissions and supplementary submissions to the inquiry into services provided or funded by Ageing, Disability and Home Care after the closing date.

6. Witnesses at future hearings

Resolved, on the motion of Mr Khan: That representatives from the following organisations and any further individuals or organisations identified by committee members or the secretariat, in consultation with the Chair, be invited to appear as witnesses during the public hearings on Thursday 26 August, Friday 3 and Monday, 27 September 2010:

- People with Disability Australia
- Paraquad
- The Benevolent Society
- The Physical Disability Council of NSW
- Multicultural Disability Advocacy Association
- Northcott Disability Services
- Life Without Barriers
- TARS: The Aged-Care Rights Advocacy Service, NSW Including The Older Persons Legal Centre (OPLS)
- Aboriginal Disability Support Network
- NSW Health
- Council on the Ageing NSW
- The Spastic Centre NSW
- The Disability Trust
- The Futures Alliance
- Official Community Visitor Consultative Group.

7. Extension of reporting date

Resolved, on the motion of Ms Ficarra: That the Chair of the Committee move a motion in the House seeking an extension of the reporting date to Thursday 28 October 2010.

8. Report deliberative

Resolved, on the motion of Mr Khan: That the Committee report deliberative be held on Friday 22 October 2010.

9. Date for additional questions on notice to be lodged by Members

Resolved, on the motion of Mr Khan: That for the duration of the Inquiry into services provided or funded by Ageing, Disability and Home Care, Members forward questions on notice for witnesses who appear at a hearing to the secretariat by close of business two days following the hearing at which the witness appeared.

10. Return of answers to questions taken on notice

Resolved, on the motion of Ms Ficarra: That, for the duration of the Inquiry into services provided or funded by Ageing, Disability and Home Care the Committee request witnesses to return answers to any questions taken during the hearings and any additional written questions on notice within 14 days of the date on which the questions are forwarded to the witness by the committee clerk.

11. Public hearing – Inquiry into services provided or funded by Ageing, Disability and Home Care

The public and media were admitted.

The Chair made an opening statement regarding the broadcasting of proceedings and other matters.

The following representatives from Ageing, Disability and Home Care were sworn and examined:

- Mr James Moore, Chief Executive
- Ms Ethel McAlpine, Deputy Director General
- Ms Lauren Murray, Deputy Director General
- Ms Marie New, Regional Director, Hunter Region.

The evidence concluded and the witnesses withdrew.

The following representatives from the Disability Council of NSW were sworn and examined:

- Professor Ronald McAllum, Chair
- Mr Douglas Herd, Executive Officer
- Ms Amelia Starr, Senior Policy Officer.

The evidence concluded and the witnesses withdrew.

The following representatives from National Disability Services, NSW, were sworn and examined:

- Mr Patrick Maher, Chief Operating Officer and State Manager
- Ms Emily Caska, State Policy Coordinator
- Ms Katherine Moore, Manager Workforce Initiative
- Mr Gordon Duff, State Manager, Policy and Projects.

The evidence concluded and the witnesses withdrew.

The following representative from Carers NSW was sworn and examined:

- Ms Elena Katrakis, Chief Executive Officer.

The evidence concluded at the witness withdrew.

The following representatives from the Council of Social Service of NSW (NCOSS) were sworn and examined:

- Ms Christine Regan, Senior Policy Officer
- Ms Samantha Edmonds, Deputy Director Policy and Communications.

Ms Regan tendered the following documents:

- NSW Aboriginal Community Care Gathering Committee, Leading Our Way In Community Care, Policy Position, April 2007
- Futures Alliance, Blue Print for People with Disability who are Ageing.

12. Auslan interpreters at public hearings

The Committee noted that the total cost for hiring Auslan interpreters for its four hearings is \$10,560.

13. Adjournment

The Committee adjourned at 5.40 pm, until 26 August 2010 (public hearing).

Rachel Simpson

Clerk to the Committee

Minutes No. 48

Thursday 26 August 2010

Jubilee Room, Parliament House at 9.05 am

1. Members present

Mr Ian West *Chair*

Mr Trevor Khan *Deputy Chair*

Mr Greg Donnelly

Ms Marie Ficarra

Dr John Kaye

Ms Helen Westwood

2. Confirmation of previous minutes

Resolved, on the motion of Ms Ficarra: That Draft minutes No. 47 be confirmed.

3. Correspondence

The Committee noted the following items of correspondence received:

- 18 August 2010 – From Dr Robert Leitner, Chairperson, Association of Doctors in Developmental Disability, requesting an opportunity to discuss their submission with the Committee.
- #####
- 6 August 2010 – From Roz Armstrong, Official Community Visitor, On behalf of Community Visitors Consult Group, requesting an opportunity for representatives to discuss their submission with the Committee.

4. Activation of vulnerable stakeholder protocol

The Committee noted that the Secretariat has activated the vulnerable stakeholder protocol in relation to the authors of two Submissions.

5. Submissions***Public submissions***

Resolved, on the motion of Ms Westwood: That according to section 4 of the *Parliamentary Papers (Supplementary Provisions) Act 1975* and Standing Order 223(1), the Committee authorise the publication of Submission Nos 34, 35, 36, 37, 38, 39, 41, 42, 45, 46, 48, 51, 52, 53, 54, 57, 58, 59, 60, 61, 62, 63, 64, 65, 66, 67, 68, 70, 72, 76, 77, 78, 80, 81, 84, 85, 90, 91, 93, 94, 95, 97, 98.

Partially confidential submissions – name suppressed

Resolved, on the motion of Mr Donnelly: That according to section 4 of the *Parliamentary Papers (Supplementary Provisions) Act 1975* and Standing Order 223(1), the Committee authorise the partial publication of Submission Nos 40, 44, 55, 56, 73, 75, 82, with name of submission author suppressed.

Partially confidential submissions – other identifying details suppressed

Resolved, on the motion of Ms Ficarra: That according to section 4 of the *Parliamentary Papers (Supplementary Provisions) Act 1975* and Standing Order 223(1), the Committee authorise the partial publication of Submission No 49, 87, 92, 96 with other identifying details suppressed.

Partially confidential submissions – name and other identifying details suppressed

Resolved, on the motion of Mr Donnelly: That according to section 4 of the Parliamentary Papers (Supplementary Provisions) Act 1975 and Standing Order 223(1), the Committee authorise the partial publication of Submission Nos 43, 69, 74, 88, 99 with name and other identifying details suppressed.

Partially confidential submissions – name, other identifying details and appendices suppressed

Resolved, on the motion of Mr Donnelly: That according to section 4 of the Parliamentary Papers (Supplementary Provisions) Act 1975 and Standing Order 223(1), the Committee authorise the partial publication of Submission Nos 47, 50, 71 with name, other identifying details and appendices suppressed.

Fully confidential submissions – at the request of the author

Resolved, on the motion of Ms Ficarra: That according to section 4 of the Parliamentary Papers (Supplementary Provisions) Act 1975 and standing order 223(1), the Committee keep the following submissions fully confidential: Nos 83.

Submission containing adverse mention

Resolved, on the motion of Ms Ficarra: That according to section 4 of the Parliamentary Papers (Supplementary Provisions) Act 1975 and standing order 223(1), the Committee authorise the partial publication of Submission No 86 and 89, with adverse mention suppressed.

Subsequent request for additional publication

Resolved, on the motion of Mr Donnelly: That according to section 4 of the Parliamentary Papers (Supplementary Provisions) Act 1975 and Standing Order 223(1), the Committee authorise the partial publication of Submission No 14.

6. Submissions containing allegations against ADHC

Resolved, on the motion of Ms Ficarra: That the Committee forwards submissions containing allegations against ADHC to the Ombudsman and the ICAC, and the Chair writes a letter to these submission authors advising them of the Committee's decision, and of their options in relation to the Ombudsman and the ICAC.

7. Acceptance and publication of documents tendered during the public hearing on Monday 9 August

Resolved, on the motion of Ms Westwood: That the Committee accept and publish, according to section 4 of the *Parliamentary Papers (Supplementary Provisions) Act 1975* and Standing Order 223(1) the following document(s) tendered during the public hearing:

- Ms Christine Regan, NCOSS, NSW Aboriginal Community Care Gathering Committee, Leading Our Way in Community Care, Policy Position, April 2007
- Ms Christine Regan, NCOSS, Futures Alliance, Blue Print for People with Disability who are Ageing.

8. Public hearing – Inquiry into services provided or funded by Ageing, Disability and Home Care

The public and media were admitted.

The Chair made an opening statement regarding the broadcasting of proceedings and other matters.

The following representative from the School of Social Sciences and International Studies, University of NSW was sworn and examined:

- Associate Professor Eileen Baldry

The evidence concluded and the witness withdrew.

The following representative from the NSW Council for Intellectual Disability was sworn and examined:

- Ms Carol Berry

The evidence concluded and the witness withdrew.

The following representatives from The Benevolent Society were sworn and examined:

- Ms Barbara Squires, General Manager, Ageing
- Ms Karen Lee, Senior Manager, Practice Development
- Ms Sharryn Llwellyn, Senior Manager, Research to Practice, Ageing and Community Care.

The evidence concluded and the witnesses withdrew.

The following representatives from Spinal Cord Injuries Australia were sworn and examined:

- Mr Sean Lomas, Policy and Advocacy Manager
- Mr Greg Kileen, Policy and Advocacy Officer.

The evidence concluded and the witnesses withdrew.

The following representative from the Multicultural Disability Advocacy Association was sworn and examined:

- Ms Diana Qian

Ms Qian tendered the following document:

- Multicultural Disability Advocacy Association, Less Talk More Action, 2003

The evidence concluded and the witness withdrew.

The following representatives from Northcott Disability Services were sworn and examined:

- Ms Kerry Stubbs, Chief Executive Officer
- Ms Liz Forsyth, Manager, Service Development and Government Relations
- Ms Anita Fisher, Senior Manager, Client Programs.

The evidence concluded and the witnesses withdrew.

9. Acceptance and publication of documents tendered during the public hearing

Resolved, on the motion of Ms Ficarra: That the Committee accept and publish, according to section 4 of the *Parliamentary Papers (Supplementary Provisions) Act 1975* and Standing Order 223(1) the following document tendered during the public hearing:

- Ms Diana Qian, Multicultural Disability Advocacy Association, Less Talk More Action, 2003

10. Notice of hearing

The Committee noted the schedule for the next public hearing, Friday 3 September 2010.

11. Adjournment

The Committee adjourned at 4.51 pm, until 3 September 2010 (public hearing).

Rachel Simpson

Clerk to the Committee

Minutes No. 49

Friday 3 September 2010

Jubilee Room, Parliament House at 9.19 am

1. Members present

Mr Ian West *Chair*

Mr Trevor Khan *Deputy Chair* (from 10:45 am until 11:30 am)

Mr Greg Donnelly

Ms Marie Ficarra

Dr John Kaye

Ms Helen Westwood

2. Confirmation of previous minutes

Resolved, on the motion of Dr Kaye: That Draft minutes No. 48 be confirmed.

3. Correspondence

The Committee noted the following items of correspondence received:

- 27 August 2010 – From Elena Katrakis, Chief Executive Officer, Carers NSW, with answers to additional questions on notice
- 31 August 2010 – From Mr Steve Kinmond, Community and Disability Services Commissioner, NSW Ombudsman, forwarding a confidential copy of a report entitled Improving service delivery to Aboriginal people with a disability: a review of ADHC's Aboriginal Policy Framework and Aboriginal Consultation Strategy
- 31 August 2010 – From Mr Jim Moore, Chief Executive Officer, ADHC, with answers to questions on notice.

4. Submissions

Subsequent request to publish name

Resolved, on the motion of Mr Donnelly: That according to section 4 of the Parliamentary Papers (Supplementary Provisions) Act 1975 and Standing Order 223(1), the Committee authorise the partial publication of Submission No 86, with submission author's name published:

- Submission No. 86

Public submissions

Resolved, on the motion of Mr Donnelly: That according to section 4 of the *Parliamentary Papers (Supplementary Provisions) Act 1975* and Standing Order 223(1), the Committee authorise the publication of Submission Nos 86a, 100, 101, 102, 104.

Resolved, on the motion of Ms Ficarra: That according to section 4 of the *Parliamentary Papers (Supplementary Provisions) Act 1975* and Standing Order 223(1), the Committee authorise the publication of Submission No 107.

Partially confidential submissions – name and other identifying details suppressed

Resolved, on the motion of Dr Kaye: That according to section 4 of the Parliamentary Papers (Supplementary Provisions) Act 1975 and Standing Order 223(1), the Committee authorise the partial publication of Submission Nos 12a and 105, with name and other identifying details suppressed.

Resolved, on the motion of Ms Westwood: That according to section 4 of the Parliamentary Papers (Supplementary Provisions) Act 1975 and Standing Order 223(1), the Committee authorise the partial publication of Submission No 106, with name and other identifying details suppressed.

Partially confidential submissions – other identifying details and appendices suppressed

Resolved, on the motion of Ms Westwood: That according to section 4 of the Parliamentary Papers (Supplementary Provisions) Act 1975 and Standing Order 223(1), the Committee authorise the partial publication of Submission No 103 with other identifying details and appendices suppressed.

5. Answers to question on notice

Resolved, on the motion of Ms Ficarra: That according to section 4 of the *Parliamentary Papers (Supplementary Provisions) Act 1975* and Standing Order 223(1), the Committee authorise the publication of answers to questions on notice received from:

- Carers NSW
- Ageing Disability and Home Care.

6. Public forum

Resolved, on the motion of Ms Ficarra: That the Committee holds a public forum for individual submission authors on Thursday 30 September 2010, and the Chair writes a letter to these people advising them of the public forum.

7. Extension of reporting date

Resolved, on the motion of Mr Donnelly: That the Chair of the Committee move a motion in the House seeking an extension of the reporting date to Thursday 11 November 2010.

8. Report deliberative

Resolved, on the motion of Ms Ficarra: That the report deliberative meeting be held on Friday, 5 November 2010, in line with the new reporting date.

9. Public hearing – Inquiry into services provided or funded by Ageing, Disability and Home Care

The public and media were admitted.

The Chair made an opening statement regarding the broadcasting of proceedings and other matters.

The following representatives from the Paraplegic and Quadriplegic Association of NSW were sworn and examined:

- Mr Max Bosotti, Chief Executive Officer
- Ms Tonina Harvey, General Manager Community Services.

Mr Khan arrived at 10:45 am.

The evidence concluded and the witnesses withdrew.

Mr Khan departed at 11:30 am.

The following representatives from the NSW Home Modification and Maintenance (HMMS) State Council were sworn and examined:

- Ms Stacey Sheppard-Smith, Executive Officer
- Ms Shalla Thomas, Chairperson HMMS State Council and Service Manager Coffs Harbor HMMS
- Mr Steve Malvern, Vice Chairperson HMMS State Council and Project Manager, NSW Statewide Level 3 Project
- Ms Ruth Ley, Secretary HMMS State Council and Service Coordinator/Builder Blue Mountains HMMS.

Ms Sheppard-Smith tendered the following document:

- Correspondence between HMMS State Council, Ageing, Disability and Home Care and the NSW Department of Health.

The evidence concluded and the witnesses withdrew.

The following representatives from the Physical Disability Council of NSW and Council on the Ageing NSW were sworn and examined:

- Ms Ruth Robinson, Chief Executive Officer, Physical Disability Council of NSW
- Ms Anne-Marie Ellis, Policy and Communication Manager, Council on the Ageing NSW.

The evidence concluded and the witnesses withdrew.

The following representatives from People With Disability were sworn and examined:

- Ms Therese Sands, Executive Director
- Ms Denise Beckwith, A/Manager Individual Advocacy.

Ms Sands tendered the following documents:

- E-Bulletin, Issue 50: Living Independently and Being Included in the Community, People With Disability, February 2009.

The evidence concluded and the witnesses withdrew.

The following members of the Futures Alliance were sworn and examined:

- Ms Jo-Anne Hewitt, also appearing as Director, UnitingCare Disability
- Mr Mike Blaszczyk, also appearing as CEO, McCall Gardens
- Mr Paul Sadler, also appearing as CEO, Presbyterian Aged Care NSW/ACT.

Mr Blaszczyk tendered the following documents:

- ADHC/Price Waterhouse Cooper statistics on people ageing with disability

The evidence concluded and the witnesses withdrew.

The following members of the Disability Trust were sworn and examined:

- Ms Margaret Bowen, Chief Executive Officer
- Ms Penelope Desmazures, Executive Manager Residential Services, Respite and Care Solutions.

Ms Bowen tendered the following documents:

- Annual Report and brochures, the Disability Trust, 2008-2009

The evidence concluded and the witnesses withdrew.

10. Acceptance and publication of documents tendered during the public hearing

Resolved, on the motion of Ms Ficarra: That the Committee accept, according to section 4 of the *Parliamentary Papers (Supplementary Provisions) Act 1975* and Standing Order 223(1) the following document(s) tendered during the public hearing:

- Ms Stacey Sheppard-Smith, Home Modification and Maintenance State Council, correspondence with Ageing, Disability and Home Care

Resolved, on the motion of Ms Ficarra: That the Committee accept and publish, according to section 4 of the *Parliamentary Papers (Supplementary Provisions) Act 1975* and Standing Order 223(1) the following document(s) tendered during the public hearing:

- Ms Therese Sands, People With Disability, E-Bulletin, Issue 50: Living Independently and Being Included in the Community, February 2009
- Mr Mike Blaszczyk, the Futures Alliance, ADHC/Price Waterhouse Cooper statistics on people ageing with disability
- Ms Margaret Bowen, the Disability Trust, Annual Report 2008-2009 and brochures.

11. Notice of hearing

The Committee noted the schedule for the next public hearing, Monday 27 September 2010.

12. Adjournment

The Committee adjourned at 4.47 pm, until Monday 27 September 2010 (public hearing).

Rachel Simpson

Clerk to the Committee

Minutes No. 50

Monday 27 September 2010

Jubilee Room, Parliament House at 9.06 am

1. Members present

Mr Ian West *Chair*

Mr Trevor Khan *Deputy Chair*

Mr Greg Donnelly

Ms Marie Ficarra

Dr John Kaye (from 9.45 am until 3.25 pm)

Ms Helen Westwood

2. Confirmation of previous minutes

Resolved, on the motion of Mr Donnelly: That Draft minutes No. 49 be confirmed.

3. Correspondence

The Committee noted the following items of correspondence received:

- 1 September 2010, confidential email correspondence from a submission author
- 2 September 2010, Mr Patrick Maher, State Manager, National Disability Services NSW, answers to questions on notice and additional questions, from hearing, 9 August 2010
- 3 September 2010, Mr Jim Moore, Chief Executive Officer, Ageing, Disability and Home Care, answers to additional questions on notice, from hearing, 9 August 2010

- 3 September 2010, Mr Jim Moore, Chief Executive Officer, Ageing, Disability and Home Care, answers to questions on notice, from hearing, 9 August 2010
- 3 September 2010, Mr Jim Moore, Chief Executive Officer, Ageing, Disability and Home Care, answers to questions on notice in the form of case studies, from hearing, 9 August 2010
- 6 September 2010, Ms Catherine Mahony, A/g Director, Council of Social Service of NSW, answers to additional questions of notice, from hearing, 9 August 2010
- 6 September 2010, Ms Catherine Mahony, A/g Director, Council of Social Service of NSW, supplementary evidence 'Working Together for NSW: Good Funding Policy and Practice' answer to questions of notice from, hearing, 9 August 2010
- 8 September 2010, Mr Sean Lomas, Spinal Cord Injuries Australia, answers additional questions on notice, from hearing 26 August 2010
- 9 September 2010, Ms Kerry Stubbs, Chief Executive Officer, Northcott Disability Services, answers to additional questions on notice, from hearing, 26 August 2010
- 12 September 2010, Ms Carol Berry, Executive Director, NSW Council for Intellectual Disability, answers to additional questions on notice, from hearing, 26 August 2010
- 12 September 2010, Ms Carol Berry, Executive Director, NSW Council for Intellectual Disability, answers to questions on notice - Australian Government Occasional Paper No. 29, Effectiveness of individual funding approaches for disability support', from hearing, 26 August 2010 (available on request)
- 12 September 2010, Ms Carol Berry, Executive Director, NSW Council for Intellectual Disability, answers to questions on notice – Short and full report 'Effectiveness of Supported Living in Relation to Shared Accommodation', from hearing, 26 August 2010 (full report available on request)
- 16 September 2010, Mr Mike Blaszczyk, Futures Alliance member and Chief Executive Officer, McCall Gardens Community Ltd., answers to additional questions on notice, from hearing 3 September 2010.

4. Ombudsman's Report

The Committee noted that the confidential report titled Improving service delivery to Aboriginal people with a disability: a review of ADHC's Aboriginal Policy Framework and Aboriginal Consultation Strategy which was forwarded to the Committee on 31 August 2010 by Mr Steve Kinmond, Community and Disability Services Commissioner, NSW Ombudsman, was tabled in Parliament on 21 September 2010 and is now public.

5. Submissions

Subsequent request for confidentiality

Resolved, on the motion of Ms Ficarra: That according to section 4 of the Parliamentary Papers (Supplementary Provisions) Act 1975 and standing order 223(1), the Committee keep the following submission fully confidential: No 92.

Public submissions

Resolved, on the motion of Mr Donnelly: That according to section 4 of the Parliamentary Papers (Supplementary Provisions) Act 1975 and Standing Order 223(1), the Committee authorise the publication of Submission No 79 and 108 and Supplementary Submission No. 100a.

Partially confidential submissions –name and other identifying details suppressed

Resolved, on the motion of Ms Westwood: That according to section 4 of the Parliamentary Papers (Supplementary Provisions) Act 1975 and Standing Order 223(1), the Committee authorise the partial publication of Submission Nos. 109 and 110 and Supplementary Submission No. 6a, with name and other identifying details suppressed.

6. Answers to question on notice

Resolved, on the motion of Ms Ficarra: That according to section 4 of the *Parliamentary Papers (Supplementary Provisions) Act 1975* and Standing Order 223(1), the Committee authorise the publication of answers to questions on notice received from:

- The NSW Council for Intellectual Disability
- Spinal Cord Injuries Australia
- National Disability Services NSW
- The Futures Alliance
- Northcott Disability Services
- Ageing, Disability and Home Care (additional answers)

- Carers NSW
- Ageing Disability and Home Care.

7. Public forum

Resolved, on the motion of Mr Donnelly: That the Committee suppress the names of individual people adversely named, during the public forum.

8. In camera evidence

Resolved, on the motion of Ms Westwood: That the Committee hear evidence from witnesses at 9:21 am on Monday, 27 September 2010 in camera.

The Committee proceeded to take *in camera* evidence.

Persons present other than the Committee: Ms Rachel Simpson, Director; Ms Emily Nagle, Principal Council Officer; Mrs Kate Mihaljek, Senior Council Officer, Committee Secretariat and Hansard Reporters.

Mr Robert Leitner tendered the following document:

- Summary of Key Issues for Parliamentary Inquiry, Association of Doctors in Developmental Disability Dr Kaye arrived at 9:45 am.

The evidence was concluded and the witnesses withdrew.

Resolved, on the motion of Mr Donnelly: That the hearing resume in public.

9. Public hearing – Inquiry into services provided or funded by Ageing, Disability and Home Care

The public and media were admitted at 10:20 am.

The Chair made an opening statement regarding the broadcasting of proceedings and other matters.

The following representatives from Ageing, Disability and Home Care were examined on a former oath:

- Mr Jim Moore, Chief Executive Officer
- Ms Lauren Murray, Deputy Director-General.

The evidence concluded and the witnesses withdrew.

The following representatives from The Aged Care Rights Service were sworn and examined:

- Mr Tom Cowen, Acting Chief Executive Officer
- Mrs Margaret Small, Acting Principal Solicitor
- Ms Jillian McDonnell, Education Officer and Advocate.

Mr Tom Cowen tendered the following documents:

- The Aged-Care rights Service (TARS), including Older Persons' Legal Service Annual Report 2008-2009
- The Aged-Care rights Service (TARS), including Older Persons' Legal Service information package, containing a variety of brochures and information sheets.

The evidence concluded and the witnesses withdrew.

The following representatives from NSW Department of Health were sworn and examined:

- Mr Richard Matthews, Deputy Director-General, Strategic Development, NSW Department of Health
- Ms Cathrine Lynch, Director, Primary Health and Community Partnerships, NSW Department of Health.

The evidence concluded and the witnesses withdrew.

The following representative from Aboriginal Disability Network was sworn and examined:

- Mr Damian Griffis, Executive Officer.

The evidence concluded and the witness withdrew.

The following representative from Official Community Visitors Scheme was sworn and examined:

- Ms Roz Armstrong, Consultation Committee Representative.

The evidence concluded and the witness withdrew.

Dr Kaye departed at 3.25 pm.

The following representatives from The Deaf Society was sworn and examined:

- Mr Colin Allen, Director of Services
- Mr Stephen Nicholson, Manager consumer and Community Services.

Mr Colin Allen tendered the following documents:

- A document containing the text of his opening statement.
- The Deaf Society of NSW information package, containing a variety of brochures and information sheets.

10. Publication of in camera evidence

Resolved, on the motion of Ms Westwood: That, in the public interest and according to section 4 of the *Parliamentary Papers (Supplementary Provisions) Act 1975* and Standing Order 223(2), the Committee authorises the publication of the in camera transcript of evidence of the following witnesses from the Association of Doctors in Developmental Disability (ADIDD):

- Dr Robert Leitner, Chairperson, Executive Committee
- A/Prof Julian Trollor, Executive Committee
- A/Prof Allan Sturgess, Executive Committee
- Dr Vivian Bayl, Executive Committee
- Dr Helen Somerville, Executive Committee.

11. Acceptance and publication of documents tendered during the public hearing

Resolved, on the motion of Ms Ficarra: That the Committee accept and publish, according to section 4 of the *Parliamentary Papers (Supplementary Provisions) Act 1975* and Standing Order 223(1) the following documents tendered during the public hearing:

- Dr Robert Leitner, Summary of Key Issues for Parliamentary Inquiry
- Mr Tom Cowen, The Aged-Care rights Service (TARS), including Older Persons' Legal Service Annual Report 2008-2009
- Mr Colin Allen a document containing the text of his opening statement.

12. Next meeting

The Committee adjourned at 5:47 pm, until Thursday, 30 September 2010, public hearing 9:00 am.

Rachel Simpson
Clerk to the Committee

Minutes No. 51

Thursday 30 September 2010

Jubilee Room, Parliament House at 9.04 am

1. Members presentMr Ian West *Chair*Mr Trevor Khan *Deputy Chair*

Mr Greg Donnelly

Ms Marie Ficarra

Dr John Kaye

Ms Helen Westwood

2. Confirmation of previous minutes

Resolved, on the motion of Mr Donnelly: That Draft minutes No. 50 be confirmed.

3. Correspondence

The Committee noted the following items of correspondence received:

- 28 September 2010 – From Dr Robert Leitner, Chairperson, NSW Association of Doctors in Developmental Disability Executive Committee, answers to questions on notice
- 28 September 2010 – From Ms Jo-Anne Hewitt, Chairperson, The Futures Alliance, answers to questions on notice
- 28 September 2010 – From Ms Ruth Robinson, Physical Disability Council of NSW, answers to questions on notice
- 28 September 2010 – From Mr Max Bosotti and Ms Tonina Harvey, ParaQuad, answers to questions on notice
- 28 September 2010 – Ms Anne-Marie Elias, Council on the Ageing, answers to questions on notice, including "We don't have any of those people here", Retirement Accommodation and Aged Care Issues for Non-Heterosexual Populations GRAI (GLBTI Retirement Association Inc) May 2010
- 28 September 2010 – From Ms Margaret Bowen, The Disability Trust, answers to additional questions on notice
- 13 September 2010 – From Mr John Le Breton, Chief Executive Officer, Disability Enterprises, advising that he would be happy to provide oral evidence to the Committee, particularly in relation to large residential facilities and their devolution.

4. Submissions***Partially confidential submission – name and other identifying details suppressed***Resolved, on the motion of Ms Ficarra: That according to section 4 of the *Parliamentary Papers (Supplementary Provisions) Act 1975* and Standing Order 223(1), the Committee authorise the partial publication of Submission No 111 with name and other identifying details suppressed.**5. Answers to question on notice**Resolved, on the motion of Mr Donnelly: That according to section 4 of the *Parliamentary Papers (Supplementary Provisions) Act 1975* and Standing Order 223(1), the Committee authorise the publication of answers to questions on notice received from:

- NSW Association of Doctors in Developmental Disability
- The Futures Alliance
- Physical Disability Council of NSW
- ParaQuad
- Council on the Ageing
- NCOSS (noted as correspondence received at meeting on 27 September 2010).

6. Public hearing – Inquiry into services provided or funded by Ageing, Disability and Home Care

The public and media were admitted at 9.09 am.

The following representative from Disability Enterprises was sworn and examined:

- Mr John Le Breton

Mr Le Breton tendered the following documents:

- Family Advocacy, Presenting the Evidence, Deinstitutionalisation: A Review of Literature, June 2007
- Greystanes Disability Services DVD, A place to call home: talking about devolution, 2010.

The evidence concluded and the witness withdrew.

7. Acceptance and publication of documents tendered during the public hearing

Resolved, on the motion of Ms Westwood: That the Committee accept and publish, according to section 4 of the *Parliamentary Papers (Supplementary Provisions) Act 1975* and Standing Order 223(1) the following document(s) tendered during the public hearing:

- Mr John Le Breton, Family Advocacy, Presenting the Evidence, Deinstitutionalisation: A Review of Literature, June 2007
- Mr John Le Breton, Greystanes Disability Services DVD, A place to call home: talking about devolution, 2010.

8. Public forum – Inquiry into services provided or funded by Ageing, Disability and Home Care

The public forum commenced at 10.20 am.

Speakers, the public and media were readmitted.

The Chair made an opening statement regarding the broadcasting of proceedings and other matters.

The Committee heard from the following speakers:

- Ms Judy Brosas
- Ms Valerie Noone
- Mr Tony Varrell
- Ms Bernadette Moloney and Charley Armstrong
- Mr Joseph Harrison
- Ms Janice Marshall
- Ms Deb Robertson
- Ms Jackie Dufty
- Mr Barrie Styles
- Ms Carolyn Mason
- Mr Greg Killeen
- Ms Sayde Sarkis
- Mr Marc Kay.

The forum concluded at 12.55 pm.

9. Next meeting

The Committee adjourned at 12.55 pm, until Friday, 5 November 2010, 9.00 am.

Rachel Simpson
Clerk to the Committee

Draft Minutes No. 52

Friday 5 November 2010

Room 1102, Parliament House at 9.40 am

1. Members presentMr Ian West *Chair*Mr Trevor Khan *Deputy Chair*

Mr Greg Donnelly

Ms Marie Ficarra

Dr John Kaye

Ms Helen Westwood

2. Confirmation of previous minutes

Resolved, on the motion of Mr Donnelly: That Draft minutes No. 51 be confirmed

3. Inquiry into substitute decision making for people lacking capacity – outstanding government response

Resolved, on the motion of Ms Ficarra: That the Chair write to the Leader of the Government to follow up on the outstanding government response to the report on substitute decision making for people lacking capacity.

4. Correspondence

The Committee noted the following items of correspondence received:

- 31 August 2010, email from Ms Justine Acar, providing comments on ADHCs service provision, funding and auditing
- 30 September 2010, email from Mr Carr, sending his apologies to the Committee that he couldn't attend the forum
- 1 October 2010, from Ms Sharon Everson, Chief Executive Officer, The Deaf Society of NSW, answers to questions on notice, from hearing 27 September, 2010
- 2 October 2010, from Mr Jim Moore, Chief Executive, Ageing, Disability and Home Care, answers to questions on notice, from hearing 27 September, 2010
- 2 October 2010, from Ms Therese Sands, Executive Director, Leadership Team, People with Disability Australia, answers to questions on notice, from hearing 3 September 2010
- 6 October 2010, from Mr John Paul Carr, apologies to Committee for non attendance at public forum, compliments to staff member and wishing to address some issues with the committee
- 7 October 2010, from Ms Ruth Ley, Blue Mountains Home Modification and Maintenance Service, answers to questions on notice, from hearing 3 September, 2010
- 8 October 2010, from Ms Stacey Sheppard-Smith, Executive Officer, NSW Home Modification and Maintenance Services State Council, answers to questions on notice, from hearing 3 September, 2010
- 12 October 2010, from Mr Damian Griffis, Executive Officer, Aboriginal Disability Network, answers to questions on notice, from hearing 27 September 2010
- 13 October 2010, from Mr Tom Cowen, Acting Chief Executive Officer, The Aged Care Rights Service, answers to questions on notice, from hearing 27 September 2010
- 18 October 2010, from Ms Roz Armstrong, Official Community Visitor, Community Visitors Consultation Group, answer to question on notice, from hearing 27 September 2010
- 18 October 2010, from Dr Robert Leitner, Chairperson, Association of Doctors in Developmental Disability, answers to questions on notice, from hearing 27 September 2010
- 21 October 2010, from Dr Richard Matthews, Deputy Director-General, NSW Department of Health, answers to questions on notice, from hearing 27 September 2010
- 22 October 2010, from Associate Professor Eileen Baldry, School of Social Sciences and International Studies, University of NSW, answers to questions on notice, from hearing 26 August 2010

5. Submissions**Public submissions**

Resolved, on the motion of Ms Westwood: That according to section 4 of the Parliamentary Papers (Supplementary Provisions) Act 1975 and Standing Order 223(1), the Committee authorise the publication of Submission No 112 and Supplementary Submission Nos 86b, 13a and 42a

Partially confidential submission – name and other identifying details suppressed

Resolved, on the motion of Ms Westwood: That according to section 4 of the *Parliamentary Papers (Supplementary Provisions) Act 1975* and Standing Order 223(1), the Committee authorise the partial publication of Supplementary Submission No 111 and Supplementary Submission No 111a, with name and other identifying details suppressed.

Subsequent request for additional publication

Resolved, on the motion of Ms Ficarra: That according to section 4 of the *Parliamentary Papers (Supplementary Provisions) Act 1975* and Standing Order 223(1), the Committee authorise the publication of Submission No 13.

6. Answers to question on notice

Resolved, on the motion of Mr Donnelly: That according to section 4 of the *Parliamentary Papers (Supplementary Provisions) Act 1975* and Standing Order 223(1), the Committee authorise the publication of answers to questions on notice received from:

- Ms Sharon Everson, Chief Executive Officer, The Deaf Society of NSW
- Mr Jim Moore, Chief Executive, Ageing, Disability and Home Care
- Ms Therese Sands, Executive Director, Leadership Team, People with Disability Australia
- Ms Ruth Ley, Blue Mountains Home Modification and Maintenance Service
- Ms Stacey Sheppard-Smith, Executive Officer, NSW Home Modification and Maintenance Services State Council
- Mr Damian Griffis, Executive Officer, Aboriginal Disability Network
- Mr Tom Cowen, Acting Chief Executive Officer, The Aged Care Rights Service
- Ms Roz Armstrong, Official Community Visitor, Community Visitors Consultation Group
- Dr Robert Leitner, Chairperson, Association of Doctors in Developmental Disability
- Dr Richard Matthews, Deputy Director-General, NSW Department of Health
- Associate Professor Eileen Baldry, School of Social Sciences and International Studies, University of NSW

7. Chair's draft report – inquiry into services provided or funded by ADHC

The Chair tabled his draft report entitled Services provided or funded by ADHC, which having been previously circulated was taken as being read.

Resolved, on the motion of Dr Kaye: That the Chair's amendments to the draft report be incorporated into the Chair's draft report to be considered at the meeting.

Chapter 1 read

Resolved, on the motion of Dr Kaye: That Chapter 1 be adopted.

Chapter 2 read

Resolved, on the motion of Ms Westwood: That Chapter 2 be adopted.

Chapter 3 read

Dr Kaye moved: That paragraph 3.17 be amended by omitting the words 'lack of quality data' and inserting instead the words 'lack of data analysis, collection and management'.

Resolved, on the motion of Mr Khan: That the motion of Dr Kaye be amended by not omitting the words 'lack of quality data' and inserting the words 'data analysis, collection and management' after the words 'lack of quality data'.

Motion of Dr Kaye, as amended, put and passed.

Dr Kaye moved: That Recommendation 1 be amended by omitting the words 'that the Minister for Disability Services audit the existing data that is collected by ADHC and data that is available to ADHC, identify any additional data that is required to accurately assess unmet need for ageing and disability services in NSW and publically report on unmet need annually' and inserting instead the words 'that the NSW Government amend the Disability Services

Act to require the Minister for Disability Services to table an annual report into unmet and under-met need for ageing and disability services in NSW.'

Mr Khan moved: That Recommendation 1 not be omitted and that Dr Kaye's Recommendation be amended by omitting the words 'an annual' and inserting instead the words 'a biannual.'

Resolved, on the motion of Ms Westwood: That Recommendation 1 read 'that the Minister for Disability Services audit the existing data that is collected by ADHC and data that is available to ADHC, identify any additional data that is required to accurately assess unmet need for ageing and disability services in NSW and publically report on unmet need annually.' 'That the NSW Government amend the Disability Services Act to require the Minister for Disability Services to table a biannual report into unmet and under-met need for ageing and disability services in NSW.'

Resolved, on the motion of Mr Khan: That a new paragraph be inserted after paragraph 3.23 discussing the timeframe for the Government's Stronger Together II announcement.

Resolved, on the motion of Mr Khan: That Recommendation 3 be amended by omitting the word 'November' and inserting instead the word 'December.'

Resolved, on the motion of Ms Westwood: That an additional recommendation be inserted after Recommendation 3 with the words 'that the Minister for Disability Services table a report to Parliament about the implementation of, and expenditure on, Stronger Together II.'

Resolved, on the motion of Dr Kaye: That Recommendation 4 be amended by omitting the word 'June' and inserting instead the word 'November' and inserting the words 'including the level of third party outsourcing by ADHC NGO contracted service providers' after the words 'November 2011.'

Resolved, on the motion of Mr Donnelly: That Chapter 3 be adopted.

Chapter 4 read

Resolved, on the motion of Mr Donnelly: That Recommendation 6 be amended by inserting the words 'access to' before the word 'individualised.'

Resolved, on the motion of Dr Kaye: That Recommendation 8 be amended by inserting the words 'convene a Working Group made up of representatives from the Disability Council of NSW, government departments, NGO service providers and other stakeholders to' after the words 'Minister for Disability Services.'

Resolved, on the motion of Dr Kaye: That Recommendation 10 be amended by inserting the words 'in consultation with the Department of Education and Training' after the words 'Minister for Disability Services.'

Resolved, on the motion of Dr Kaye: That an additional Recommendation be inserted after paragraph 4.91 with the words 'that ADHC case management should be available as part of discharge planning and that ADHC is more proactive in ensuring transitional care is provided.'

Resolved, on the motion of Ms Ficarra: That Chapter 4 be adopted.

Chapter 5 read

Resolved, on the motion of Dr Kaye: That an additional Recommendation be inserted after paragraph 5.14 with the words 'that the Minister for Disability Services introduces standardised income/means testing forms across all ADHC provided or funded programs and ensure forms are available in multiple languages and formats.'

Resolved, on the motion of Dr Kaye: That Recommendation 19 be amended by inserting an additional bullet point with the words 'provision for information sharing and co-ordination of data exchange between ADHC and NGO service providers.'

Resolved, on the motion of Ms Westwood: That Recommendation 21 be amended by inserting the words 'who are deaf or those' after the word 'people'.

Resolved, on the motion of Dr Kaye: That Recommendation 22 be amended by inserting the words 'convene a Working Group made up of representatives from the Disability Council of NSW, government departments, NGO service providers and other stakeholders to' after the words 'Minister for Disability Services' and by inserting the words 'that the Working Group undertake consultation with a range of ADHC service users and ensure eligibility criteria are consistent with the UN Convention on the Rights of Peoples with Disability' after the words 'that revised eligibility criteria determine service eligibility based on need rather than disability.'

Resolved, on the motion of Dr Kaye: That an additional paragraph be inserted after paragraph 5.118 with the words 'the Committee notes that waiting lists and registers of service requests are an important mechanism to track and measure unmet and under-met need. Waiting lists or registers of service requests may also be used to log communication history with ADHC service users.'

Resolved, on the motion of Dr Kaye: That Chapter 5 be adopted.

Chapter 6 read

Resolved, on the motion of Ms Ficarra: That the title of Chapter 6 be amended by inserting the words 'and under-met' after the word 'unmet.'

Resolved, on the motion of Dr Kaye: That Recommendation 33 be amended by omitting the words 'Minister for Disability Services' and inserting instead the word 'ADHC' and inserting the words 'that in cases where a family has remained on the Register of Requests for Supported Accommodation for more than 6 months, ADHC is to advise the Minister of the unfulfilled request.'

Resolved, on the motion of Dr Kaye: That Recommendation 38 be amended by omitting the word 'provide' and inserting instead the words 'investigate the implementation of a program of' and inserting the words 'and other people with disability after the words 'service users.'

Resolved, on the motion of Dr Kaye: That Chapter 6 be adopted.

Chapter 7 read

Resolved, on the motion of Ms Westwood: That Chapter 7 be adopted.

Chapter 8 read

Resolved, on the motion of Mr Khan: That Chapter 8 be adopted.

Chapter 9 read

Resolved, on the motion of Mr Donnelly: That Recommendation 47 be moved to after Paragraph 9.162

Resolved, on the motion of Mr Donnelly: That Chapter 9 be adopted

Chapter 10 read

Resolved, on the motion of Ms Ficarra: That the title above paragraph 10.6 be amended by omitting the words 'NSW Government.'

Resolved, on the motion of Mr Khan: That an additional paragraph be inserted after paragraph 10.11 discussing the Private Members Bill Carers Recognition Bill 2010 that was introduced to Parliament.

Resolved, on the motion of Dr Kaye: That the NSW Carers Charter be inserted after paragraph 10.12.

Resolved, on the motion of Ms Ficarra: That Chapter 10 be adopted.

Chapter 11 read

Resolved, on the motion of Dr Kaye: That Chapter 11 be adopted.

8. 'Easy Read' version of the report

Resolved, on the motion of Mr Donnelly: That the Executive Summary of the Committee's report be converted into Easy Read format.

9. Adjournment

The Committee adjourned at 12.40 pm.

The Chair expressed his thanks to the Secretariat for the ongoing support and hard work they had provided over the Committee's four inquiries over the current Parliament.

The Committee members expressed their thanks to the Chair for his leadership of the Committee during the current Parliament.

Rachel Simpson
Clerk to the Committee