General Purpose Standing Committee No. 2

The Program of Appliances for Disabled People

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Terms of reference

The terms of reference for the Inquiry are:

That General Purpose Standing Committee No 2 inquire into and report on the Program of Appliances for Disabled People (PADP), and in particular:

1. Adequacy of funding for present and projected program demand
2. Impact of client waiting lists on other health sectors
3. Effects of centralising PADP Lodgement Centres and the methods for calculating and implementing financial savings from efficiency recommendations
4. Appropriateness and equity of eligibility requirements
5. Future departmental responsibility for the PADP
6. Any other related matter.[1]

These terms of reference were self-referred to the Committee on 26 June 2008.

1 LC Minutes No. 62, Thursday 26 June 2008, Item 16, p 726

Committee membership

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Hon Christine Robertson MLC	Australian Labor Party	*Deputy Chair*
Hon Tony Catanzariti MLC	Australian Labor Party	
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Chair's foreword

The ability to participate in everyday society is something that most people take for granted. While activities such as going to school, having a job, going to the park, visiting friends, even moving around freely within the comfort of our own homes may not seem special to some, for many people with a disability these activities signify freedom, independence, belonging.

The Program of Appliances for Disabled People (PADP) intends to assist clients to do just these things – to engage and participate within the community. However, it has become clear that there is a vast gap between the intention of the program and the reality of what it is delivering.

Sadly, due to a staggering lack of funding, PADP clients have routinely been placed on equipment waiting lists for years at a time. The Committee heard of clients who have literally died and had still not received their PADP equipment. For others, their existing conditions have deteriorated or new conditions have developed as a direct result of prolonged waiting. For example, children with scoliosis waiting to receive appropriate seating and sleeping equipment have been left to endure excruciating pain, as structural damage to their skeleton and pressure on their internal organs increases by the day. Lymphoedema sufferers waiting for pressure garments have been left with no choice but to watch in despair as their limbs swell by the day. Clients waiting for pressure cushions and mattresses have developed agonising pressure sores, leading to months in hospital for treatment at a cost of up to $100,000 on the hospital system, and for some leading to fatality.

Clients in these situations have approached PADP because they are financially disadvantaged and cannot afford to purchase essential equipment themselves. However, ironically it would seem that PADP itself is financially disadvantaged. The recent funding boost of $11 million to clear waiting lists is an indication of how much additional money is required to meet current demand for the program. Yet that figure does not even touch upon how much is required to meet unmet and future demand – both of which are significant in their own right.

Importantly, it was emphasised in evidence that as the Federal Government has ratified the United Nations Convention on the Rights of Persons with Disabilities, Australian governments are legally obligated to ensure people with a disability enjoy all human rights and fundamental freedoms. These include the right to live independently, be included in the community, and have access to personal mobility.

Surely these obligations indicate that access to PADP equipment should be an entitlement, not (as is the present situation) determined by strict financial eligibility criteria. Surely these obligations denote that all people with a disability who require assistance should – as a right – receive it?

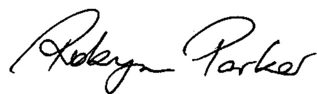
We judge a society by how it looks after its most vulnerable. At present, due to inadequate funding, the NSW Government's treatment of PADP clients can be described as negligent and inconsistent. However this can be fixed. We urge the NSW Government to provide adequate funding for current demand, beginning immediately. We then urge the Government to aim for the ultimate goal of providing essential disability equipment as an entitlement to all those in need, now and into the future.

Finally, we note that a recent review of PADP by PricewaterhouseCoopers included a number of recommendations regarding the program, the primary one being to centralise PADP's functions to a single state-wide administration. The NSW Government has agreed to implement this recommendation, and the Committee supports that endeavour. However, we are of the firm view that

the proposed completion date of 2011 for the administrative reforms is too long. Change must ensue quickly to better help clients who are already in dire need of assistance. To that end, we strongly recommend that the completion date be brought forward to the end of 2009.

On behalf of the Committee I would like to thank all participants in this Inquiry, those people and organisations that took the time to write submissions outlining their concerns and suggestions, and those that appeared to give evidence in person.

I would also like to thank my Committee colleagues, who share my concerns about the adequacy of assistance for people with a disability; and I thank Beverly Duffy, Teresa Robinson, Cathryn Cummins, Christine Nguyen and Kate Mihaljek in the Committee secretariat for their assistance during the Inquiry and in the preparation of this report.



Hon Robyn Parker MLC
Committee Chair

Summary of key issues

The Program of Appliances for Disabled People (PADP) assists financially disadvantaged people by providing appliances, aids and equipment to eligible NSW residents with long-term or life-long disabilities to enable them to engage and participate within the community.[2] This is a broad category of people which not only encompasses people with disabilities such as cerebral palsy and spinal injuries, but also extends to the elderly, patients in palliative care and patients with medical conditions such as cancer and multiple sclerosis. In 2006/07, PADP provided assistive items to over 14,000 people, with each new applicant receiving an average of three items of equipment.[3]

This Inquiry and other reviews of PADP have revealed a program that is under-funded, inefficient, inconsistent and inequitable for clients across NSW. As one participant told the Committee: 'Far too often the potential joy of receiving greater mobility, independence, comfort and dignity becomes a frustrating and personally debilitating process'.[4]

In June 2006, PricewaterhouseCoopers (PwC) published a report on PADP following a major review of the program. The report made 30 recommendations regarding PADP management and administration, target population and demand, and budgetary requirements and financial management. The key recommendation from the review was that all PADP functions be transferred from the current 22 lodgement centres to a single state-wide administration.[5] The NSW Government has agreed to implement the majority of the recommendations, and has already begun reforms to centralise the program's administrative functions.

This summary provides a broad outline of the key issues raised during this Inquiry, many of which were also raised in the PwC Review, or have arisen as a result of that Review. Much of the evidence from NSW Health and some representatives of interest groups related to the current implementation processes for the majority of the recommendations of the PwC Review. These issues will be examined in detail throughout this report.

Waiting lists

One of the major issues raised during this Inquiry, as well as the PwC Review, regards PADP waiting lists. Despite being approved to receive aids or appliances through the program, many people experience considerable delays in receiving their equipment. People commonly wait several months, even years for their aids or appliances. Indeed, the Committee heard of instances where people had died and had still not received their PADP equipment.[6]

2 Submission 72, NSW Health, p 3

3 Submission 72, p 7

4 Mr Christopher Sparks, Executive Officer, Independent Rehabilitation Suppliers Association of New South Wales, Evidence, 2 October 2008, p 22

5 PricewaterhouseCoopers, *NSW Health – Review of the Program of Appliances for Disabled People*, June 2006, p 19. Throughout the chapter this report will be referred to as the PwC Report

6 Submission 3, Disability Enterprises (formerly known as Greystanes Children's Home), p 1. See also Submission 30 , Mr George King, p 2

Lengthy waiting lists can have profound consequences on clients and their carers – physically, mentally, socially and financially. One example commonly heard throughout the Inquiry was of clients developing pressure sores while waiting for appropriate seating and sleeping equipment. This usually results in months spent in hospital for treatment of the sores, at a cost of up to $100,000 on the hospital system.[7] In some cases these sores can ultimately be fatal.[8]

Situations such as these naturally have a flow-on effect to other health sectors, increasing costs and pressures on already stretched health resources by the exacerbation or creation of additional health conditions.

Long waiting lists have also resulted in increased costs and workloads for suppliers and therapists through the need for constant reassessments and re-prescriptions.

Timely access to aids and appliances is essential for the health and wellbeing of people with a disability. It is equally essential for reasons of independence and social inclusion, which according to one inquiry participant should 'in a wealthy democracy such as ours - be a basic human right'.[9]

It is critical that waiting lists be reduced as a matter of urgency. While the program recently received a funding boost of $11 million to address this issue, as this report demonstrates, this will not solve the waiting list problem in the long term. Instead, a substantial increase in funding is necessary, as is the introduction of performance indicators establishing reasonable waiting periods.

Funding

The existence of long waiting lists at most lodgement centres across NSW is a consequence of the structural issues identified by this and other inquiries, as well as ongoing and long term inadequate program funding. Inadequate funding was a key theme identified by clients, suppliers and therapists during the Inquiry, who argued that insufficient funding has prevented the program from efficiently and effectively meeting client needs. According to the Australian Association of Occupational Therapists NSW:

> The lack of adequate funding for PADP is the root cause of many of the other inefficiencies experienced by the scheme. Scarcity of funding has spawned time consuming bureaucratic processes to protect budgets and spread available resources as thinly as possible.[10]

The Committee received a large volume of evidence that demonstrates that the program is seriously under funded. For example, one inquiry participant was left to cover the entire cost of a powered wheelchair to ensure that their young child did not experience developmental delays.[11] Other inquiry participants requiring new feeding tubes daily have only been provided with two feeding sets per week, resulting in many being left with no choice but to reuse the sets at the risk of bacterial infection.[12]

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7 Submission 75, Spinal Cord Injuries Australia, p 4

8 Submission 70, Aboriginal Disability Network NSW, p 2. See also Submission 71, Spinal Pressure Care Clinic, p 2 and Submission 75, p 5

9 Submission 77, Ms Faye Galbraith, p 1

10 Submission 37, Australian Association of Occupational Therapists NSW, p 2

11 Submission 16, Ms Heike Fabig, p 2

12 Submission 48, Nutricia Australia Pty Ltd, p 1

The PADP budget requires a substantial increase if it is to meet current demand for the program. Even further increases are needed to meet unmet and future demand for the program. Future demand in particular is expected to increase dramatically over the next decade as a result of the ageing population and medical advances in technology, which have – for example – resulted in greater numbers of people surviving catastrophic injuries[13] and a greater number of infants surviving life-threatening conditions.[14]

While the program has received various funding boosts over the years, these have failed to address the underlying need for adequate recurrent funding to meet demand. The most recent increase of $11 million to clear waiting lists fails to address unmet and future demand, and is therefore but a mere indication of how much additional funding is required.

As such, the Committee recommends that the recurrent funding for the program be increased immediately. As a minimum, the $11 million should be made part of the core budget, to bring the recurrent funding base up to $36.6 million. This amount is supported by peak disability organisations.[15]

Recommendation 1

That the NSW Government increase the base recurrent funding level for PADP in 2008/09 to $36.6 million.

Data

The lack of accurate data on the number of people with a disability and their equipment requirements is a major constraint on the ability to determine future funding levels for PADP. The lack of disability data is not only confined to PADP, but affects disability programs across NSW and Australia.[16]

The Committee supports inquiry participants' calls for the immediate state-wide collection of data on current use, unmet need and projected need of disability equipment, in order to accurately determine the full extent of current and unmet demand, and to assist in the prediction of future demand.

It has also been suggested that the accuracy of data regarding waiting lists and current usage of PADP is unreliable.[17] Participants requested improved data collection and information regarding the length and monetary value of PADP waiting lists and status of applications, and better tracking of equipment.[18] This was also a recommendation from the PwC Review.

13 Dr Richard Matthews, Deputy Director General, Strategic Development, NSW Health, Evidence, 24 October 2008, pp 4- 5

14 Dr Richard Matthews, Deputy Director General, Strategic Development, NSW Health, Evidence, 1 October 2008, p 2

15 Submission 54, National Disability Services NSW, p 9. See also Submission 52, Disability Council of NSW, p 2

16 Submission 52, p 2

17 Submission 54, p 15

18 NSW Health, NSW Government response to the Review of the Program of Appliances for Disabled People, November 2007, p 11

NSW Health has agreed to implement a new information system by March 2009. The Committee supports the expeditious implementation of that system.

Co-payment

The Committee received a great deal of evidence relating to the efficacy and necessity of the $100 co-payment. The overwhelming majority of evidence suggested that the co-payment was an unnecessary financial burden for clients of PADP and an unnecessary administrative burden for PADP.

The Committee feels that the current annual co-payment for low-income earners needlessly exacerbates the considerable financial pressures of living with a disability, and that the co-payment should therefore be abolished for PADP recipients.

Eligibility vs Entitlement

At present, access to PADP is determined by meeting strict financial eligibility criteria. However, the Committee received a great deal of evidence arguing that PADP should operate as a full entitlement scheme, where all those who are require assistance receive it.

Inquiry participants argued that people with a disability should receive aids and appliances on the basis of demonstrated clinical need only, given that such aids are essential for the independence, mobility and in some cases, survival of people with a disability. Several peak disability organisations emphasised that if the Government is serious about meeting its commitments to the rights of people with a disability under the United Nations Convention on the Rights of Persons with Disabilities, it must move towards a full entitlement system.

The Committee agrees with these arguments, and believes that a radical rethink is required about how we provide essential items to allow people with a disability to best engage with the community and maximise their independence. We are aware that converting an already inadequately funded PADP to an entitlement program would require a massive injection of funding. We are also mindful that governments need to balance competing and ever-increasing demands for the health dollar. However this does not excuse the NSW Government from taking action on what is admittedly a vexed policy challenge.

The Committee therefore urges both State and Federal governments to consider how to ensure essential aids are provided to all who need them.

Recommendation 2

That the NSW Government:

- acknowledge that under the United Nations Convention on the Rights of People with a Disability access to PADP should be provided on an entitlement (not eligibility) basis; and
- conduct financial modelling in conjunction with the Federal Government and the disability sector, in recognition of the financial implications of moving towards an entitlement model.

Inconsistency between lodgement centres

Another concern expressed by inquiry participants is the variation that exists between lodgement centres across NSW. The Committee heard that 'many people are approaching PADP for assistance and they are getting a multitude of different answers, depending on where they apply'.[19]

The lack of consistency extends across several facets of the program, with differences in the processing and prioritisation of applications, prescription processes, types of medical equipment available, and management of waiting lists.

The disparity in service seems to be heightened the further away from Sydney that an applicant lives. Mr Andrew Buchanan, Chairperson of the Disability Council of NSW indicated that:

> It is regarded as being accurate that those who live in the regional and remote parts of the State are at a disadvantage … Whether you and I live in an isolated area like Cobar, as an example, surely we should not be inconvenienced or deprived simply because we are there rather than living in a sort of component of Sydney.[20]

Similarly, the Disability Council of NSW stated in their submission: 'PADP in the past has been characterised by levels of inconsistency in the administration and provision of equipment. This has resulted in what others have justifiably described as a 'post code lottery''.[21]

The lack of consistency between lodgement centres was a major concern in the PwC Review and the impetus behind many of its recommendations, including the need to rationalise lodgement centres and centralise administration of PADP. This recommendation has been adopted by NSW Health and is supported by the Committee.

Centralisation

While the majority of inquiry participants supported moves to centralise PADP, several expressed concern about the possible impact of this move on the provision of local services. NSW Health has assured the Committee that clinical assessment and prescription services for the program will remain local, along with repair and maintenance services where possible.

The Committee wholly supports the move to centralisation of PADP. We acknowledge the concerns raised by inquiry participants regarding the reforms, however believe that many of these concerns may not actually eventuate given that clinical services will be remaining local. The centralisation of PADP's 'back office' functions is long overdue and we welcome the efficiencies and cost savings that this will bring.

The Committee's main concern regarding centralisation is the extended timeframe to rollout the reforms, estimated by NSW Health to be complete by 2011. Change must ensue quickly to better help clients who are already in dire need of assistance. We have recommended that the completion date for the reforms be brought forward to the end of 2009.

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19 Mr Barry Bryan, Coordinator, Lymphoedema Support Group, Evidence, 1 October 2008, p 21

20 Mr Andrew Buchanan, Chairperson, Disability Council of New South Wales, Evidence, 1 October 2008, p 36

21 Submission 52, p 3

Further, while most stakeholders are broadly aware of the centralisation reforms, many have been unable to ascertain details of what (or when) these changes will affect them. Clear information and communication is critical during the rationalisation of lodgement centres to ensure as smooth a transition as possible. This will need to begin with a public awareness campaign of the EnableNSW helpline and website, which currently many people are unaware of.[22]

Prescriptions

Suitably qualified professionals, such as occupational therapists, are required to provide a prescription in order for clients to access equipment under PADP. The PwC Review found that inappropriate equipment prescriptions were being prepared as a result of inexperience and/or lack of adequate clinical supervision. Conversely, appropriate prescriptions by highly qualified professionals were being challenged by lodgement centre staff.[23]

Further, inadequate program funding and the shortage of therapists, especially in rural and regional areas, have been major contributors to the problems afflicting the prescription process.

Repairs and maintenance

The apparent lack of a routine maintenance program and efficient system to repair aids and appliances, is a problem for PADP clients, as well as those who have secured their equipment from a non-government agency or charitable organisation. While NSW Health acknowledged the problems regarding the maintenance and repair of disability equipment, and is introducing various initiatives to address these concerns, the Committee is mindful yet again of the need for adequate funding to ensure these reforms are properly implemented.

Departmental responsibilities

The Committee considered whether departmental responsibility for PADP would be better located in NSW Health or the Department of Ageing, Disability and Home Care (DADHC). While there were equally strong arguments both ways, the Committee agreed with the recommendation from the PwC Review for NSW Health to retain the program.

A more significant matter however is the interrelation of disability programs within NSW Health and DADHC. Demarcation issues have arisen as to which department is responsible for certain clients, and problems with coordination between services (for example, between NSW Health supplying PADP equipment and DADHC providing home modifications to accommodate the equipment) have also led to significant delays.

To overcome these issues the Committee has recommended that the EnableNSW Advisory Council consider ways to improve coordination and integration of NSW Health and DADHC disability support services, beginning immediately.

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22 Mr Sean Lomas, Spinal Cord Injuries Australia, Evidence, 1 October 2008, p 44

23 PwC, June 2006, pp 145-146

Conclusion

For many years PADP has been marred by inconsistencies and administrative inefficiencies, the effects of which have taken a major toll on clients and their carers, and impacted on suppliers and therapists. Centralisation of the program's administrative functions should go a long way in addressing these issues, and will assist in ensuring that the program is delivered equitably to all clients regardless of where they live in NSW.

However, while the reform agenda will improve many aspects of PADP, it fails to address the root cause of the program's problems – that is, inadequate funding. Insufficient funding is the primary reason behind long waiting lists and a program structured around rationing resources rather than meeting client needs. As put by one inquiry participant, this has only served to create a further impediment to clients' already difficult lives:

> It is a sad indictment on our governments - past and present - that people with disabilities are not supported and facilitated to have as normal, equitable a life as possible. In fact it can be said that actual "disability" only arises when society fails to accommodate differences and fails to facilitate equality by removing barriers to equitable access, these barriers can be social, economic or physical. PADP is a barrier to inclusion, the poor provision of aids/equipment is an obstacle to those with differing abilities thus creating the "disability".[24]

A substantial and immediate increase in funding is essential to meet demand for the program. Ultimately however people with a disability should be entitled to necessary aids and appliances as a basic human right. This should not be a distant pipedream, but a genuine goal for the Government to achieve in the near future.

[24] Submission 77, p 1

Summary of recommendations

Recommendation 1 **xv**
That the NSW Government increase the base recurrent funding level for PADP in 2008/09 to $36.6 million.

Recommendation 2 **xvi**
That the NSW Government:

- acknowledge that under the United Nations Convention on the Rights of People with a Disability access to PADP should be provided on an entitlement (not eligibility) basis; and
- conduct financial modelling in conjunction with the Federal Government and the disability sector, in recognition of the financial implications of moving towards an entitlement model.

Recommendation 3 **14**
That the EnableNSW Advisory Council apply strict performance indicators to PADP waiting lists. Performance against these indicators should be published on the EnableNSW website monthly.

Recommendation 4 **15**
That EnableNSW ensure that all PADP Advisory Committees meet monthly to consider high cost and complex applications.

Recommendation 5 **23**
That the NSW Minister for Health initiate discussions with the Federal Treasurer regarding ways to increase tax relief for the costs associated with a disability.

Recommendation 6 **46**
That EnableNSW publicly report the results of its performance against its Key Performance Indicator to pay supply invoices within government terms. These results should be published on the Enable website monthly.

Recommendation 7 **55**
That NSW Health increase the allowance to cover the cost of a disability added to Income Bands 2 and 3 as a matter of urgency.

Recommendation 8 **62**
That NSW Health abolishes the $100 co-payment for PADP recipients.

Recommendation 9 **62**
That NSW Health examine the evidence received by General Purpose Standing Committee No. 2 regarding the abolition of the $100 co-payment, in its proposed review of the financial eligibility criteria for PADP.

Recommendation 10 **72**
That NSW Health ensure that EnableNSW assist with the cost of repairing items supplied by non-government or charitable organisations, as per the NSW Health Policy on PADP.

Recommendation 11 **76**
That NSW Health immediately commence supplying one single use feeding set per day to PADP clients who require tube feeding, as per Therapeutic Goods Administration policy.

Recommendation 12 **76**
That the NSW Minister for Health:

- initiate through the Council of Australian Governments process a national review on the guidelines and policy for equipment use, including enteral feeding tubes; and
- make a submission to the Therapeutic Goods Association on this specific issue.

Recommendation 13 **79**
That the NSW Government implement a vehicle modification subsidy scheme for people with a disability.

Recommendation 14 **86**
That to improve the efficiency of the equipment assessment and delivery process, NSW Health complete Stage 1 of PADP reforms by the end of 2009.

Recommendation 15 **87**
That NSW Health ensure there is supplier representation on the EnableNSW Advisory Council.

Recommendation 16 **89**
That EnableNSW consider the viability of equipment suppliers in rural and regional areas as part of its new procurement strategy.

Recommendation 17 **92**
That the NSW Government collect data on current, unmet and future demand for disability equipment in New South Wales as a matter of priority.

Recommendation 18 **94**
That EnableNSW conduct a public awareness campaign informing PADP stakeholders of its website and 1800 number before June 2009.

Recommendation 19 **95**
That EnableNSW ensure that access to PADP information is made available to people with sensory impairments by March 2009.

Recommendation 20 **97**
That EnableNSW ensure that PADP information is made more accessible to people from culturally different backgrounds, including being made available in a variety of community languages.

Recommendation 21 **102**
That the EnableNSW Advisory Council consider ways to improve coordination and integration of NSW Health and Department of Ageing, Disability and Home Care disability support services, beginning immediately.

Glossary

ABS	Australian Bureau of Statistics
AHS	Area Health Service
AIDAS	Aids for Individuals in DADHC Accommodation Services
DADHC	Department of Ageing, Disability and Home Care
ELP	Equipment Loan Pool
KPI	Key Performance Indicator
LTCS	Lifetime Care and Support
LTCSA	Lifetime Care and Support Authority
NESB	Non-English Speaking Background
OT	Occupational Therapist
PADP	Program of Appliances for Disabled People
PADPIS	Program of Appliances for Disabled People Information System
PwC	PricewaterhouseCoopers
SESUP	Specialised Equipment Set-Up Program
UNCRPD	United Nations Convention on the Rights of Persons with Disabilities

Chapter 1 Introduction

This chapter provides an overview of the Inquiry process and the structure of the report. It also includes a summary of several recent reviews of the Program of Appliances for Disabled People (PADP), and a brief discussion of the Lifetime Care and Support scheme.

Terms of reference

1.1 The Inquiry terms of reference were adopted on 26 June 2008, under the Committee's power to make a self-reference, and are reproduced on page iv.

1.2 The terms of reference required the Committee to examine PADP, including the adequacy of funding for present and projected demand for the program, the impact of client waiting lists on other health sectors, the effects of centralising lodgement centres management and the appropriateness and equity of eligibility requirements.

Conduct of the Inquiry

Submissions

1.3 The Committee called for submissions through advertisements in the *Sydney Morning Herald* and *The Daily Telegraph* on 23 July 2008, and by writing to key stakeholders and interested parties.

1.4 The Committee received a total of 79 submissions, including two supplementary submissions. Submissions were received from a wide range of stakeholders in PADP, such as NSW Health, the Disability Council of NSW and the Independent Rehabilitation Suppliers Association of NSW. The Committee also received submissions from PADP consumers and from carers of people with a disability.

Public hearings

1.5 The Committee held three public hearings at Parliament House on 1, 2 and 24 October 2008.

1.6 During those hearings, the Committee took evidence from representatives of NSW Health, non-government organisations and peak disability associations. In addition, the Committee heard evidence from PADP consumers, carers of people with a disability and suppliers of disability equipment and services.

1.7 A list of witnesses is set out in Appendix 2 and published transcripts are available on the Committee's website. The list of documents tabled at the public hearings is provided at Appendix 3.

1.8 The Committee would like to extend its thanks and appreciation to all the individuals, agencies, representative bodies and non-government organisations that contributed to this

Inquiry either by making a submission or by appearing at a hearing. We especially acknowledge the contribution of PADP consumers and their families.

Recent reviews of PADP

Carla Cranny Review

1.9 In 1998, a State Equipment Scoping Study, jointly commissioned by NSW Ageing and Disability Department and NSW Health, undertook a detailed review of PADP.[25]

1.10 The report, known as the Carla Cranny Review, found that the program was not performing as expected, and highlighted the '[i]nsufficient funding, lengthy delays for needed equipment, an outdated equipment list and eligibility requirements that varied across the state …'.[26]

1.11 The Review made a number of recommendations, broadly with respect to a whole of Government approach; a state-wide PADP Advisory Committee; management of PADP (including budget management); eligibility; consumer information and budget requirements.[27]

1.12 NSW Health have progressively implemented the majority of recommendations from this review, however (at the time of the PricewaterhouseCoopers Review) were still developing state-wide performance indicators and the PADP Information System.[28]

PricewaterhouseCoopers Review

1.13 In 2005, the former Minister for Health, the Hon Morris Iemma MP, commissioned PricewaterhouseCoopers (PwC) to undertake a major review of PADP. The Review focused on key areas of management and administration; target population and demand; and budgetary requirements and financial management.

1.14 Completed in June 2006, the PwC Review made 30 recommendations aimed at improving the consistency, efficiency and quality of PADP.[29]

1.15 The PwC Review is discussed in greater detail in chapter 2, with specific findings and recommendations referred to in the relevant sections of the report.

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25 PricewaterhouseCoopers, *NSW Health – Review of the Program of Appliances for Disabled People*, June 2006, p 44. Throughout the chapter this report will be referred to as the PwC Review

26 PWD E-Bulletin, *Program of Appliances for Disabled People (PADP): Update,* Issue 6, February 2004 <http://www.pwd.org.au/e-bulletin/pwd_e-bulletin_6.html> (accessed 31 October 2008)

27 PwC Review, p 44

28 PwC Review, p 44

29 Submission 72, NSW Health, p 3

Oakton audit report

1.16 NSW Health engaged Oakton, a business-consulting firm, in early 2007 to conduct an audit of each PADP lodgement centre. The audit focused on the areas of compliance, finance and performance related issues, covering the financial years of 2005/06 and 2006/07.

1.17 The Oakton report was published in response to an order for papers moved in the Legislative Council by Mr Ian Cohen MLC.[30]

1.18 The report found that across the lodgement centres there was non-compliance with several PADP operational guidelines relating to:

> … policies and procedures, diagnosis and prescription, transfer of clients' files to new locations, documentation of clients records, application documents, co-payment processes, utilisation of the management information system, lodgement centre operating hours, and procurement activities.[31]

1.19 Dr Richard Matthews, Deputy Director General, Strategic Development, NSW Health noted the findings of the Oakton audit as identifying 'significant inconsistency in the quality, efficiency and accountability of service delivery amongst the various lodgement centres'.[32] He also indicated that the ongoing changes to PADP would help to eliminate the inconsistencies across the lodgement centres.

Lifetime Care and Support Scheme[33]

1.20 During the course of the Committee's inquiry, access to appliances under PADP was compared to the Lifetime Care and Support (LTCS) Scheme. Both programs offer access to disability related equipment and appliances, with inquiry participants favourably viewing the assistance provided under the LTCS Scheme.

1.21 The LTCS Scheme evolved out of the Motor Accidents Authority (MAA) administered Motor Accidents Compensation Scheme, and was established under the *Motor Accidents (Lifetime Care and Support) Act 2006* (NSW).

1.22 The LTCS Scheme is administered by the Lifetime Care and Support Authority (LTSCA) and provides 'lifelong treatment, rehabilitation and attendant care services to people severely injured in motor accidents in NSW, regardless of who was at fault in the accident'.[34]

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30 LC Minutes No. 66, Wednesday 24 September 2008, Item 5, p 776

31 Oakton, *Financial, compliance and performance related audits of Area Health Lodgement Centres Program of Appliances for Disabled People – For EnableNSW*, June 2008, p 4

32 Dr Richard Matthews, Deputy Director General, Strategic Development, NSW Health, Evidence, 24 October 2008, p 1

33 The information in this section is sourced from NSW Legislative Council, Standing Committee on Law and Justice, *Review of the exercise of the functions of the Lifetime Care and Support Authority and the Lifetime Care and Support Advisory Council: First Report*, October 2008

34 LTCSA, *Annual Report, 2006-2007*, p 44

1.23 The Scheme began on 1 October 2006 for people under the age of 16 and on 1 October 2007 for people aged 16 and over. Funding is derived from the Medical Care and Injury Services Levy paid by motorists when they purchase a CTP Green Slip insurance policy.

1.24 Eligibility for the Scheme is determined on the basis of medical assessment, with different eligibility criteria set out in respect of spinal cord injuries, serious traumatic brain injuries, severe burns, bilateral amputations and permanent blindness.

1.25 Once a participant is accepted into the Scheme, the LTCSA will pay for treatment, rehabilitation and care services that are reasonable and necessary to help meet their needs and achieve their goals. Each participant is assigned a coordinator who serves as the primary point of contact between the participant, service providers and the LTCSA.

1.26 All participants are initially accepted as interim participants for two years, with an assessment at least two months before the end of the interim period to determine eligibility for lifetime participation.

Report structure

1.27 **Chapter 2** discusses the findings of the PwC Review, and provides an overview of PADP.

1.28 The impact of waiting lists on PADP clients, their carers and other areas of the health sector are considered in **Chapter 3.**

1.29 **Chapter 4** examines the adequacy and distribution of PADP funding in relation to the current, unmet and future demand for the program.

1.30 In **Chapter 5**, the eligibility requirements that determine access to the program are considered, as well as the arguments in support of converting PADP into a full entitlement scheme.

1.31 The prescription process, as well as the maintenance and repair of aids and appliances are discussed in **Chapter 6.**

1.32 The final chapter, **Chapter 7**, examines the broader reforms to PADP as recommended by the PwC Review, and highlights further areas for improvement.

Chapter 2 Background

This chapter discusses the findings of the PricewaterhouseCoopers (PwC) Review of the Program of Appliances for Disabled People (PADP), published in 2006, and examines the Government's response to the Review's recommendations. The chapter also provides an overview of PADP and outlines the major issues confronting the program.

People with a disability

2.1 According to a 2003 Australian Bureau of Statistics (ABS) report, one in five people in Australia, or approximately four million people, had a reported disability. The rate of disability was similar for both males (19.8 per cent) and females (20.1 per cent).[35]

2.2 Of those people with a disability, 86 per cent were restricted in terms of their self-care, mobility, communication, schooling or employment, with most people with a disability limited in one or more of these core activities.[36] One in 10 Australians with a disability used a piece of equipment or an aid to help them cope with their condition or manage with their everyday life.[37]

2.3 In regards to the NSW experience of disability, National Disability Services NSW, citing the same 2003 ABS statistics, reported to the Committee that:

- one in five people in NSW had a disability (approximately 1.2 million people)
- of those people with a disability, 88 per cent were restricted in terms of their self-care, mobility, communication, schooling or employment
- for 85 percent of people with a disability, their disability was of a physical nature
- people of working age with a disability have a lower rate of workforce participation (50 per cent) than those without a disability (80 per cent)
- the median gross weekly income of people with a disability ($190) was less than half that of people without a disability ($390)
- more than half of people with a disability were reliant on a government pension or benefit as their main source of income.[38]

2.4 The incidence of disability within the Indigenous community is of a higher proportion to that of the non-Indigenous population. The ABS states that 36 per cent of Indigenous Australians

35 Australian Bureau of Statistics, *Disability, Ageing and Carers: Summary of findings*, 2003, p 3 <http://www.ausstats.abs.gov.au/ausstats/subscriber.nsf/0/978A7C78CC11B702CA256F0F007B1311/$File/44300_2003.pdf> (accessed 29 October 2008)

36 *Disability, Ageing and Carers: Summary of findings,* p 4

37 *Disability, Ageing and Carers: Summary of findings,* p 7

38 Submission 54, National Disability Services NSW, p 4

aged over 15 years have a disability or a long-term health condition.[39] The Aboriginal Disability Network indicated that this 'doubles the non-Aboriginal rate of disability'.[40]

2.5 People from a Non-English Speaking Background (NESB) also make up a large proportion of the disabled community. In their submission to the Inquiry, the Multicultural Disability Advocacy Association (MDAA) observed that 'people from NESB with disability equate to 25% of all people with disability living in NSW'.[41]

2.6 The PwC Review forecast a dramatic increase in the incidence of disability in the next 10 years 'driven by the general ageing of the population and the high prevalence of disability in older age groups'.[42] There is also a predicted increase as a result of medical advances in technology, which has – for example – resulted in greater numbers of people surviving catastrophic injuries[43], and a greater number of infants surviving life-threatening conditions.[44]

Overview of PADP

Scope of the program

2.7 The program assists financially disadvantaged people by providing appliances, aids and equipment to eligible NSW residents with long-term or life-long disabilities to enable them to engage and participate within the community.[45] This is a very broad category of people, which extends to the elderly, patients in palliative care and patients with medical conditions such as cancer and multiple sclerosis.

2.8 Eligibility to PADP is universal for all children under the age of 16, while access for people over the age of 16 is means tested. Each client is required to make a $100 co-payment to the

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39 Australian Bureau of Statistics, *The Health and Welfare of Australia's Aboriginal and Torres Strait Islander Peoples*, 2005, p 56 <http://www.ausstats.abs.gov.au/ausstats/subscriber.nsf/0/F54883AEE4071013CA25706800757A2E/$File/47040_2005.pdf> (accessed 13 November 2008)

40 Mr Damian Griffis, Executive Officer, Aboriginal Disability Network, Evidence, 2 October 2008, p 60

41 Submission 35, Multicultural Disability Advocacy Association, p 3. MDAA uses the term Non-English Speaking Background (NESB) in preference to Culturally and Linguistically Diverse Background. The MDAA explains that the intention of using NESB is to highlight the inequity people experience due to linguistic and cultural differences.

42 PricewaterhouseCoopers, *NSW Health – Review of the Program of Appliances for Disabled People*, June 2006, p 85. Throughout the chapter this report will be referred to as the PwC Review

43 Dr Richard Matthews, Deputy Director General, Strategic Development, NSW Health, Evidence, 24 October 2008, pp 4- 5

44 Dr Richard Matthews, Deputy Director General, Strategic Development, NSW Health, Evidence, 1 October 2008, p 2

45 Submission 72, NSW Health, p 3

program in any year they are supplied equipment[46] (exceptions to this are discussed in Chapter 5).

2.9 The objectives of PADP are to ensure:

- improved access to appropriate equipment and appliances based on a person's needs
- improved quality of life for people with disabilities
- improved capacity of people with disabilities to participate in family and community activities, and to avoid premature or inappropriate entry to institutional care facilities.
- continuity of care
- effective management of existing resources
- timely and efficient service
- improved customer service.[47]

2.10 Clients of PADP are provided with the most cost effective and clinically appropriate equipment. The items of equipment that are most commonly supplied by the program include wheelchairs, seating support systems, patient lifters, showering and toileting aids, continence aids, communications devices and prostheses.[48]

2.11 In order to receive appliances, aids and equipment from PADP, there are several steps that must be undertaken prior to the item being supplied. The process involves:

- identification of the need for an appliance, aid or piece of equipment;
- an assessment is undertaken by a qualified professional (usually an occupational therapist) who then issues a prescription for the item;
- once the eligibility of the client is confirmed, the item will be classified as either high or low cost. Low cost items are approved by local PADP lodgement centres[49] and cost less than $800. High cost items are those costing over $800, and must be approved by the local Advisory Committee;
- after approval has been received to purchase the item, the client will the either receive the item or be placed on a waiting list until funds become available;
- the client will be given a previously used piece of equipment if it is clinically appropriate for their specific need. If no recycled item is available, a new item is purchased.[50]

2.12 In 2006/07, PADP provided assistive items to over 14,000 people, with each new applicant receiving an average of three items of equipment.[51]

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46 PwC Review, p 155

47 PwC Review, pp 31-32

48 PwC Review, p 15

49 Lodgement centres are the current administrators of PADP. See 2.14.

50 PwC Review, pp 33-34

Budget of the program

2.13 The PADP budget for 2008/09 includes $25.6 million of recurrent funding. This was supplemented by a one-off allocation of $11 million, consisting of $6 million from the NSW Government and $5 million from the Federal Government.[52]

2.14 The program is currently administered by 22 lodgement centres in eight Area Health Services (AHSs) across NSW, with funding allocated to each AHS via a resource distribution formula based on the size and demographics of the Area's population.[53]

2.15 The program budget is discussed in further detail in chapter 4.

The PricewaterhouseCoopers Review

2.16 The PwC Review of PADP, published in June 2006, made 30 recommendations regarding PADP management and administration; target population and demand; and budgetary requirements and financial management.

2.17 The central recommendation was 'that all PADP functions be transferred from the current Lodgement Centres to one state-wide administration covering the state'.[54] The Review found that greater transparency, efficiency and consistency could be achieved by having fewer centres.

2.18 Other recommendations made by the Review broadly included:

- the establishment of standards, performance indicators, policies and procedures to improve transparency and accountability
- the establishment of a new information system to allow improved management, reporting and equipment management
- improved access to information on the program, including a 1800 number and a website containing information on eligibility criteria, application forms, wait list information and a list of available equipment
- better guidance and support to improve the competency of equipment prescribers.[55]

2.19 The specific recommendations from the Review are referred to in the relevant sections of the Committee's report.

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51 Submission 72, p 7

52 Hon Justine Elliot MP, Minister for Ageing and Hon Reba Meagher MP, Minister for Health, '$11 million investment to eliminate disability equipment waiting list,' *Media Release*, 15 July 2008

53 Submission 72, p 6

54 PwC Review,p 19

55 PwC Review, pp 19-27

NSW Government's response to the Review

2.20 In their response to the Review, the NSW Government acknowledged the serious problems with the operation of PADP.

2.21 Of the 30 recommendations made by the PwC Review, the Government fully supported 21 recommendations, commissioned further work on four recommendations and did not support two minor recommendations.[56] Three recommendations required no response.[57] Consideration of these recommendations and the Government's implementation of them are discussed in the relevant sections throughout this report.

2.22 The Government response to the PwC Review noted that:

> … there are significant inefficiencies and inconsistencies inherent in the program's current administrative arrangements. The NSW Government has therefore decided to implement major reforms to improve the program's efficiency including full program centralisation, procurement strategies and information management initiatives …[58]

2.23 In particular, the Government supported the centralisation of PADP lodgement centres, to be delivered through a newly established body, EnableNSW.[59]

2.24 EnableNSW will serve as the central administrative body for the program, and will facilitate fair and consistent access to the program for applicants across NSW. [60] EnableNSW is discussed in further detail in chapter 7.

2.25 NSW Health indicated to the Committee that the final implementation of the reform package will not be completed until the end of 2010 or early 2011.[61] Dr Richard Matthews, Deputy Director General, Strategic Development, NSW Health informed the Committee that the long roll-out time was necessary because '[w]e want to be certain that we get it right'.[62]

EnableNSW

2.26 In its submission to the Inquiry, NSW Health listed the reforms that had been achieved to date (or are soon to be implemented) in relation to EnableNSW. These include:

- creation of a 1800 telephone number, launched in September 2007

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56 The Government did not support Recommendation 9 (to establish a state-wide Steering Committee with a smaller membership and a focus on governance), nor did it support Recommendation 30 (to change the name of the program to Program of Aids for People with Disabilities – PADP).

57 NSW Health, NSW Government response to the Review of the Program of Appliances for Disabled People, November 2007, p 2

58 NSW Government response, November 2007, p 2

59 NSW Government response, November 2007, p 3

60 Submission 72, p 7

61 Ms Bronwyn Scott, Director, EnableNSW, NSW Health, Evidence, 1 October 2008, p 3

62 Dr Matthews, Evidence, 24 October 2008, p 2

- creation of a new website
- establishment of an advisory council to provide governance for EnableNSW programs
- a pilot program for new prescription processes.[63]

2.27 NSW Health also indicated that an information system with computer telephony interface would be implemented by March 2009.[64]

2.28 Once completed, it is hoped that the reforms enacted under EnableNSW will result in the creation of a fair and consistent program that is able to efficiently and effectively meet the needs of its clients. NSW Health described the challenges facing EnableNSW:

> … the processes for assessing assistance needs to be simpler and clearer, and we appreciate the need to provide clinicians with better support to assist them with the critical task of assessing and prescribing equipment. We also agree the program needs to use its budget more efficiently to make sure we assist as many people as possible …[65]

2.29 The role of EnableNSW and the aforementioned reforms will be considered further in chapter 7.

63 Submission 72, p 4

64 Submission 72, p 4

65 Dr Matthews, Evidence, 1 October 2008, p 2

Chapter 3 Waiting lists

One of the major issues raised during the Inquiry regards PADP waiting lists. Despite being approved to receive aids or appliances through the program, many people experience considerable delays in receiving their equipment. The existence of long waiting lists at most lodgement centres across New South Wales is a direct consequence of inadequate program funding (discussed in chapter 4).

Waiting for equipment, sometimes for several years, has profound consequences for clients and their carers – physically, mentally, socially and financially. These consequences in turn have a flow-on effect to other health sectors. This chapter examines those issues and highlights the importance of ensuring timely access to appropriate aids and appliances.

Length and cost of waiting lists

3.1 A common story heard throughout the Inquiry was of PADP clients waiting more than one or two years to receive equipment that they had already been approved for, with some reports of participants being on a waiting list for up to four years.[66] In evidence to the Committee, Mr Chris Sparks, Executive Officer, Independent Rehabilitation Suppliers Association of NSW, commented: 'Imagine going to see your optometrist to get a glasses prescription today knowing full well you are not going to order them for 18 months or more. It is simply absurd'.[67]

3.2 The combined waiting list for equipment at all PADP lodgement centres across NSW as at 30 June 2008 is set out in the following table:

Table 1 Waiting list as at 30 June 2008 [68]

Total number of people	3688
Total number of children	964
Total number of adults	2724
Average waiting time (days)	209
Total value of wait list	$7,454,817

3.3 Separate lodgement centre waiting lists varied significantly across NSW, ranging from $0.7 million - $1.7 in metropolitan Sydney, to $0.3 million - $0.6 million in the four rural Area Health Service's (AHSs).[69]

66 Submission 75, Spinal Cord Injuries Australia, p 3; Submission 63, Mr Greg Killeen, p 1

67 Mr Christopher Sparks, Executive Officer, Independent Rehabilitation Suppliers Association of NSW, Evidence, 2 October 2008, p 22

68 Answers to questions on notice taken during evidence 1 October 2008, Dr Richard Matthews, NSW Health, Question 2, p 1

69 Submission 72, NSW Health, p 6

3.4 Inquiry participants despaired over the length of waiting lists, accentuating the point that the need for disability aids and appliances is exactly that – a need, not a desire. This was articulated by Mr Andrew Buchanan, Chairperson, Disability Council of NSW:

> How can one say this well enough, with sufficient force? A colostomy bag is not a fashion accessory … If you are a ventilator dependent quad, the key word in that description is "dependent". If you are going to breathe you need the equipment that substitutes for those bits of your body that no longer function.[70]

3.5 The need for timely equipment was noted by Northcott Disability Services in their submission: 'The bottom line is – families seek our help with equipment when there is a need, often an urgent need, not when there is going to be a need 6 to 18 months into the future'.[71]

3.6 Public information about the length of waiting lists and clients' positions on the lists are discussed at 7.46 – 7.50.

Life expectancies

3.7 While the need for equipment is undoubtedly urgent for all clients, for some it is more urgent than others. For example, the Motor Neurone Disease Association of NSW advised that the median life expectancy for their members is 27 months from diagnosis to death.[72] Similarly, the Cancer Council NSW noted that the concept of being placed on a waiting list for over two years is simply untenable for cancer patients in the end-stage of their illness.[73]

3.8 The Disability Enterprises submission observed that in some instances, equipment has been delivered to clients that have passed away.[74] This sad reality was also raised by Mr George King: 'For many years people have literally died waiting for their name to come to the top of the list'.[75]

3.9 Many people with a disability experience shorter life spans. For example, the Muscular Dystrophy Association advised that people with duchenne muscular dystrophy usually only survive to their early twenties.[76] In their submission they commented on the effect of their clients waiting over two years for equipment, remarking '[f]or some that is 10% of their entire life!'[77]

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70 Mr Andrew Buchanan, Chairperson, Disability Council of NSW, Evidence, 1 October 2008, p 33

71 Submission 49, Northcott Disability Services, p 3

72 Mr Graham Opie, Chief Executive Officer, Motor Neurone Disease Association of NSW, Evidence, 1 October 2008, p 27

73 Submission 73, The Cancer Council NSW, p 6

74 Submission 3, Disability Enterprises, p 1

75 Submission 30, Mr George King, p 1

76 Submission 31, Muscular Dystrophy Association NSW, p 1

77 Submission 31, p 2

Factors contributing to waiting lists

3.10 Inadequate funding (discussed in chapter 4) is the obvious cause of lengthy waiting lists, however NSW Health asserted that it is not the only factor. In their evidence they stated that other factors impacting the lists include administrative delays, current procurement practices, and incorrect prescriptions.[78]

3.11 Dr Richard Matthews, Deputy Director General, Strategic Development, NSW Health, added that variable pricing and differences in local business processes and lodgement centres are also contributing factors. Dr Matthews told the Committee: 'We hope that the new standardised prescription processes, the statewide procurement contracts, and all the new business and information processes will eliminate a lot of those inequalities and inefficiencies'.[79]

3.12 Prescription processes will be discussed in chapter 6. State-wide procurement contracts and information processes will be discussed in chapter 7.

Other waiting lists

3.13 Inquiry participants highlighted that clients have to wait on more than one list before they can receive PADP equipment.[80] The Disability Enterprises submission stated:

> There are different levels of waiting. The client has to wait for an assessment, wait for quotes, wait at the GP for signature, wait for a reply from program, wait for prioritisation, wait for a therapist etc.[81]

3.14 The Association for Children with a Disability NSW also raised the issue of different waiting lists, outlining the process for children with a disability to receive equipment:

- 'The first waitlist is to see a therapist to assess the child, identify and organise a trial of possible solutions. This can take 12 months.
- The therapist then has to write a report to PADP specifying the problem, best solutions and likely outcome for the child. This can take a further 3 months.
- This report then goes on a waitlist for submission to PADP regional assessors, who decide whether to recommend the equipment for funding. This can take 6 months.
- If successful, the request for equipment then goes onto another waitlist until funding becomes available. This can take another 12 months'.[82]

3.15 The length of time it can take to see a therapist to assess and prescribe equipment, particularly in rural and remote areas, was a significant issue raised during the Inquiry. This is discussed further in chapter 6.

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78 Submission 72, p 9

79 Dr Richard Matthews, Deputy Director General, Strategic Development, NSW Health, Evidence, 1 October 2008, p 5

80 For example, see Submissions 3, 37, 52 and 53.

81 Submission 3, p 1

82 Submission 53, Association for Children with a Disability NSW, p 2

3.16 Where a therapist makes a prescription for a high cost (over $800) or complex item, it must first be assessed by a PADP committee who decide whether or not to approve the application (see Chapter 5).[83] The Spinal Pressure Care Clinic noted that many of these committees only meet bi-monthly, therefore if a committee requires more information regarding an application, it will not be reviewed again for a further two months.[84]

3.17 Some committees meet even less regularly. Spinal Cord Injuries Australia stated that some only meet four times per year.[85] This was acknowledged by the Director of EnableNSW, Ms Bronwyn Scott:

> Some of the lodgement centres have regular monthly committee meetings and some of them have meetings every three months. Some of them have meetings even less often than that.[86]

3.18 Ms Scott indicated that this situation will change with the reforms to PADP, so that all committees meet more regularly to consider these applications.[87]

Committee comment

3.19 The Committee is strongly of the opinion that the length of PADP waiting lists is unacceptable. Prompt access to equipment is essential for people with a disability for reasons that will be further discussed below.

3.20 We believe that strict performance indicators should be applied to waiting lists, specifying acceptable maximum timeframes for client's to wait for their equipment. These timeframes will need to vary accordingly depending on the urgency for the aid or appliance in question. For example, incontinence pads and feeding tubes may have a performance indicator of a few days, whereas a powered wheelchair might have an indicator of three months.

3.21 The specific timeframes of these indicators should be set by the EnableNSW Advisory Council. Once established, performance against these indicators should be published on the EnableNSW website on a monthly basis.

Recommendation 3

That the EnableNSW Advisory Council apply strict performance indicators to PADP waiting lists. Performance against these indicators should be published on the EnableNSW website monthly.

3.22 With regard to the issue of waiting lists to see therapists, we note that it forms part of the much broader issue of health and rural recruitment. That issue will be considered in chapter 6.

83 PricewaterhouseCoopers, *NSW Health – Review of the Program of Appliances for Disabled People*, June 2006, p 106. Throughout the chapter this report will be referred to as the PwC Review

84 Submission 71, Spinal Pressure Care Clinic, p 5

85 Submission 75, p 3

86 Ms Bronywn Scott, Director, EnableNSW, Evidence, 1 October 2008, p 7

87 Ms Bronywn Scott, Evidence, 1 October 2008, p 7

3.23 As for the frequency of PADP committee meetings, we acknowledge Ms Scott's evidence that these committees will meet more regularly, however note that we have not received evidence specifying exactly how often that will be. We therefore recommend that they meet monthly, in order to assist in the minimisation of waiting lists.

Recommendation 4

That EnableNSW ensure that all PADP Advisory Committees meet monthly to consider high cost and complex applications.

Aids and appliances for DADHC clients

3.24 One anomaly identified during the Inquiry relates to the provision of aids and appliances to clients in Department of Ageing, Disability and Home Care (DADHC) Group Homes. Clients in these residencies are not subjected to lengthy waiting lists for disability equipment like PADP clients.

3.25 Dr Matthews explained that one reason for the different treatment of the two groups, who otherwise both fall into the same category of 'people with a disability', merely comes down to an historical separation: '[W]e [NSW Health] do the broad community and the Department of Ageing, Disability and Home Care provides services for those in group homes'.[88]

3.26 He pointed out that the demand for equipment in the broader community is much 'deeper, longer, broader and more varied' then the demand for equipment in the finite group of people in DADHC Group Homes.[89] Nonetheless, in response to questioning from the Committee regarding the fairness of this situation, Dr Matthews conceded:

> In the broader sense, I guess I cannot justify it. I think we would all agree that people with disability should receive the aids and appliances they need in as timely a manner as is possible ... In all honesty, I cannot provide a justification for people waiting.[90]

Committee comment

3.27 The Committee is concerned about the unfairness of this situation, where one person with a disability being cared for by DADHC may only need to wait one week for equipment, yet another person with the same disability but being cared for in the community by their family may have to wait two years for the same equipment.

3.28 It is clear to us that the only way to overcome this anomaly is to provide adequate recurrent funding for PADP. This will be discussed chapter 4.

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88 Dr Richard Matthews, Deputy Director General, Strategic Development, NSW Health, Evidence, 24 October 2008, p 3

89 Dr Richard Matthews, Evidence, 24 October 2008, p 3

90 Dr Richard Matthews, Evidence, 24 October 2008, p 3

Physical impacts

3.29 As a result of lengthy waiting lists, PADP applicants can be left without appropriate aids or appliances for extended periods of time. This has a range of physical impacts on both clients and their carers.

Impacts on clients

3.30 Lengthy waits for aids and appliances often results in a client's condition deteriorating, or new conditions developing. For example, in addition to causing excruciating pain and discomfort,[91] unsuitable seating and sleeping equipment may lead to muscular-skeletal problems and deformities.[92]

3.31 Scoliosis in particular will worsen without appropriate seating and sleeping equipment, which has the effect of:

> … undoing the beneficial effects of therapy and surgery and leading to secondary, sometimes life-threatening medical conditions caused by the structural damage to the skeleton and resultant pressure on lungs, stomach.[93]

3.32 According to the Spinal Cord Injuries submission, a recently released PADP waiting list revealed one child in western Sydney waiting over 18 months for a back brace.[94] Such long delays for essential equipment were commented on by Ms Faye Galbraith, the mother of two children with disability:

> It is completely unacceptable that children should suffer lifelong pain and disfigurement because in NSW we do not have adequate access to disability aids, equipment and therapy. I have met parents of children whose internal organs have been adversely affected by severe scoliosis, respiratory and gastroenterological organs have been irreversibly affected - all exacerbated by inappropriate, ill-fitting equipment and lack of intervention.[95]

3.33 Clients are also likely to develop pressure sores, leading to prolonged periods of hospitalisation[96], and in some cases even death.[97] Pressure sores are considered in more detail later in this chapter.

3.34 Another impact of waiting lists commonly raised in evidence is the swelling of limbs for lymphoedema[98] sufferers. The Cancer Council advised that one of the few evidence-based

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91 Submission 53, p 2

92 Submission 51, Physical Disability Council of NSW, p 10; Submission 70, Aboriginal Disability Network NSW, p 2

93 Submission 53, p 2

94 Submission 75, p 5

95 Submission 77, Ms Faye Galbraith, p 3

96 Submission 70, p 2

97 Submissions 70, 71 and 75

treatment options to reduce lymphoedema symptoms is the use of compression sleeves in conjunction with professional lymph drainage massage.[99] The effect of waiting long periods to receive compression sleeves is that the oedema builds up during that time. Therefore if a client has been measured for garments, then is required to wait six or eight weeks to receive them, the garments will no longer fit. Manufacturers refuse to send out garments in these situations until the client is re-measured, which then delays the process even further.[100]

3.35 The impact of this on lymphoedema clients, who are 'swelling by the day',[101] was articulated by Mr Barry Bryan, the Coordinator of a Lymphoedema Support Group:

> The problem from a patient's point of view is that it is very, very frustrating. You have got the condition, you have then spent the money on getting oedema down. You have got the measurements and then if there is a delay at the stage of ordering the garments the whole effort has been wasted.[102]

Case Study: Client A*

Client A underwent a lumpectomy to remove cancer in her breast. During her cancer treatment she also had her lymph nodes removed, resulting in lymphoedema. The client now suffers from painful blockages and swelling, and is required to wear compression garments and receive regular lymphatic drainage treatments to ease her condition.

The compression garments used by Client A cost her $80, and to work effectively they need to be replaced at least every three to four months, at a total cost of $320 per year. However due to high medical expenses she can only afford one sleeve at a time. Lymphatic drainage treatments are also necessary to keep the swelling under control, however at $80 a session Client A also struggles to pay for these treatments.

These costs are impeding Client A's quality of life and are causing her additional discomfort, as without regularly replaced garments her oedema builds up. Timely support from PADP would be a welcome relief to assist this client as she continues her remission from breast cancer.

* Submission 24, Hunter Lymphoedema Support Group, p 5

98 Lymphoedema is an accumulation of lymphatic fluid which causes swelling, mostly in the arms and legs. It can develop when lymphatic vessels are missing or damaged, or when lymph nodes have been removed (as often occurs during cancer treatment).

99 Submission 73, p 3

100 Submission 8, Mr Barry Bryan, p 1

101 Mr Barry Bryan, Evidence, 1 October 2008, p 22

102 Mr Barry Bryan, Evidence, 1 October 2008, p 24

3.36 In commenting on the current waiting list situation, the Association of Occupational Therapists asked:

> Given that people need enabling equipment at the time they are assessed, the question arises as to what they are expected to do while they are waiting for the prescribed products to arrive[?][103]

Impact on carers

3.37 There is also a risk of physical injury to carers if appropriate equipment, such as lifting equipment, is not provided. While professional carers will not provide services without this equipment due to Occupational Health and Safety (OH&S) requirements,[104] it is more than likely that family carers will: 'In a family setting if there is no item of equipment you have to make do'.[105]

3.38 This can often lead to injury. Northcott Disability Services noted:

> Once a parent has an injury, they too need medical treatment and may even need the assistance of Home Care and more Respite services for their child. So many of the parents of the children we see already have back and shoulder injury or pain by the time the much-needed hoist, wheelchair or shower chair is funded.[106]

Case Study: Client B*

Client B is a young girl who has Spinal Muscular Atrophy. She and her family have been waiting for nearly a year for a range of equipment to help her throughout the day, including a pressure relieving mattress, electric bed, shower/commode chair, wheelchair and a supportive car seat.

Client B is difficult to lift because her body is somewhat floppy due to weak muscles. She is too heavy for her mother to lift, and her father also struggles to lift her due to a back injury.

Unfortunately, Client B's PADP simply has no funds available. The family is having a tough time managing their daily lives and are concerned about developing further injuries. The physical impacts of not being provided with timely aids and appliances takes a huge toll on families like these, and could be prevented through early intervention from the health care system.

* Submission 49, Northcott Disability Services, p 4

3.39 The impact of a lack of appropriate aids on the general health of family carers was observed by the Association of Occupational Therapists, who stated that '[t]he flow on effect to families can mean that they are required to spend more time in a caring role, which can have a

103 Submission 37, Australian Association of Occupational Therapists NSW, p 2

104 Submissions 11, 14 and 37

105 Submission 75, p 5

106 Submission 49, p 4

deleterious effect on their health and capacity to remain in the workforce'.[107] The Spinal Cord Injuries submission further commented:

> They [carers] have increased workloads placing a greater strain on both themselves and on the family; if a family member. When it is a partner that is being cared for a carer can often be at great risk of physical injury and owing to the long term harshness of caring, may suffer premature ageing.[108]

Committee comment

3.40 The Committee notes with concern the serious physical impacts caused by lengthy waiting lists. We note that these impacts have been acknowledged by the NSW Government and PwC Review, and that NSW Health is in the process of implementing a broad range of reforms which are expected to improve waiting times (which are discussed throughout this report).

3.41 However, while these reforms should reduce waiting lists, without additional funding they will only increase again. We believe that this can only be achieved through adequate recurrent funding (which will be considered in chapter 4).

Social and emotional impacts

3.42 A common theme raised in evidence was the social and emotional impact of not having access or having delayed access to appropriate disability aids and appliances. Some inquiry participants suggested that this is particularly the case with children, as it impedes their ability to take part in school and leisure activities,[109] and therefore impedes their ability to learn new skills and develop independence.[110] Northcott Disability Services reflected:

> The long delay means that their child doesn't have equipment to assist them with their mobility or function to allow them to join in with their peers or participate in the community or achieve age-appropriate independence. This dominos because it affects social, emotional, and academic skills as well as physical ones.[111]

3.43 Lengthy waiting lists also impact on the ability of adults to socially interact, participate in family and community activities, and engage in employment.[112] The Spastic Centre of NSW asserted:

> Access to equipment such as mobility (wheelchairs, walking frames), communication devices and other assistive equipment products are an essential requirement to allow a person to integrate and participate in their communities.[113]

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107 Submission 37, p 4

108 Submission 75, p 5

109 Submissions 37, 38, 53 and 77; and Miss Rebecca Phillips, Manager, Service Development and Government Relations, Northcott Disability Services, Evidence, 2 October 2008, p 2

110 Submission 77, p 1

111 Submission 49, p 3

112 Submissions 4, 35, 37, 38, 51 and 61; and Miss Rebecca Phillips, Evidence, 2 October 2008, p 2

113 Submission 38, The Spastic Centre of NSW, p 2

3.44 The emotional impact on clients was outlined by Spinal Cord Injuries Australia, which stated:

> If you look at the emotional costs, lack of participation in the community and life, a feeling of isolation, loss of self-control, you have people paying a far higher cost for PADP.[114]

3.45 According to Spinal Cord Injuries Australia, the delay in receiving appropriate equipment has also contributed to clients' mental health problems.[115]

Sourcing equipment outside of PADP

3.46 Many clients and their families seek to source their own equipment, rather than wait on lengthy PADP waiting lists. This may be through private procurement or via fundraising or charities. While these options may prove to be faster, they also present a number of issues.

Costs of equipment

3.47 The costs of disability aids and appliances for clients and families who wish to purchase their own equipment can be quite substantial. For example, the General Manager of Services from the Spastic Centre, Mr Chris Campbell, informed the Committee that for a motorised wheelchair with specialised seating systems and a communication device, 'you are looking at potentially $20,000 or more'.[116]

3.48 The Muscular Dystrophy Association NSW advised that the average cost of aids and appliances for a person with duchenne muscular dystrophy ranges from around $24,300 to $36,000. This is for a powered wheelchair, pressure seat, shower/commode chair, hoist and sling for transferring between bed to chair, high low electric bed, pressure mattress and breathing support machine. Many of these items will also need to be replaced throughout the client's lifetime.[117] Further, the Association added:

> People that have other types of muscular dystrophy and allied neuromuscular disorders require some or all of the above equipment but over a significantly longer time frame and may need to replace items three or four times. Therefore it may cost upwards of $100,000 over their life time.[118]

3.49 Other examples of costs provided in evidence include $600 for a pair of compression sleeves for lymphoedema clients (which need to be replaced at least once a year),[119] $3,000 for special orthopaedic boots,[120] and $250-$800 per month for gastrostomy feeding.[121]

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114 Submission 75, p 5

115 Mr Sean Lomas, Policy and Information Manager, Spinal Cord Injuries Australia, Evidence, 1 October 2008, p 46

116 Mr Chris Campbell, General Manager, Services, the Spastic Centre, Evidence, 1 October 2008, p 47

117 Submission 31, p 2

118 Submission 31, p 2

119 Submission 73, p 3

3.50 There are also significant costs involved to accommodate certain equipment, as outlined by Ms Fiona Anderson, the mother of a child with a disability:

> If you have a power wheelchair you need a van to transport it. You also need an accessible house. We have tried to make renovations to our house. It is far more expensive to renovate the house and do retrofittings than it is to rebuild it, so we have been forced to rebuild. Our costs have just blown out exponentially.[122]

3.51 Home and vehicle modifications are discussed further in chapter 6.

Reduced earning capacity

3.52 A significant barrier to self-funding expensive disability equipment is that people with a disability are likely to have a restricted capacity to earn an income. This point was demonstrated by the Council of Social Services of NSW, which noted that the poverty rate amongst people with a disability exceeds that of people without a disability by more than six-fold.[123]

3.53 There is also a substantial impact on the income of family carers through the long-term loss of a first or second income. Inquiry participants stressed that not only is immediate income affected, but so are retirement funds.[124] This was illustrated by Ms Anderson, who has endeavoured to pay for as much of her son's equipment and services as possible without relying on government assistance:

> However, if we pay for all the equipment, therapy and services that my son needs, which we have done by taking out another mortgage using the 40 percent equity in our home, and taking out superannuation, we can fund this at the front end but that leaves us nothing for when we retire. So my son may not be a burden on the State at this stage but we certainly will be in 10 or 20 years' time.[125]

3.54 Ms Anderson added: 'You are caught in a noose because although our costs are significantly higher than many other families without a child with a disability, we have less capacity to earn income because there is no after-school care and no vacation care'.[126]

Assistance for private procurement of equipment

3.55 The Committee heard from families, such as Ms Anderson and Ms Fabig (see case study in chapter 6), who expressed their desire to purchase their own equipment wherever possible.

120 Ms Wendy Hall, Senior Manager Client Programs, Northcott Disability Services, Evidence, 2 October 2008, p 5

121 Submission 42, Gastronomy Information and Support Society NSW

122 Ms Fiona Anderson, Evidence, 1 October 2008, p 12

123 Submission 61, Council of Social Services of NSW, p 4

124 Submission 53, p 1

125 Ms Fiona Anderson, Evidence, 1 October 2008, p 12

126 Ms Fiona Anderson, Evidence, 1 October 2008, p 12

However, these families suggested that it would be desirable if some form of assistance (other than direct funding) were available to assist them in doing this.

3.56 For example, Ms Faye Galbraith suggested in her submission that it would be of considerable benefit if disability equipment were tax deductible:

> [If] the government gave all equipment/aids 100% tax-deductible status it would allow for people who wanted to and were able to self-fund to do so, thus freeing up PADP funding for others.[127]

3.57 The Association for Children with a Disability expanded on this to recommend that all 'self-funded expenditure on necessary equipment, services and therapy due to the effects of disability' be 100 per cent tax deductible.[128]

3.58 The author of Submission 39 suggested that a grant or tax scheme could be introduced to assist with the purchase of equipment:

> Could a grant (similar to the once a year $1,000 pension scheme) or a tax scheme to allow the total return of such expenses, be made available for disabled people to use to purchase essential equipment and aids? Based on one's level of disability, the grant/tax return could be scaled and allowed to be accumulated over years so that large purchases such as motorized wheelchairs could be achieved on an individual basis.[129]

3.59 Under the Federal net medical expenses tax offset, people can claim an offset of 20 per cent of their net medical expenses over $1,500. Medical expenses which qualify for the tax offset include payments:

- to a carer who looks after a person who is blind or permanently confined to a bed or wheelchair
- for medical aids prescribed by a doctor
- for artificial limbs or eyes and hearing aids.[130]

Committee comment

3.60 The Committee agrees that some form of assistance, subsidy or incentive should be provided to encourage clients and their families – who are in a financial position to do so – to purchase their own equipment where possible. There are clear benefits and cost savings to be made from this approach, which would alleviate pressure and demand on the overstretched PADP.

3.61 While people with a disability may be eligible for tax relief in relation to the cost of appliances under the net medical expenses tax offset, the Committee recognises that inquiry participants proposed far more generous taxation relief than currently offered under this scheme. That is,

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127 Submission 77, p 3

128 Submission 53, p 5

129 Submission 39, Name suppressed, p 1

130 http://www.ato.gov.au/individuals/content.asp?doc=/content/19181.htm (accessed 24 November 2008)

for a 100 per cent tax deduction in relation to the costs of having a disability, not just aids and appliances. So for example, tax relief in relation to vehicle and home modifications.

3.62 The Committee believes the Federal Government should examine options within the tax system for reducing the taxation burden for people who have to bear the cost of a disability. This matter could perhaps be examined as part of the current review of Australia's tax system.[131]

3.63 Accordingly, the Committee recommends that the NSW Minister for Health initiate discussions with the Federal Treasurer regarding ways to assist people with a disability to receive tax relief for the costs associated with a disability.

Recommendation 5

That the NSW Minister for Health initiate discussions with the Federal Treasurer regarding ways to increase tax relief for the costs associated with a disability.

Reliance on charities

3.64 In many cases private procurement is not feasible, so families seek help from charitable organisations such as the Spastic Centre, Variety Club, Rotary, Lions, St George Foundation and Clubs NSW.[132] The Spastic Centre alone has raised over $2 million to date to purchase aids and appliances for people with a disability.[133]

3.65 According to the Spastic Centre, there appears to be an increasing reliance on charities to provide disability equipment,[134] which raises a number of issues. One such issue relates to problems with maintenance. The Committee received evidence that equipment provided by charities may not be maintained by PADP, resulting in those costs instead being borne by the user and their family.[135] This issue is considered in chapter 6.

3.66 Another issue raised in evidence is that disability service providers are being diverted from providing essential clinical services to engaging in fundraising activities.[136] It was highlighted that this is particularly a problem given the current shortages of health professionals in the workforce.[137]

3.67 In their submission, MS Australia told the Committee that where their charity is unable to meet equipment provision requests, 'it can exacerbate clients' disappointment, frustration,

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131 <http://taxreview.treasury.gov.au/content/Content.aspx?doc=html/reference.htm> (accessed 24 November 2008)

132 Submission 38, p 3

133 Submission 54, National Disability Services NSW, p 11

134 Submission 38, p 4

135 Ms Wendy Hall, Evidence, 2 October 2008, p 3

136 Submission 61, p 4; Submission 68, MS Australia, p 7

137 Submission 54, p 11

anger, stress, negative perception of allied health, MS Australia, government and/or community service providers'.[138]

3.68 Mr Dougie Herd, Executive Director, Disability Council of NSW, also commented on the current situation where charities are relied upon as a fallback equipment provider:

> It has an ability to operate in a way in which perhaps we do not really want people to have to operate, which is that it knocks on the doors of Rotary or local communities and says, "We have this individual with this need who needs a wheelchair. Can we get it quickly please?" And the community dips into its pockets. We perhaps maybe want to move away from that if we can, yet hold on to the compassion, the passion and commitment that is exhibited in that fundraising effort, but perhaps to remove some of the lack of dignity, the charitable need, so that people can get equipment as a matter of right.[139]

3.69 The right to equipment as an entitlement will be considered in chapter 5.

Impact of waiting lists on other health sectors

3.70 Nearly all of the physical impacts (outlined earlier in this chapter) of not having appropriate aids and appliances have a flow-on affect to other parts of the health sector. Without early intervention, clients can require acute rehabilitation, pain medication and/or therapy.[140]

Early intervention

3.71 The timely and appropriate provision of aids and appliances can lead to significant cost savings to clients and the community. For example, National Disability Services NSW enunciated that timely provision of equipment enables people with a disability to be cared for in the community, reduces the demand for more costly personal assistance, reduces the risk of hospital admissions, and has broader benefits through facilitating the person to participate in community and employment activities.[141] They stated in their submission:

> The value of the PADP extends beyond the individual. Significant economic and social benefits from investing in the timely and appropriate provision of aids and equipment are also important to consider - the rates of return in areas like health and educational outcomes are much higher from early investments than those made later in life.[142]

3.72 Inquiry participants emphasised that when considering the level of funding for PADP (see chapter 4), the importance of early intervention cannot be underestimated.[143] A simple example provided by the Disability Council of NSW illustrates this point:

138 Submission 68, p 7

139 Mr Dougie Herd, Executive Director, Disability Council of NSW, Evidence, 1 October 2008, p 37

140 Submission 52, Disability Council of NSW, p 3

141 Submission 54, p 10

142 Submission 54, p 13

143 For example, see Submissions 52, 54 and 61

> The cost of a manual hoist is approximately $1200. This is significantly less than the cost of two home care staff that is required to manually transfer a person with a physical disability. This does not include the OH&S liability if a staff member were to injure themselves. Council is therefore of the strong opinion that early intervention is imperative and will subsequently decrease the burden on other health sectors.[144]

3.73 The importance of providing timely equipment to enable carers to support people with a disability in the community was emphasised in evidence:

> Personal carers who are supported in their role with the appropriate tools and aids can provide higher quality at-home care that in turn can lead to a reduction in expenditure on acute health care, residential aged care, supported accommodation for people with disabilities and other community care services. Maintaining individuals at home is cost effective when compared to institutional care.[145]

3.74 According to Invacare Australia, conservative estimates indicate that carers save the economy $16 billion annually by providing 74 per cent of all community care services.[146]

3.75 The importance of early childhood intervention was raised by Ms Heike Fabig, the mother of two children with a disability, who referred to research findings on the benefit of early equipment usage on development. Ms Fabig's son missed out on a power wheelchair at an early age, and as such has experienced developmental delays.[147] Ms Fabig said:

> The whole idea of early intervention is in the first word "early". You intervene while they are still young so they will learn skills that down the track you do not have to pay the money in helping them. So if someone says to me "Yes, your daughter can have a wheelchair, but she needs to wait two years" I know that that is two years where you build up a developmental delay that we do not need.[148]

Pressure sores

3.76 An example of the impact of not providing appropriate equipment on other parts of the health sector is provided by an examination of the prevention and treatment of pressure sores. A 2004 study on spinal cord injury clients in NSW found that pressure sores accounted for 6.6 per cent of all readmissions to hospital, and those admissions accounted for 27.9 per cent of re-hospitalisation bed days. The study found that the average length of stay for those cases was 65 days.[149]

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[144] Submission 52, p 3

[145] Submission 14, Invacare Australia, p 2

[146] Submission 14, p 2

[147] Ms Heike Fabig, Evidence, 1 October 2008, p 13

[148] Ms Heike Fabig, Evidence, 1 October 2008, p 16

[149] Submission 72, p 10

3.77 Spinal Cord Injuries Australia informed the Committee that modest estimates in 2006 placed the cost of treating pressure sores between $61,230 and $100,000, stating 'the false economy of not providing equipment in a timely manner is very obvious'.[150]

3.78 Likewise, the MS Society asserted: 'The purchase of an $8,000 mattress and good seating in addition to self management support can prevent such episodes. Saving just one hospital admission per lifetime for a person at risk of pressure ulcers justifies the investment'.[151]

3.79 Another issue, raised by the Spinal Injury Practitioner Group NSW, is that clients who require higher level pressure care equipment cannot be discharged from hospital until the equipment is provided.[152] Delays in this provision result in prolonged hospital stays, costing NSW Health approximately $1,000-$1,500 per bed per day.[153]

Hospital discharges

3.80 The issue of people waiting to be discharged from hospital but who are unable to do so due to a lack of appropriate equipment was also raised by other inquiry participants.[154] Mr Greg Killeen commented on the absurdity of this situation: 'Everyone hears about waiting lists and about people trying to get into hospital to get a public hospital bed. In this situation people cannot get out of hospital because they cannot get their support needs'.[155]

3.81 NSW Health stated that they are unaware of specific instances where a person has been kept in hospital because they are waiting for equipment.[156] They advised however that there are systems in place to assist with the timely discharge of patients with equipment requirements. These include Equipment Loan Pools (ELPs) (discussed at 3.101 – 3.112) and the Specialised Equipment Set-Up Program.

Specialised Equipment Setup Program

3.82 Patients with catastrophic injury or illness such as spinal cord injury or acquired brain injury have been recognised as a distinct group that require accessible accommodation and appropriate community care in order to be discharged from hospital. The provision of aids and appliances to assist these clients with newly acquired injuries has put a considerable strain on PADP offices in the past due to the short timeframes involved in providing necessary equipment.[157]

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150 Submission 75, p 4

151 Submission 68, p 7

152 Submission 56, Spinal Injury Practitioner Group NSW, pp 2-3

153 Submission 63, p 2

154 Submission 46, Greater Metropolitan Clinical Taskforce, GMCT Brain Injury Rehabilitation Program Summary Paper, p 1; Submission 63, Mr Greg Killeen, p 2

155 Mr Greg Killeen, Evidence, 1 October 2008, p 21

156 Answers to questions on notice taken during evidence 1 October 2008, Dr Richard Matthews, NSW Health, Question 2, p 2

157 Submission 72, p 10

3.83 The PwC Review recommended that a state-wide set up fund be established to assist with necessary equipment provision for non-compensable patients in NSW public hospitals due to catastrophic injury or disease.[158]

3.84 The NSW Government supported the concept of this recommendation, and established the Specialised Equipment Set-Up Program (SESUP) on 1 July 2008. SESUP provides timely access to equipment for clients in the above category to assist in their discharge from hospital. The recurrent SESUP budget for 2008/09 is $1.8 million.[159]

3.85 While still in its early days, there has already been positive feedback on the program. The Greater Metropolitan Clinical Taskforce submission commented:

> We have … found the decision making over applications by the set-up fund to be made rapidly and in a timely fashion. In addition we have found the set-up fund to be quite flexible around finding solutions to meet the individual needs of patients.[160]

3.86 A separate but related program is the Lifetime Care and Support Scheme.[161] That Scheme provides life long care and equipment to children who have been catastrophically injured in a motor vehicle accident on or after 1 October 2006, and adults catastrophically injured in a motor vehicle accident on or after 1 October 2007.[162] Due to the overlapping target group, this Scheme ameliorates some of the demand on SESUP.[163]

Nursing homes

3.87 The Committee also received evidence of people with a disability having to move into inappropriate accommodation while they wait for aids and appliances. This includes younger people being placed into nursing homes, who then become supported by the Department of Ageing, Disability and Home Care.[164]

3.88 Some people with a disability may remain in nursing homes permanently. The Spinal Pressure Care Clinic noted that this too is just a cost shifting process:

> … many nursing home clients are "ineligible" for PADP equipment however many Nursing Homes do not have sufficient funding to purchase equipment esp. High level pressure mattresses. Thus these clients are supported by hospital ELP stock (for up to 2+ years).[165]

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158 PwC Review, p 10

159 Submission 72, p 10

160 Submission 46, p 2

161 The Scheme is run by the Lifetime Care and Support, a statutory Authority established by the *Motor Accidents (Lifetime Care and Support) Act 2006*.

162 NSW Health, 'NSW Government response to the Review of the Program of Appliances for Disabled People', November 2007, p 10

163 NSW Government response, November 2007, p 10

164 Submission 52, p 2

165 Submission 71, p 4

Committee comment

3.89 The Committee strongly supports early intervention, and recognises that the costs for timely equipment today are often significantly outweighed by the costs of hospital admissions and therapy services tomorrow. We also recognise the benefits early intervention has on peoples' development and social and economic wellbeing. Given that there is an expected increase in demand for PADP (see chapter 4), the need for early intervention is even more important in order to manage resources in the future.

Reassessments

3.90 A key issue regarding lengthy waiting lists raised by suppliers and therapists is that they often lead to the need for costly reassessments and re-prescriptions.[166] Situations have commonly occurred where a client finally reaches the top of a waiting list only to find that their circumstances have changed and they require a new assessment.

3.91 This may be due to a client's physical needs having changed;[167] the equipment no longer being available or having been superseded;[168] pricing changes[169] or quotes (which are usually only valid for three months) having expired.[170]

3.92 In any of these cases, clients will require a new prescription. As explained by Mr Killeen, this involves 'the duplication of the entire equipment trialling, assessment and prescription process involving the PADP customer, the therapist/prescriber and a number of equipment suppliers'.[171] Evidence from the Independent Rehabilitation Suppliers Association of NSW suggested that approximately 40-50 per cent of quotes require reassessment.[172]

3.93 Suppliers raised concerns about the resource implications of reassessments. According to the PwC Review, per annum, reassessments take up approximately 68 hours per assessor at a cost of almost $2,000 per assessor.[173]

3.94 Reassessments also cause inconvenience to clients, who in some instances may even be required to return to the waiting list.[174]

3.95 In their submission, NSW Health acknowledged that waiting lists often lead to the need for new assessments and prescriptions, and recognised the impact of the 'duplication in work for already busy clinicians'.[175]

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166 Submissions 45, 49, 54, 55

167 Submission 45, Otto Bock Australia, p

168 Submission 43, Independent Rehabilitation Suppliers Association of NSW, p 3

169 Submission 43, p 9

170 Submission 37, Australian Association of Occupational Therapists NSW, p 4

171 Submission 63, p 2

172 Submission 43, p 9

173 PwC Review, p 96

174 Submission 37, p 4

Case Study: Technical Aid to the Disabled*

Technical Aid to the Disabled (TAD) NSW is a supplier of custom equipment for people with a disability. Long delays in PADP waiting lists have caused significant disruptions to the company, who regularly experience delays of 6 to 12 months between equipment prescriptions and the release of PADP funds.

Fifty per cent of TAD equipment projects are undertaken for children under the age of 12. When there are significant delays from PADP, children's measurements often change, resulting in the need for expensive reassessments and redesigning of equipment.

The cost of materials can also rise sharply during this time, which often exceeds the original quotes given. For example, TAD provided one quote for a bathing aid for $200, however after waiting 12 months for funding from PADP, the cost of stainless steel rose by almost 60 per cent. The new cost of materials for the bathing aid exceeded $320.

TAD believes that the program is practical and essential, however stated: 'PADP works, but ever so slowly'.

* Submission 54, National Disability Services NSW, p 24

Pre-approval

3.96 Evidence received by the Committee suggested that the best way to avoid costly reassessments (other than to increase funding to eliminate waiting lists) is to have a pre-approval system for prescriptions.[176] The concept of pre-approval was explained by Mr George King:

> … the best most cost effective way to reduce costs and stress for all is for the relevant Therapist to submit an application for the equipment with an approximate cost. When approved the full assessment process can occur, a quote be submitted and then if within a pre-approved range a purchase order can be raised within the PADP system.[177]

3.97 It is believed that a system of pre-approval would reduce the practice of costly reassessments and re-prescriptions, and save Government and businesses approximately $4,000,000 per annum.[178] Additionally, as noted by Mr Sparks from the Independent Rehabilitation Suppliers Association of NSW, '[t]he client is better off because they are not being dragged through a

175 Submission 72, p 11

176 See for example Submissions 30, 38, 43, 45, 50, 55, 71 and 72

177 Submission 30, Mr George King, p 3

178 Submission 43, p 3

lengthy assessment only to be not given anything for 18 months and for it all to be done again'.[179]

3.98 NSW Health has agreed that there is merit in a pre-approval system, and is planning a Pre-approval Pilot through EnableNSW for complex seating and mobility equipment in early 2009. The Department estimates that this may reduce clinical assessment times by 50 per cent.[180]

3.99 While supportive of the pilot, Mr Sparks noted that the Western Area Health Service already implemented a successful pre-approval system several years ago. Mr Sparks expressed his frustration in already knowing that pre-approval is efficient and effective, yet still having to go through a pilot scheme.[181]

Committee comment

3.100 The Committee agrees with inquiry participants that a pre-approval system should be implemented to address the issue of reassessments. Such a system will introduce efficiencies to alleviate pressure on the PADP waiting list. We therefore support the pilot being implemented by EnableNSW early in 2009.

Equipment pools

3.101 A short-term remedy for clients on waiting lists is to provide them with equipment sourced through equipment pools. Inquiry participants supported the use of these pools as an effective means of addressing urgent needs while waiting for permanent aids and appliances to be supplied or repaired.

Loan pools and recycling

3.102 As mentioned earlier, short-term loan equipment is available to assist people who need aids or appliances before they can be discharged from hospital back into the community. These are provided through hospital equipment loan pools (ELPs) and include items such as wheelchairs, pressure cushions, shower commodes and electric hoists.[182]

3.103 AHS's are responsible for operating the loan pools within their Area. Most Areas have a number of separately administered ELPs, which are usually hospital based or client specific (such as palliative care patients).[183] While these pools primarily cater for people with short-term or temporary conditions, they can also be used to meet the needs of clients waiting for PADP equipment.[184]

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179 Mr Christopher Sparks, Executive Officer, Independent Rehabilitation Suppliers Association of NSW, Evidence, 2 October 2008, p 28

180 Submission 72, p 11

181 Mr Christopher Sparks, Evidence, 2 October 2008, p 28

182 Submission 72, p 9

183 NSW Government response, November 2007, p 20

184 NSW Government response, November 2007, p 20

3.104 Another type of equipment pool involves recycled equipment. The scope of re-using equipment was noted by the General Manager of Invacare Australia, Mr Shaun Jenkinson: 'You only have to go to PADP areas around the State to see the effective bone yard of equipment sitting outside, unused, un-maintained and wasted, which is hugely inefficient'.[185]

3.105 The ability to 'recycle' wheelchairs, for example, was explained by the owner of GTK Rehab, Mr Gregory Kline: 'These days most chairs are flexible enough to grow in different dimensions so we reconfigure it for the new individual and it goes out again. We think that is a great use of resources'.[186]

3.106 Recycling equipment is particularly beneficial to children, who quickly outgrow aids and appliances which can then be adapted and re-used by another child. Ms Wendy Hall, Senior Manager Client Programs, Northcott Disability Services, told the Committee: 'I know that schools often say they have storerooms full of equipment that has been prescribed for children who have moved on'.[187]

3.107 Dr Matthews advised that NSW Health is indeed looking to re-use and recycle some low-cost PADP equipment that has been returned by clients.[188] Once refurbished, suitable equipment will be registered on a state-wide recycling webpage for reallocation to clients where appropriate.[189]

3.108 Dr Matthews also informed the Committee that where necessary, people in receipt of equipment from loan pools who need to keep it permanently may be able to do so. He explained that 'it will flip, if you like, out of the loan pool into a PADP item'. [190]

3.109 With regard to patients who require equipment to be discharged from hospital, but are unable to benefit from ELPs due to specialised equipment requirements, the Committee was advised that EnableNSW plans to work with hospital management to prioritise these clients for PADP funding.[191]

3.110 To ensure fairness and equity across the State, the PwC Review recommended that AHS's combine all equipment pools within their Area to a single equipment service within each Service.[192] The recommendation stated that '[t]his administrative process would be responsible to ensure all equipment, regardless of the origin of the funds that purchased it, is available for the most appropriate use within the Area'.[193]

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185 Mr Shaun Jenkinson, General Manager, Invacare Australia, Evidence, 2 October 2008, p 26

186 Mr Gregory Kline, Owner, GTK Rehab, Evidence, 2 October 2008, p 26

187 Ms Wendy Hall, Evidence, 2 October 2008, p 6

188 Dr Richard Matthews, Evidence, 24 October 2008, p 13

189 Submission 72, p 15

190 Dr Richard Matthews, Evidence, 24 October 2008, p 9

191 Submission 72, p 9

192 PwC Review, p 20

193 PwC Review, p 26

3.111 The NSW Government strongly supported this recommendation, and as part of its centralisation reforms will develop an integrated ELP service for each AHS. Each Area will be required to meet a minimum standard of service, provide a standard set of equipment, and meet minimum standards for maintenance and safety checking.[194] The integrated services will provide a central contact and coordination point between each Area and EnableNSW.[195]

3.112 Dr Matthews advised that '[t]he pools will remain local [to each AHS] but they will be coordinated centrally so that there is an overall understanding of what there is and where it is and who currently has it'.[196]

Equipment database

3.113 To assist with better management of the equipment pools, inquiry participants raised the need for an accurate database to keep track of equipment.[197] The earlier examples illustrated the lack of tracking in the current system, which has resulted in the loss of much valuable PADP equipment. This idea was elaborated on by Mr Dougie Herd, the Executive Director of the Disability Council of NSW:

> … people get prescribed equipment that sometimes sits in their back room and is never used; some bits of equipment vanish. We do not know what happens to them. Somebody dies, that is tragic. A family member comes along and says, "Oh, we'll sell this wheelchair because grandmother does not need it anymore" not realising that it is owned by the New South Wales Department of Health.[198]

3.114 NSW Health advised that it will be implementing a new information system in March 2009 which will include an asset management function to keep track of equipment, maintenance schedules and replacement timeframes.[199] Clients will be contacted regularly to ascertain whether they still require the equipment.[200] The information system is discussed further in chapter 7.

Committee comment

3.115 The Committee supports the use of equipment loan pools and equipment recycling as an efficient and cost-effective means of providing timely support to people with a disability. We realise that these options may not be suitable for everyone, such as clients with complex needs, nonetheless they will still benefit a substantial number of people.

3.116 It is clear from the evidence that these avenues have not been taken advantage of in the past, and we are optimistic that the new asset management system will remedy this situation. We

194 NSW Government response, November 2007, p 20

195 NSW Government response, November 2007, pp 4-5

196 Dr Richard Matthews, Evidence, 24 October 2008, p 9

197 Submission 52, p 3

198 Mr Dougie Herd, Evidence, 1 October 2008, p 38

199 NSW Government response, November 2007, p 19

200 Submission 72, p 17

believe that the effective use of loan pools and equipment recycling will also go some way to easing the burden on PADP resources and provide more short term relief for people on waiting lists. Having said that, we note that in many cases this will only be a temporary solution, and maintain that additional recurrent funding is still required to ensure the viability of PADP (discussed next in chapter 4).

Conclusion

3.117 Timely access to aids and appliances is essential for the health and wellbeing of people with a disability. It is equally essential for reasons of independence and social inclusion, which according to one inquiry participant should 'in a wealthy democracy such as ours - be a basic human right'.[201]

3.118 The frequent occurrence of PADP clients waiting years for vital equipment is inexcusable, and has resulted in increased costs and pressures on already stretched health resources by exacerbating and/or creating additional health conditions for clients and carers.

3.119 Long waiting lists have also impacted on the health and safety of carers, and resulted in increased costs and workloads for suppliers and therapists through the need for constant reassessments.

3.120 For all of these reasons it is critical that waiting lists be reduced as a matter of urgency. This will require a substantial increase in recurrent funding (discussed in chapter 4), and will be measured through the introduction of performance indicators establishing reasonable waiting periods.

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201 Submission 77, Ms Faye Galbraith, p 1

Chapter 4 Funding and data

The adequacy and distribution of PADP funding was a major theme identified by clients, suppliers and therapists during the Inquiry. The program has received various funding boosts over the years, however these have failed to address the underlying need for adequate recurrent funding to meet existing demand. Further, there has been a lack of consideration of unmet and future demand for the program, highlighting the need for a significant and permanent increase in PADP funding.

Budget

Distribution

4.1 The core PADP budget in 2008/09 is $25.6 million. This has increased by 141.6 per cent since 1999/00.[202] Funding for PADP primarily comes from NSW Health, however the Department of Ageing, Disability and Home Care (DADHC) contributes $2 million of the recurrent budget to help meet the equipment needs of children under sixteen.[203]

4.2 In addition to recurrent funding, a one-off funding boost of $11 million was announced on 15 July 2008 to eliminate existing waiting lists. This boost comprises of $6 million from the NSW Government and $5 million from the Federal Government.[204] Funding boosts will be considered in more detail later in this chapter.

4.3 The funding for PADP is currently spread across the 22 lodgement centres located in the eight Area Health Services (AHSs), and the Children's Hospital at Westmead. Funding is proportionally allocated using a resource distribution formula based on the size and demographics of the population in each AHS.[205]

4.4 In 2006/07, 80 per cent of the PADP budget was spent on the purchase of disability equipment. The remaining 20 per cent was spent on administration.[206] In evidence, Dr Richard Matthews, Deputy Director General of Strategic Development, NSW Health, advised that the Department expects to achieve efficiency gains through its centralisation reforms (discussed in chapter 7), which they hope will allow them to increase the proportion of the PADP budget spent on equipment to 84 per cent.[207]

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202 Submission 72, NSW Health, p 6

203 Submission 66, Department of Ageing, Disability and Home Care, p 1

204 Submission 72, p 6

205 Submission 72, p 6

206 Dr Richard Matthews, Deputy Director General, Strategic Development, NSW Health, Evidence, 1 October 2008, p 2

207 Dr Matthews, Evidence, 1 October 2008, p 2

Variations in spending

4.5 Although lodgement centres are allocated funds based on a resource distribution formula, there have been significant inconsistencies across AHSs regarding how these funds have been spent. For example, one lodgement centre might approve a client for certain equipment, while another may not.[208]

4.6 There are also variations in the way each AHS prioritises clients for funding, and major impacts which can result from one or two very high cost applications in smaller centres.[209] This latter point was explained by Ms Cathrine Lynch, Director, Primary Health and Community Partnerships, NSW Health: '[I]n rural areas, because the population is smaller the amount of funding to that area is smaller. So, if there are a couple of high-cost items it can impact that budget'.[210]

4.7 It was further observed by the Australian Association of Occupational Therapists NSW that there is 'poor financial control over PADP funds' by some AHSs.[211] The Association indicated that in some Areas, PADP funds have been spent on non-PADP programs, as 'the funds are not quarantined'.[212]

4.8 A similar observation was made in the Otto Bock Australia submission, which stated: 'We have received reports that some Health Services allocate their PADP equipment funds to cover general hospital running costs'.[213]

4.9 A recently released audit of PADP lodgement centres found a number of significant financial discrepancies by AHSs in the spending of funds.[214] One discrepancy, for example, involved spending of PADP funds on a specialised seating clinic, the Bathurst Seating Clinic. In evidence, Dr Matthews noted that the spending on the Clinic was to assist in the provision of services for people with a disability, being totally funded by the Area Health Service PADP budget. Dr Matthews acknowledged that other seating clinics were not using PADP funding, and that the spending 'for that particular purpose is technically outside the rules'.[215]

4.10 Another discrepancy involved expenditure on oxygen. The audit found that certain area health services spent PADP funds on the Home Oxygen Program.[216] The Committee was informed

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208 Submission 8, Mr Barry Bryan, p 1

209 Submission 72, p 6

210 Ms Cathrine Lynch, Director, Primary Health and Community Partnerships, NSW Health, Evidence, 24 October 2008, p 9

211 Submission 37, Australian Association of Occupational Therapists NSW, p 2

212 Submission 37, p 2

213 Submission 45, Otto Bock Australia, p 6

214 Oakton, 'Financial, Compliance and Performance Related Audits of Area Health Service Lodgement Centres, Program of Appliances for Disabled People (PADP) for Enable NSW', June 2008, pp 5-12. Throughout this chapter this report will be referred to as the Oakton audit.

215 Dr Richard Matthews, Deputy Director General, Strategic Development, NSW Health, Evidence, 24 October 2008, p 14

216 Oakton audit, p 5

that NSW Health has directed all relevant monies spent on this program to be returned to the PADP budget.[217]

4.11 The variations in PADP budget spending have been acknowledged by the NSW Government,[218] and were considered as part of the PwC Review. The existence of these variations was one of the reasons for the Review recommending that PADP lodgement centres be centralised to a single state-wide administration.[219]

4.12 NSW Health has agreed to implement this recommendation, and will be consolidating the different PADP budgets as part of its reforms (see chapter 7).

Committee comment

4.13 The Committee notes the current variations across different AHSs regarding budget spending. We note that NSW Health has acknowledged these variations, and that it is in the process of consolidating and centralising PADP budgets to eliminate these differences as part of its response to the PwC Review. The Committee supports the centralisation of the PADP budget to ensure equitable access for clients regardless of where they live in NSW.

Inadequacy of funding

4.14 While there are undoubtedly a number of different factors that have led to the problems with PADP outlined in chapter 2, the key issue that has either caused or exacerbated many of those factors is inadequate funding.

Funding shortfall

4.15 In its review of the program, PwC found that that there was a 'failure of the available funds to adequately satisfy the reasonable expectation of the client group'.[220]

4.16 This point was exemplified in evidence from Ms Wendy Hall, Senior Manager of Client Programs, Northcott Disability Services, who spoke of her experiences with PADP:

> They just tell our staff when they ring that they have no funds. All these applications have been before the local PADP committee and we are told they have no funds to provide the equipment.[221]

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217 Dr Matthews, Evidence, 24 October 2008, p 8

218 NSW Health, 'NSW Government response to the Review of the Program of Appliances for Disabled People', November 2007, p 4

219 PricewaterhouseCoopers, 'Review of the Program of Appliances for Disabled People', June 2006, p 19. Throughout the chapter this report will be referred to as the PwC Review

220 PwC Review, p 16

221 Ms Wendy Hall, Senior Manager Client Programs, Northcott Disability Services, Evidence, 2 October 2008, p 5

4.17 The funding shortfall is clear from the PADP waiting lists, which were considered in chapter 3. Another consequence of the shortfall suggested by inquiry participants is that the scarcity of resources has had a negative effect on the program's development. For instance, the Australian Association of Occupational Therapists stated:

> The lack of adequate funding for PADP is the root cause of many of the other inefficiencies experienced by the scheme. Scarcity of funding has spawned time consuming bureaucratic processes to protect budgets and spread available resources as thinly as possible.[222]

4.18 The Association asserted that this has resulted in poor client outcomes, extended wait times, and equipment prescriptions based on availability rather than client needs.[223] (Prescriptions will be examined in chapter 6).

4.19 A similar statement was made by the Spastic Centre, which expressed the view that PADP 'has evolved and reacted to an environment of "scarcity of resources"', declaring that 'the unpredictable waiting periods for funding approval highlight a system that is unable to respond to existing demand and is even less able to be proactive in assessing and responding to future demand'.[224]

4.20 In evidence to the Committee, the Director of the Council of Social Services of NSW (NCOSS), Ms Alison Peters, agreed that the lack of funding has resulted in the program being structured around rationing resources. Ms Peters added:

> It is fair to say that whenever you have inadequate resources problems with administration will be worse because they become about rationing inadequate resources as opposed to perhaps more systemic issues about whether you are doing a good job or not.[225]

4.21 Inquiry participants stressed that the needs of people with a disability must not be sidelined due to a lack of funding, and that the program should be provided enough funding to meet essential equipment requirements.[226] Consideration of appropriate funding levels is discussed at sections 4.44 – 4.53.

Funding boost

4.22 As mentioned earlier, a one-off $11 million funding boost to eliminate the existing equipment waiting list was announced in July 2008. The boost is expected to deliver essential equipment to around 5,000 PADP clients.[227] Approximately 10 per cent of the funding is to be allocated to other disability support equipment outside of PADP.[228]

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222 Submission 37, p 2

223 Submission 37, p 2

224 Submission 38, The Spastic Centre of NSW, p 2

225 Ms Alison Peters, Director, Council of Social Services of NSW, Evidence, 1 October 2008, p 60

226 Submission 64, Vision Australia, p 2; Submission 68, MS Australia, p 4

227 Submission 72, pp 4-5

228 Submission 72, p 9 (footnote a)

4.23 While certainly a welcome relief for many, the boost has also sparked some criticism. Noting that $11 million represents around 40 per cent of the program's total recurrent funding, Spinal Cord Injuries Australia remarked:

> Surely this is further evidence of how bad things have become. It is embarrassing for the NSW Government to formally recognise that a program is under funded within the 07/08 budget to the tune of around 40%.[229]

Case Study: Client C*

Client C is a four year-old boy who has Spinal Muscular Atrophy, a condition that causes his muscles to become progressively weaker, limiting his ability to move. He requires a highly supportive seating system and power wheelchair to allow him greater mobility and enable him to participate in preschool and other activities. Client C's family and therapists are concerned that his inability to move independently will impact negatively on his cognitive and social development, which has already been delayed.

Client C's parents submitted an application for funding in December to Liverpool PAPD. In February the application was approved, however there were no funds available to procure the wheelchair. Assuming that Liverpool PADP would receive additional funding in July, as it had the past 10 years, the family turned down an offer from the local services club to pay for the wheelchair due to an understanding that PADP does not fund maintenance and repairs for equipment donated by charities. They were distraught when in July their PADP failed to receive enhancement funds and they learnt that their child may have to wait an additional 12 months for his chair.

The family welcomes the injection of $11 million designed to eliminate PADP waiting lists. However due to a lack of information provided about the funding boost they are uncertain as to if and when this will assist their child. The long and uncertain waiting lists and inadequate program funding have caused undue burden on the family.

Client C is still without his power wheelchair and is currently being assessed for additional necessary aids and appliances. The family's feelings of being 'left up in the air' are compounded by the knowledge that further funding delays are hampering Client C's development.

* Submission 49, Northcott Disability Services, p 3

4.24 Other inquiry participants queried how the boost would affect the service capacity of industry providers, expressing concerns that the increase in equipment provision would place additional pressure on therapists, suppliers, manufacturers and PADP staff.[230]

[229] Submission 75, Spinal Cord Injuries Australia, p 4

[230] Submission 54, National Disability Services NSW, p 9; Mr Shaun Jenkinson, General Manager, Invacare Australia, Evidence, 2 October 2008, p 24

4.25 This issue was recognised by NSW Health, who advised that the funding boost is being distributed to lodgement centres on a quarterly basis, in order to help manage the increased workload.[231]

4.26 The Committee was informed that this is not the first funding boost that the program has received. Over recent years, DADHC has also made a number of non-recurrent contributions to PADP totalling $5 million[232] (in addition to its $2 million recurrent contribution). The effect of such contributions on the program was discussed by MS Australia:

> As a way of managing the demand for equipment, one-off injections of money in State Budgets is inert. It focuses on clearing waiting lists but does not contribute to PADP being able to deliver on its purpose more generally across the health or disability system. Waiting lists always leapfrog funding injections, so Government is always playing catch up. It also makes it almost impossible to establish what the program budget actually is - an essential number for any analysis.[233]

4.27 Invacare Australia also criticised the inconsistent and 'lumpy' funding approach of non-recurrent contributions, commenting that it creates difficulties for suppliers and therapists who then need to adapt their resources to meet the fluctuating demand. Invacare suggested that '[s]moother funding with more streamlined approvals will result in significantly improved planning and ultimately much greater customer service for the clients'.[234]

4.28 A similar statement was made by the MS Society, who maintained that an adequate and indexed level of recurrent funding was preferred to improve service delivery:

> … one-off injections of money out of each State budget do not solve the challenge of meeting the ongoing need for equipment in the community. The problems of the scheme are longstanding and as much about the administration of an underfunded scheme (that is more about rationing than providing equipment) as anything. Adequate recurrent funding would allow better operation of the program, and encourage operational policy aimed at delivering individual and program outcomes, not merely budget targets.[235]

Committee comment

4.29 While we welcome any additional funding, the Committee agrees with inquiry participants that the provision of non-recurrent funding boosts is not a preferable solution to the budget issues faced by PADP. We view one-off boosts to be band-aid solutions, and note the added difficulties of inconsistent funding flows on suppliers and therapists.

4.30 It is our opinion that many of the problems pertaining to PADP can only be solved through additional recurrent funding, which will be discussed later in this chapter.

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231 Answers to questions on notice taken during evidence 1 October 2008, Dr Richard Matthews, NSW Health, Question 2, p 2

232 Submission 72, p 23

233 Submission 68, p 4

234 Submission 14, Invacare Australia, p 3

235 Submission 68, p 4

Unmet demand

4.31 While the funding boost was granted to clear PADP waiting lists, it failed to take into account unmet demand. The unmet demand group for PADP was defined by Spinal Cord Injuries Australia as people who:

- are deterred from applying for equipment owing to an understanding of the length of the waiting list;
- have been on the waiting list for a long time and simply dropped off it;
- are making do with inappropriate equipment;
- through severe need have sourced the equipment through a service provider or other arrangement; or
- who through language, cultural barriers or lack of understanding of the program have never applied.[236]

4.32 The 2001 Australian Institute of Health and Welfare report 'Unmet Needs for Disability Services' estimated that within the Australian health system, as few as one in ten people are successful in accessing programs.[237] The Aboriginal Disability Network NSW claimed that 'it would not be unreasonable to suggest that for every person who has registered a request, there are two who have not'.[238]

4.33 Determining the exact size of this group is an onerous task, particularly given the lack of data collection on people with a disability in NSW and their equipment requirements.[239] However, without this information, it is impossible to ascertain the full extent of funding required: 'How can funding thus be properly allocated if need isn't recognised?'[240] The need for better data collection is considered in chapter 7.

4.34 Nonetheless, whatever the size of this group may be, it is clear that the equipment waiting list (which had over $7.4 million in equipment outstanding as at 30 June 2008[241]) indicates only a fraction of the size of the total group of people with a disability who would benefit from receiving aids or appliances under PADP.

Increasing demand

4.35 The inadequacy of existing funding levels is even more concerning given that future demand for PADP is expected to increase significantly. There are a variety of factors behind this predicted increase.

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236 Submission 75, pp 2-3

237 Submission 75, p 2

238 Submission 70, Aboriginal Disability Network NSW, p 2

239 See for example Submissions 63, 64, 68, 72 and 75

240 Submission 75, p 3

241 Answers to questions on notice taken during evidence 1 October 2008, Dr Richard Matthews, NSW Health, Question 2, p 1

4.36 One is the increased lifespan of people with disabilities as a result of better health care.[242] Another is the ageing population,[243] as older age groups have a high prevalence of disability.[244] Related to both factors is the ageing of carers and the deterioration of equipment.[245]

4.37 Advances in medical science have also led to increasing demand, due to a greater incidence of 'children (congenital) and adults (acquired) surviving with a higher severity of disability'.[246] For example, NSW Health noted that there is a now a higher occurrence of people surviving catastrophic injuries, and acknowledged that 'the future demand for this particular form of assistance is unquantifiable and will be a problem for every government at every level going into the future'.[247] Equipment provision for people in this category was discussed in chapter 3.

4.38 In evidence to the Inquiry, Dr Matthews provided an example of the budget implications that stem from advancements in medical technology involving ventilator assisted neonates (i.e. children being born being ventilator assisted) who are to be discharged home:

> These are children who, not many years ago, would not have survived. We have had to commence that [neonatal ventilated assistance] program because we found ourselves in the situation where there were children who had nowhere to go beyond the intensive care unit at Westmead kids, and Sydney kids, and that was unacceptable.[248]

4.39 Dr Matthews informed the Committee that it costs NSW Health up to $0.5 million per year to fund each child in this program.[249]

4.40 The Spastic Centre suggested that there would also be an increase in demand due to higher community expectations to access current technology and equipment to facilitate social inclusion:

> For example a younger generation of children with severe physical disabilities will expect access to specialised mobility and communication equipment to participate in the curriculum at school and communicate with their peers. Adults from previous generations did not have the same expectations or access to this equipment. Children with disabilities will expect the same level of access to technology as their able bodied peers.[250]

4.41 NSW Health also raised the issue of the rising obesity rate and concurrent costs associated with appropriate equipment for clients within that group: 'For example, the cost of a bariatric

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242 Submission 38, p 3

243 Australian Bureau of Statistics 2008, 'New South Wales In Focus - Population', Cat. No. 1338.1, ABS, Canberra

244 Submission 72, p 7

245 Submission 71, Spinal Pressure Care Clinic, p 2

246 Submission 38, p 3

247 Dr Matthews, Evidence, 24 October 2008, p 5

248 Dr Matthews, Evidence, 1 October 2008, p 2

249 Dr Matthews, Evidence, 24 October 2008, p 17

250 Submission 38, p 3

commode for a person who is obese costs $489 compared with $265 for a standard commode'.[251]

4.42 The increased cost of equipment as a result of technological advances was outlined by inquiry participants as a factor that will need to be taken into account in future planning for PADP,[252] as will increasing awareness and regulations concerning Occupational Health and Safety (OH&S) standards.[253]

4.43 The PwC Review also acknowledged that demand on PADP would continue to increase with estimated increases in population prevalence of disability.[254]

Suggested level of funding

4.44 There was a clear consensus in evidence that PADP requires a significant increase in its recurrent level of funding. The suggested level of this increase varied amongst participants, many of whom suggested specific amounts based on various formulas.

4.45 For example, the Aboriginal Disability Network NSW suggested that funding be increased to at least $40 million recurrent per annum immediately and then progressively increased by 10 per cent per annum over the next five years:

> In other words, the value of the one-off 'bail-outs' of the program in the past two years ought to be made recurrent, and there ought to be stable program growth to keep pace with increasing demand which will be, hopefully, associated with greater program visibility and penetration to its intended beneficiaries.[255]

4.46 Based on analysis of data provided by PricewaterhouseCoopers, NCOSS recommended that PADP be allocated an additional $24.4 million in 2009/10, rising to a total budget of $100 million in 2014/15. NCOSS stated that this figure includes incremental budget increases to assist in supporting future increases in program demand.[256]

4.47 Likewise, the Physical Disability Council of NSW (PDCN) also recommended an increase of $24.4 million to the 2008/09 budget to fund existing unmet need, followed by additional increases of $10 million to accommodate the ageing population.[257]

4.48 Other providers, such as National Disability Services NSW, suggested that at the very least, the funding boost of $11 million should be the minimum additional amount injected into PADP on a recurrent basis.[258] The Disability Council of NSW also supported this:

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251 Submission 72, p 7

252 Submissions 45, p 4; Submission 64, Vision Australia, p 3; Dr Matthews, Evidence, 24 October 2008, p 4

253 Submission 68, p 5

254 PwC Review, p 85

255 Submission 70, p 2

256 Submission 61, Council of Social Services of NSW, p 3

257 Submission 51, Physical Disability Council of NSW, p 6

> There is strong evidence, however, from non-government advocacy organisations, from NGO disability service providers, from latent demand, population trends and research that a compelling case exists to transform the one off addition into recurrent allocation in the years to come. We commend such a view to members of the standing Committee and would propose, therefore, that this year's allocation of approximately $36.5 Million be used as the base budget figure for future expenditure.[259]

4.49 The PwC Review also found that the PADP budget of $21 million (in 2005/06) was inadequate to meet the needs of the disabled community. The Review estimated that at least $50 to $100 million would be required if it were to meet full, unrestricted demand for the program.[260] It did not, however, make any recommendations for additional funding for the program.

4.50 NSW Health asserted in its submission that the improvements and efficiencies being made through its centralisation reforms will free up more of the PADP budget to be spent on equipment.[261] However, Dr Matthews acknowledged in evidence that this will only go some way in meeting demand:

> … the gap between funding and demand will be partly picked up by our efficiencies – I have no doubt about that – and some of the waiting times will be improved purely by efficiencies. There will then emerge the difference between the budget and the demand, and that will need to be the subject of growth funding applications in the same way that the rest of Health is.[262]

Committee comment

4.51 The Committee is in no doubt that the existing recurrent level of funding for PADP is inadequate, and has been inadequate for a long time. It is evident that the scarcity of resources has caused and/or exacerbated most of the existing problems with the program, not least of which include the lengthy waiting lists discussed in chapter 3.

4.52 The Committee acknowledges that NSW Health is taking steps to increase the amount of the budget to be spent on equipment, however note that even the Department recognises that the expected efficiency gains will not be enough to meet either current, unmet or future demand for the program.

4.53 We refer to Recommendation 1 of this report, that the recurrent funding for the program be increased immediately to $36.6 million.

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258 Submission 54, p 9

259 Submission 52, Disability Council of NSW, p 2

260 Submission 73, The Cancer Council NSW, p 5

261 Submission 72, p 9

262 Dr Matthews, Evidence, 24 October 2008, p 3

Overdue accounts

4.54 A significant proportion of submissions received by the Committee were from suppliers, nearly all of whom raised serious concerns regarding the impact of late payments of accounts by PADP, which appears to have become a standard practice.

4.55 PADP invoices are supposed to be paid within 30 days, however the Committee received evidence of delays in payment of accounts of up to 120 days.[263] One supplier claimed to have had payments overdue by more than six months.[264] The owner of GTK Rehab, Mr Gregory Kline, stated: 'The closest we get to getting paid in 30 days would be 45, and there is only one PADP who normally meets that criteria …'[265] Mr Kline added, 'three weeks ago I had over $300,000 out over 90 days. I am a small business. We cannot carry that sort of debt'.[266]

4.56 Suppliers have simply been told that funds are not available to pay their invoices.[267] The impact of this on the cash flow of small businesses in particular is considerable, with suppliers facing increased finance and overdraft charges,[268] and some even struggling to pay their staff.[269]

4.57 Invacare Australia advised that such debts may force a supplier to reduce inventory levels, which can cause delays in supplying equipment to clients and reduce expected service levels.[270] Cole Orthotics told the Committee: 'Notwithstanding these delays, as responsible people we realise that disabled patients desperately need support and we are faced with having to realise on personal assets (and pay Capital Gains Tax) to fund our continued operation'.[271]

4.58 In some cases, suppliers may be prevented from providing the equipment altogether. The personal impact of this was observed by the General Manager of Invacare, Mr Shaun Jenkinson:

> … the emotional strain of saying, "We can't provide this equipment because we don't know if we are going to get paid" means that it is very emotive when you have a user at the end who really desperately needs that equipment.[272]

4.59 According to the Independent Rehabilitation Suppliers Association of NSW, overdue PADP payments are estimated to cost businesses over $1,200,000 annually in interest and recovery expenses.[273]

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263 Submission 30, Mr George King, p 4

264 Submission 45, pp 3-4

265 Mr Gregory Kline, Owner, GTK Rehab, Evidence, 2 October 2008, p 23

266 Mr Kline, Evidence, 2 October 2008, p 23

267 Submission 76, Cole Orthotics Pty Ltd, p 1

268 Submission 43, Independent Rehabilitation Suppliers Association of NSW, p 11

269 Mr Christopher Sparks, Executive Officer, Independent Rehabilitation Suppliers Association of NSW, Evidence, 2 October 2008, p 24

270 Submission 14, p 4

271 Submission 76, p 1

272 Mr Jenkinson, Evidence, 2 October 2008, p 24

4.60 Representatives from NSW Health acknowledged that delayed payments are a significant problem for suppliers, and advised that payment of invoices will be 'core business'[274] for EnableNSW, with one of their KPIs being payment within government terms for supplies. Ms Bronwyn Scott, the Director of EnableNSW, stated: 'We recognise that suppliers have to put food on the table and that late payment can affect their business. That is one of our key concerns and key priorities'.[275]

4.61 Ms Scott said that to help facilitate this, Enable are using faster and more efficient systems to process invoices compared to what is being used within most lodgement centres.[276]

Committee comment

4.62 The Committee notes the substantial delays in account payments to suppliers, and the effect this has on both suppliers (particularly small businesses) and clients.

4.63 We support EnableNSW's KPI regarding timely payment of supplier accounts, and acknowledge that they are using a more efficient system for processing accounts. We believe that performance against this KPI should be published on the Enable website on a monthly basis.

Recommendation 6

That EnableNSW publicly report the results of its performance against its Key Performance Indicator to pay supply invoices within government terms. These results should be published on the Enable website monthly.

4.64 However the Committee also refers to the evidence that some suppliers are being told that the reason for late payment is due to a lack of funds, and note that more efficient processing systems will not address this problem. It is our view that this problem can only be addressed through increased recurrent funding, and refer to our previous Recommendation 1.

Conclusion

4.65 The recurrent budget for PADP is clearly inadequate and requires a substantial increase if it is to meet current demand for the program. The program requires even further budget increases in order to meet unmet and projected demand for the program – both of which appear certain to increase significantly in the near future.

4.66 In addition to the obvious impacts caused by lengthy waiting lists discussed in chapter 3, the lack of funding has also had a detrimental impact on the nature of the program and its

273 Submission 43, p 3

274 Dr Matthews, Evidence, 1 October 2008, p 9

275 Ms Bronywn Scott, Director, EnableNSW, Evidence, 1 October 2008, p 9

276 Ms Scott, Evidence, 1 October 2008, p 9

administration. The effect of decisions being based on budgets rather than client needs was commented on by one inquiry participant:

> Sometimes the decision making and the processes that people with disabilities experience have been, in a way, almost creating additional barriers to access to that equipment, rather than being responsive to the delivery of equipment.[277]

4.67 The recent $11 million boost is but a mere indication of how much additional funding is required. At the very least, that amount should be made part of the recurrent PADP budget immediately.

[277] Mr Chris Campbell, General Manager, Services, The Spastic Centre, Evidence, 1 October 2008, p 47

Chapter 5 Eligibility

This chapter examines the eligibility requirements that determine access to PADP and highlights the difficulties that arise from these criteria. The chapter also discusses the appropriateness of using financial eligibility criteria to determine access to a program designed to assist people with a disability to live and participate in their community.

Overview

5.1 PADP is intended to assist financially disadvantaged people, with access to the program determined by general and financial eligibility criteria.[278]

General criteria

5.2 Eligibility for PADP is based around several general criteria. An applicant must have a long term (that it, likely to last more than 12 months) or permanent disability, and be a permanent resident in NSW.[279]

5.3 Other general eligibility criteria include that an applicant must:

- be unable to obtain equipment from any other government program;
- not have received compensation or damages in relation to their disability, nor can they be entitled to private health fund coverage for aids and equipment;
- be discharged from hospital for more than one month, and not be eligible for the provision of equipment through loan or on a permanent basis from a hospital or health service.[280]

5.4 Additionally, residents in group homes funded (but not operated) by the Department of Ageing, Disability and Home Care (DADHC); Department of Community Services (DOCS) or NSW Health, are also able to apply for assistance (whereas residents in group homes funded *and operated* by DADHC are not).[281]

5.5 The PADP policy directive states that applications for high cost items, or borderline or complex applications, should be referred to a local PADP Advisory Committee for final approval.[282] High cost items are classified as costing over $800, with items costing less than $800 approved by lodgement centre coordinators.[283]

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278 NSW Health, Program of Appliances for Disabled People – NSW Health Policy, PD2005_563, p 3

279 PricewaterhouseCoopers, *NSW Health – Review of the Program of Appliances for Disabled People*, June 2006, p 32, throughout the chapter this report will be referred to as the PwC Review

280 PwC Review, p 32. See also Submission 54, National Disability Services NSW, p 6

281 PwC Review, p 123

282 NSW Health Policy, PD2005_563, p 16

283 PwC Review, p 106

5.6 Applicants to PADP are also prioritised according to the clinical urgency of their need, income levels and the expected benefit to be gained from the provision of the aid or appliance.

5.7 Once an applicant is found to meet these general eligibility criteria, they are then subject to an assessment of their financial eligibility.

Financial eligibility bands

5.8 Access to PADP is universal for children under the age of 16. There are financial bands that determine the eligibility of people over 16 years of age to receive funding for an aid or appliance.

5.9 The financial eligibility bands for PADP are:

- Band 1 – people who receive a Centrelink pension or have a Health Care Card
- Band 2 – taxable income of up to $26,759 for singles and $45,490 for couples
- Band 3 – taxable income of $26,760 - $39,941 for singles and $45,491 - $67,899 for couples
- Band 4 – taxable income above $39,941 for singles and $67,899 for couples.[284]

5.10 The financial eligibility bands also determine the priority of equipment requests. For instance, applicants in Band 1 are more likely to receive funding for equipment than applicants in Band 4.

5.11 In addition to the four income bands, there is a requirement in Bands 1-3 to make a $100 co-payment to the program in each calendar year that aids or appliances are received. Band 4 applicants are required to pay 20 per cent of the cost of their equipment.[285]

5.12 The issue of the co-payment is discussed in more detail later in this chapter.

5.13 The financial eligibility bands are based on income information from 1997/98 and have not been indexed since that time.[286] The current financial eligibility criteria will be reviewed by December 2009, with new eligibility criteria to be implemented on 1 January 2010.[287] In the interim, NSW Health advised the Committee that the income bands would be adjusted to take into account changes in the Consumer Price Index.[288]

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284 Submission 72, NSW Health, p 19

285 Submission 72, p 20

286 PwC Review, p 157

287 Submission 72, p 20

288 Submission 72, p 20

5.14 The financial eligibility criteria have also been referred to the Interdepartmental Standing Committee on Disability to ensure that 'any changes to eligibility criteria are fair and do not result in undue hardship and are consistent with other Government programs'.[289]

Appeals Committee

5.15 EnableNSW informed the Committee that a 'readily accessible' Appeals Committee would soon be established within EnableNSW should an applicant wish to dispute a decision regarding their application.[290] The Appeals Committee will include expert clinicians and people with a disability.[291]

5.16 Dr Richard Matthews, Deputy Director General, Strategic Development, NSW Health, emphasised the importance of an accountable and transparent appeals process. He outlined the benchmarks that he envisages for the process, which he intends to be the same as for complaints:

> … there is a benchmark of acknowledging receipt of the complaint – which is, I think, three days … Then there is a second benchmark, which is that the matter is resolved within 35 days or if not resolved there is a further communication, which says "This is the process for resolution". So people are communicated with and understand exactly what is happening.[292]

The application process

5.17 Significant inconsistencies in the application process exist across the various lodgement centres. PADP applicants have reported that the application process itself is complex and confusing.

5.18 Vision Australia encapsulated the concerns regarding the application process in their submission to the Inquiry:

> There remains a lack of consistency in application forms and process, including who is eligible to sign off on an application form … It is also an unnecessarily complex application process, which needs to be simplified. There remain inconsistencies with processes between different allocation committees.[293]

5.19 The lack of certainty about what information is required for an application to be processed means that applicants have faced considerable frustration when lodging their forms. The General Manager of Services from the Spastic Centre, Mr Chris Campbell, said:

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289 Submission 72, p 20

290 Dr Richard Matthews, Deputy Director General, Strategic Development, NSW Health, Evidence, 1 October 2008, p 5

291 Answers to questions on notice taken during evidence, 1 October 2008, Ms Bronwyn Scott, Director, EnableNSW, NSW Health, Appendix 3, p 3

292 Dr Matthews, Evidence, 1 October 2008, pp 7-8

293 Submission 64, Vision Australia, pp 3-4

> Our organisation feels that there do need to be some consistent processes for lodging applications and for the expectation of how much information is required before a decision is made to approve. A lot of our staff time, which I classify as unproductive, goes into demonstrating and articulating information to a person who may not necessarily understand the significance of that information but we have to jump through those hoops.[294]

5.20 One submission author described their difficulties with the PADP application process:

> I have only just abandoned my attempt to access the scheme because of total frustration with the bureaucracy involved … I find the PADP system hard to understand and feel it is definitely not patient orientated …[295]

5.21 In addition to the frustration that discrepancies between lodgement centres can cause, the inconsistency has also resulted in complaints about the equity of the eligibility assessment process. The Disability Council of NSW stated in their submission:

> Our Council is of the belief that historically the operation of PADP's eligibility criteria has not been consistent across the State, lacks equity and transparency from region to region and, therefore, subject of justifiable concern and complaint by clients.[296]

5.22 The PwC Review also identified these concerns. Recommendation 13 of the Review recommended that single, state-wide application and prescription forms be introduced.[297] NSW Health has stated that they will implement this recommendation and that 'work is currently underway to standardise these forms for use in the NSW disability equipment schemes …'.[298]

5.23 The single application form is likely to be implemented as part of the rollout of key reforms to improve processes and systems.[299] Prescription processes will be discussed in chapter 6

Committee comment

5.24 The Committee fully supports reforms to the application process to improve transparency and fairness in the PADP application process. These reforms are part of the centralisation of PADP, which is discussed in detail in chapter 7.

5.25 It is essential that the procedural aspect of applying for assistance is clear and consistent to guarantee that no applicants to the program are disadvantaged because of circumstances beyond their control, such as variances in application processes, administrative errors or confusing forms.

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294 Mr Christopher Campbell, General Manager - Services, The Spastic Centre, Evidence, 1 October 2008, p 49

295 Submission 50, Mr Don Howe, p 1

296 Submission 52, Disability Council of NSW, p 4. See also Submission 25, CNC Dysphagia Clinic, p 3

297 PwC Review, p 144

298 NSW Health, NSW Government response to the Review of the Program of Appliances for Disabled People, November 2007, p 12

299 Ms Bronwyn Scott, Director, Enable NSW, NSW Health, Evidence, 1 October 2008, p 3

Income bands and the cost of disability

5.26 As noted at paragraph 5.9, the PADP policy directive identifies four income bands to determine financial eligibility. The calculation of Bands 2 and 3 includes an allowance of $5,000 per annum to cover the cost of a disability.[300]

5.27 Concern was expressed by many participants that the financial eligibility bands do not adequately take into account the additional living costs that are incurred by people with a disability. These costs were noted by the Physical Disability Council of NSW:

> … a lot of the costs associated with disability alone actually put a terrible dent into people's opportunities for income at all for disposable payments. There are costs associated with disability like personal care costs, transport costs, equipment costs, modification costs and like those, and sometimes even specialist kind of food products.[301]

5.28 For example, the Committee heard that therapist fees alone can cost $40,000 per year.[302]

5.29 Inquiry participants strongly argued that when assessing applicants against financial eligibility criteria, PADP should consider 'an individual or family's ENTIRE expenditure on disability-related equipment, services and therapies', thus providing a complete understanding of the extra costs associated with living with disability.[303]

5.30 The Committee was advised that an anomaly exists with the additional $5,000 per annum that is added to Band 2 and Band 3 applicants' preceding years' taxable income. This additional money is added to take into account the extra costs of living with disability. However, this is in contradiction with the PADP policy directive, which cites the average annual cost of a disability as between $7,494 - $8,783.[304]

5.31 There was limited support expressed for maintaining the eligibility bands as they currently exist. The Multicultural Disability Advocacy Association (MDAA) felt that the current bands should simply be indexed to take into account changes in the Consumer Price Index:

> The current bands should be maintained but should also be indexed. Band 1 particularly needs to be carefully monitored in light of increases in the cost of equipment exceeding the growth in a person's income.[305]

5.32 The PwC Review stated that any financial eligibility criteria for programs such as PADP:

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300 PwC Review, p 157

301 Ms Ruth Robinson, Executive Officer, Physical Disability Council of New South Wales, Evidence, 1 October 2008, p 52

302 Ms Fiona Anderson, Evidence, 1 October 2008, p 12

303 Submission 17, Ms Fiona Anderson, p 2. See also Submission 29, Coffs Harbour and Bellingen, Local Disability Advisory Committee, p 3 and Submission 61, Council of Social Services of NSW, p 4

304 NSW Health Policy, PD2005_563, p 6. See also Submission 56, Spinal Pressure Care Clinic, p 4

305 Submission 35, Multicultural Disability Advocacy Association, p 7

> … needs to meet the test of simplicity, clarity, objectivity and efficiency of application. It must be clear and easy to understand for those making an application and the prescribers, and clear and easy to administer by those managing the program.[306]

5.33 The Review continued to say that the current financial eligibility criteria do not meet this test. It recognised the high expenditure incurred by people living with disability, but expressed concern that any eligibility criteria that attempted to take into consideration the complete costs associated with different disabilities and different personal circumstances would fail the test of simplicity, clarity, objectivity and efficiency.[307]

5.34 The Review highlighted the necessity to adjust an applicant's annual income to factor in the cost of very expensive equipment purchased throughout the year. For instance, a person earning $35,000 would have an adjusted income of $25,000 if they had purchased a $10,000 piece of equipment. The Review acknowledged that this scenario does not consider the accumulative effect of low cost equipment on a person's income.[308]

5.35 The Government's response to the PwC Review acknowledged the importance of adjusting a person's income to take into account the cost of their equipment, and committed to conducting additional research on the financial eligibility criteria.[309]

PricewaterhouseCoopers Review recommendation

5.36 As discussed above, the PwC Review recommended that the current financial eligibility tiers be abolished due to their lack of clarity.

5.37 The Review suggested that the current criteria be replaced with two income tiers, with the first tier encompassing:

- all pensioners, part pensioners and Health Care Card holders, except holders whose sole justification for a Health Care Card is the mobility allowance criteria;
- all persons receiving an adjusted income less than $29,683;
- people who are Health Care Card holders because of mobility allowance criteria would be subjected to the same income test as non Health Care Card holders;
- children whose parents earn an adjusted income less than $45,000.[310]

5.38 The definition of Tier 2 includes all applicants aged over the age of 16 with an adjusted income of less than the average income for NSW (around $45,000 for singles and $75,000 for couples) and greater than the top limit for Tier 1. Children whose parents earn a combined adjusted income of higher than $45,000 will also fall into Tier 2.[311]

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306 PwC Review, p 158

307 PwC Review, p 159

308 PwC Review, p 160

309 NSW Government response, November 2007, p 16

310 PwC Review, p 161

311 PwC Review, p 162

5.39 In addition to these requirements, Tier 2 would be subject to the following rules:

- annual co-payment of $1,000 for each year they have equipment;
- funds allocated only when all people in Tier 1 have received aids or equipment;
- 50 per cent co-payment for the cost of the item up to a limit of $10,000;
- persons seeking equipment with a cost greater than $20,000 would not be required to make a co-payment greater than $10,000;
- priority ordered, in part, based on the percentage of their total adjusted income that the cost of the equipment represents.[312]

5.40 People in both proposed income tiers will have their income adjusted to reflect the cost of the aid or appliance they have requested from PADP.[313]

5.41 In their response to the Review, the Government indicated that it was concerned about certain aspects of the proposed two-tier system and that further work would need to be conducted 'to ensure that income eligibility criteria are fair, do not cause financial hardship and do not preclude clients from being able to access the assistance that they need'.[314]

Committee comment

5.42 The Committee is acutely aware of the enormous financial burden faced by people living with a disability.

5.43 The Committee believes that the additional costs of living with a disability should be given consideration when setting financial eligibility criteria, but acknowledges the inherent difficulty in determining a simple, equitable and appropriate measure of those costs for individual applicants. We believe that tax relief to assist with disability equipment purchases would assist in this regard, and refer to Recommendation 5.

5.44 Additionally, we are also of the opinion that greater recognition must be given to the extra costs faced by people living with a disability. In revising the financial eligibility criteria for PADP, NSW Health should increase the current allowance to cover the cost of a disability added to Band 2 and Band 3 to better take into account the additional costs of living with a disability.

Recommendation 7

That NSW Health increase the allowance to cover the cost of a disability added to Income Bands 2 and 3 as a matter of urgency.

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312 PwC Review, p 162

313 PwC Review, p 162

314 NSW Government response, November 2007, p 16

Eligibility vs. Entitlement

5.45 PADP is currently an eligibility program, meaning that eligible persons must meet certain criteria before being supplied with an aid or appliance.

5.46 The Committee received a great deal of evidence arguing that PADP should operate as an entitlement scheme, where all those who are require assistance receive it. Several participants argued that PADP should be an entitlement scheme without restriction, while others suggested that the program should be entitlement based with limited exceptions to restrict access.

5.47 The Committee received a significant volume of evidence in support of PADP functioning as an entitlement based scheme. Ms Heike Fabig, a mother of three children, two of whom have early onset, non-degenerative and as yet unidentified form of autosomal recessive hereditary spastic paraplegia, articulated that:

> … fundamentally what we are looking at is people need this equipment to grow and be part of society. To say no just because there is no money, somehow in this country – if we were living in Senegal sure – does not seem quite fair …[315]

5.48 The National Disability Council stated that PADP should be an entitlement scheme:

> The current underlying rationale and limited funding of PADP is essentially restrictive. NDS recommends that PADP be changed from a system requiring proven eligibility to automatic entitlement through demonstrated clinical need.[316]

5.49 The Spastic Centre also indicated that they would 'strongly support an "entitlement" program once eligibility has been met by the person with the disability'.[317]

5.50 The Aboriginal Disability Network agreed that the existing eligibility-based focus of PADP is inappropriate, emphasising that the program provides people with disabilities with equipment that is essential to their ability to participate within the community:

> The PADP currently operates as a budget-capped discretionary program. In our view this is absolutely inappropriate. As we have noted, the equipment, aids and appliances provided under the PADP are essential for the autonomy and independence of persons with disability, and their health, wellbeing and survival.[318]

5.51 The Aboriginal Disability Network further argued that the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), as ratified by the Federal Government, means that people with a disability should not be subject to any eligibility criteria other than the identification of need for a particular piece of equipment. The Network thus believes:

> In our view, because PADP is a principal means by which the fundamental human rights and freedoms set out in Article 20 may be realized, it ought to operate as an

[315] Ms Heike Fabig, Evidence, 1 October 2008, p 13

[316] Submission 54, p 12

[317] Submission 38, The Spastic Centre, p 6

[318] Submission 70, Aboriginal Disability Network NSW, p 3

> uncapped entitlement program, under which equipment, aids and appliances are made available to all eligible persons.[319]

5.52 According to People with Disability Australia, the convention states that people with a disability should live independently and be included in the community (Article 19), and that persons with a disability should have personal mobility (Article 20).[320] People with Disability Australia contended that the ratification of the Convention places an obligation on the Government to provide sufficient funding to support an entitlement based program:

> These articles outline the responsibility of the NSW government. They provide the government with the impetus for change. PWD believes that to comply with the UNCRPD the program must be appropriately funded and become an entitlement based program.[321]

5.53 An alternative viewpoint to a full entitlement scheme was provided by submission authors who advocated for a broad ranging entitlement scheme, with certain restrictions relating to high-income earners.

5.54 For example, NCOSS recommended that 'income-based eligibility criteria for PADP be removed, and that any exclusions only apply to very high income earners'. NCOSS did not make a suggestion as to the definition of high-income.[322]

5.55 A distinction was further made that basic and clinically urgent equipment should be made available for free. MS Australia advocated for the free provision of fundamental equipment, indicating in their submission to the Inquiry that:

> … as a minimum, there should be no means testing or co-payment for clinically urgent aids and equipment such as continence products, customised equipment or pressure care equipment.[323]

5.56 In evidence to the Committee, the Disability Council of NSW also stated that 'essential equipment that meets fundamental need ought to be made available free at the point of delivery'.[324]

Committee comment

5.57 Many inquiry participants believe that people with a disability should receive aids and appliances on the basis of demonstrated clinical need only.

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319 Submission 70, p 3

320 Submission 47, People with Disability Australia, pp 3-4. To view the full Convention, go to <http://www.un.org/disabilities/documents/convention/convoptprot-e.pdf> (accessed 20 November 2008)

321 Submission 47, p 3

322 Submission 61, p 5

323 Submission 68, MS Australia, p 11

324 Mr Andrew Buchanan, Chairperson, Disability Council of NSW, Evidence, 1 October 2008, p 34

5.58 They argued that additional eligibility requirements, such as income-based criteria, are fundamentally unjust, because disability aids are essential for the independence, mobility and in some cases, survival of people with a disability. As one participant told us, these items are not fashion accessories. Several of the peak disability organisations emphasised that if we are serious about meeting our commitments to the rights of people with a disability under the UNCRPD, we must move towards a full entitlement system.

5.59 The Committee heard moving evidence during this Inquiry of the difficulties that stem from a lack of access to disability aids. There is no justification in a wealthy country such as Australia, for allowing a child's development to be delayed because she or he is not eligible to receive a powered wheelchair until they start school. Nor is it acceptable that a person who is unable to eat solid food, is provided with only two feeding sets per week, instead of the seven recommended by the Therapeutic Goods Association necessary to avoid bacterial infections.

5.60 What kind of a society allows a fourteen year old boy with a profound disability to endure five months squeezed into a wheelchair that is clearly too small for him, while his mother spends weeks organising the paperwork that proves the chair needs to be modified? These real life scenarios exist not because the people who work for PADP are heartless, but simply because they are trying to manage a service that is staggeringly underfunded. The result is that people with a clearly demonstrated clinical need for appliances are routinely rejected for entrance to the program, or otherwise languish on long waiting lists because they only earn $40,000 per year, much of which is spent on the significant costs of living with a disability.

5.61 A radical rethink is required about how we provide essential items to allow people with a disability to best engage with the community and maximise their independence. We are aware that converting an already inadequately funded PADP to an entitlement program would require a massive injection of funding. We are also mindful that governments need to balance competing and ever-increasing demands for the health dollar. But this does not mean that we say or do nothing about what is admittedly a vexed policy challenge.

5.62 The Committee urges both State and Federal governments to consider how to ensure essential aids are provided to all who need them, and refers to Recommendation 2.

Co-payment

5.63 As part of accessing aids or appliances through PADP, a co-payment of $100 is required from each PADP client in Bands 1-3 in every calendar year that aids or appliances are received. Applicants assessed as being in Band 4 do not contribute a co-payment, but are required to pay 20 per cent of the cost of their equipment. Co-payments may be waived if applicants are facing severe financial hardship.[325]

5.64 In addition, the co-payment scheme is grand-fathered, meaning that '[a]nyone who had been receiving PADP before the co-payment was introduced is not required to pay it …'.[326]

[325] Submission 72, p 20

[326] Mr Gregory Killeen, Evidence, 1 October 2008, pp 25-26

5.65 The Committee received a great deal of evidence relating to the efficacy and necessity of the co-payment. Two divergent views of the co-payment emerged from the evidence received.

5.66 The first view was that the co-payment is an appropriate method to engage and involve families in the provision of equipment. While Ms Fiona Anderson supports a co-payment in principle, she said that contribution to the program should be determined by a family's ability to afford a co-payment:

> … most families want to take as much responsibility as they can and it depends on personal income. In that way, a $100 co-payment or a $500 co-payment, or whatever it is, should be assessed on a family's capacity to pay based on all their expenditure …[327]

5.67 Mr Barry Bryan, Co-ordinator of a Lymphoedema Support group, also felt that while a co-payment was fair, an increase in the cost of the co-payment may put unnecessary financial pressure on many clients of PADP:

> A lot of the people who come through our system in the support group do not have a major hassle with $100; they see that as a fair and equitable thing. Whether it should be increased, I would reserve judgment on their reaction because most of them are pensioners … So an increase would probably be an impost on those in the majority of cases but not all.[328]

5.68 The second viewpoint, supported by the majority of evidence received, was that the co-payment was an unnecessary financial burden for clients of PADP and an unnecessary administrative burden for PADP.

5.69 The Aboriginal Disability Network encapsulated the prevailing attitude towards the co-payment:

> The administration of PADP is beleaguered by a complex and confusing co-payment system that is difficult and inefficient to administer … This co-payment requirement also produces financial hardship and adds to the costs of disability in many instances.[329]

5.70 Spinal Cord Injuries Australia advocated for the abolition of the co-payment, expressing the view that a co-payment should not be a pre-requisite to access the program:

> It is unfair from the perspective of equity across services. There is no real precedence for this to exist. If I call an ambulance I do not have to reach into my pocket and pull out $20 before the person will take me to hospital; it just does not happen.[330]

5.71 Submission authors highlighted that the requirement to make a co-payment can place significant financial pressure on people living with a disability, particularly as they are more

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[327] Ms Anderson, Evidence, 1 October 2008, p 14

[328] Mr Barry Bryan, Coordinator, Lymphoedema Support Group, Evidence, 1 October 2008, p 25

[329] Submission 70, p 3

[330] Mr Sean Lomas, Policy and Information Manager, Spinal Cord Injuries Australia, Evidence, 1 October 2008, p 41

than likely already dealing with additional living expenses: '[E]xtra costs on health, medical, equipment, personal care, transport—you name it, it is all there'.[331]

5.72 NCOSS cited these additional living costs as being the reason to discontinue the practice of requiring co-payments:

> NCOSS supports the removal of co-payments from the program, in recognition that co-payments are inequitable and that people with a life-long or long-term disability face considerable additional costs associated with that disability and that co-payments are inequitable.[332]

5.73 As stated earlier, the co-payment can be waived for PADP clients who are experiencing financial hardship. The correlation between severity of disability and the ability to earn income means that the people most likely to need assistance from PADP are from low-income households that are unlikely to be able to easily afford to contribute a co-payment:[333]

> They are on low incomes anyway. To then ask for a co-payment we think is somewhat difficult and problematic and further disadvantages those people in their access to equipment, which we believe is essential for them to lead as normal a life as possible.[334]

5.74 A significant issue with co-payments is the cost of administering the scheme. The Disability Council of NSW, who are official advisors to the NSW Government, felt that 'the administrative fees associated with monitoring and enforcing the co-contribution payment is costly and counter productive'.[335] The Council was of the understanding that the co-payment would be abolished.[336]

5.75 NSW Health acknowledged the difficulty of administering the co-payment, saying that the system is 'difficult to administer consistently and mechanisms for obtaining financial co-payments from applicants are inefficient'.[337]

5.76 In evidence before the Committee, Mr Dougie Herd, Executive Director, Disability Council of NSW emphasised that:

> I think it is clear to everybody that the co-payment is not functioning as an income generating tool and that therefore seems to me clear that there is no purpose served in collecting it. Why pay staff to collect money that is not going towards equipment provision? It is not differing the course of the program so just get rid of it.[338]

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331 Mr Killeen, Evidence, 1 October 2008, p 26

332 Submission 61, p 5

333 Submission 75, Spinal Cord Injuries Australia, p 8

334 Ms Alison Peters, Director, Council of Social Service of New South Wales, Evidence, 1 October 2008, p 58

335 Submission 52, p 5. See also Submission 35, Multicultural Disability Advocacy Association, p 7

336 Submission 52, p 5

337 Submission 72, p 18

338 Mr Dougie Herd, Executive Director, Disability Council of New South Wales, Evidence, 1 October 2008, p 35

5.77 The Physical Disability Council of NSW posited that the co-payment should be eliminated for people in Band 1 of the financial eligibility criteria, and that changes be made to how high-income earners make their co-payment. In their submission to the Inquiry, the Council suggested that a one-off payment, set at $1,000, should be levied on high-income earners.[339]

5.78 The PwC Review stated that if all PADP clients were charged the $100 co-payment, an additional $1.5 million would be injected into the program.[340] However, the Oakton audit report estimated that PADP only received $754,813 from co-payments in 2006/07.[341] NSW Health was unable to provide an estimate of the costs of administering the co-payment as the costs 'are difficult to quantify due to variations in local practices and debt collection practices'.[342]

5.79 The Review acknowledged the difficulty in producing accurate figures on the amount of revenue generated by the co-payment, saying that as lodgement centres are able to exercise discretion as to who is charged the co-payment, 'no details are available on the actual percentage of clients charged or the amount generated'.[343]

5.80 Recommendation 19 of the PwC Review suggested that the following actions be taken in relation to co-payments:

- increase the co-payment to at least $200 annually for Tier 1 and to $1,000 for Tier 2
- require persons with equipment on loan to make the co-payment each year they have the equipment
- discontinue the grand-parenting arrangements that have been in place since 2000
- allow clients with disposable supplies (such as continence products) to have the option to produce receipts, to the value of the co-payment, in lieu of a cash payment each year.[344]

5.81 In response to this recommendation, the NSW Government undertook 'to ensure that co-payments are reasonable, consistent with other similar government programs and do not impose financial hardship on an individual or family'.[345]

5.82 Dr Matthews referred to the issue of the co-payment as 'difficult and vexing':

> On the one hand, many people with a disability require assistance and have a capacity to pay, and there are very large numbers of people who do not. It is administratively

339 Submission 51, Physical Disability Council of NSW, p 9

340 PwC Review, p 155

341 Answers to questions on notice taken during evidence 24 October 2008, Dr Richard Matthews, NSW Health, Question 6, p 4

342 Answers to questions on notice taken during evidence 24 October 2008, Dr Matthews, Question 6, p 4

343 PwC Review, p 155

344 PwC Review, p 156

345 NSW Government response, November 2007, p 15

> burdensome and requires additional transactional time and costs. If it is to be done away with, it removes a contribution towards the program.[346]

5.83 NSW Health indicated that EnableNSW would be producing a discussion paper on the viability of the co-payment, to be released by June 2009.[347]

5.84 The Government response to the PwC Review indicated that the cumulative effects of co-payments across government agencies would be considered, to ensure that clients who access assistance from multiple agencies 'are not required to make an unreasonable total co-payment for the services they need'.[348] This issue has also been referred to the Inter-Departmental Standing Committee on Disability for consideration.[349]

Committee comment

5.85 The Committee strongly agrees with inquiry participants that the co-payment is both administratively burdensome for PADP and financially burdensome for applicants.

5.86 The Committee acknowledges that the PwC recommendations to increase the co-payment are made in the context of the entire reform package to PADP proposed by the Review. Nevertheless, we are concerned by the prospect of any increase in the co-payment for people who are already considered to be financially disadvantaged.

5.87 The Committee is not convinced of the need to distribute a discussion paper on the viability of the co-payment, particularly one that is not due to be released for another six months. NSW Health should instead consider the considerable evidence received by this Committee from individuals and peak disability organisations regarding the merits or otherwise of the existing co-payment.

5.88 In light of this evidence, the Committee feels that the current annual co-payment for low-income earners unnecessarily exacerbates the considerable financial pressures of living with a disability, and that the co-payment should therefore be abolished for PADP recipients.

Recommendation 8

That NSW Health abolishes the $100 co-payment for PADP recipients.

Recommendation 9

That NSW Health examine the evidence received by General Purpose Standing Committee No. 2 regarding the abolition of the $100 co-payment, in its proposed review of the financial eligibility criteria for PADP.

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346 Dr Matthews, Evidence, 1 October 2008, p 4

347 Ms Scott, Evidence, 1 October 2008, p 4

348 NSW Government response, November 2007, p 15

349 Submission 72, p 20

Conclusion

5.89 The current financial eligibility criteria fail to take into account the complete costs associated with living with a disability. In addition, the co-payment is an unnecessary financial and administrative burden.

5.90 PADP should operate as an unrestricted entitlement scheme and the co-payment should be abolished. As an interim measure in the progression to an unrestricted entitlement scheme, it is crucial that the NSW Government provide a greatly enhanced level of recurrent funding to the program to meet the needs of existing PADP clients.

Chapter 6 Prescriptions and equipment

This chapter examines specific concerns regarding the PADP prescription process, and the maintenance and repair of aids and appliances. It also considers difficulties in accessing certain types of equipment under the program such as communication devices.

Issues with the prescription process

6.1 Ensuring people with a disability can access the right equipment for their condition at the right time is a fundamental goal of PADP. The prescription process is thus a critical aspect of an effective disability equipment program.

6.2 A prescription from a suitably qualified professional, such as an occupational therapist, is a prerequisite for access to equipment under PADP.

6.3 A number of concerns regarding the efficiency and effectiveness of the prescription process were addressed by the PwC Review. The Review found that inappropriate equipment prescriptions were being prepared as a result of inexperience and/or lack of adequate clinical supervision. Conversely, appropriate prescriptions by highly qualified professionals were being challenged by lodgement centre staff. The Review also found that the lack of consistent prescription processes across lodgement centres were confusing and inequitable.[350]

6.4 The NSW Government is implementing several initiatives to address concerns about the prescription process raised by the Review. State-wide equipment advisors are being recruited to prepare training and education programs and to provide high-level advice to clinicians regarding prescriptions.[351] In addition, standard processes and documentation for equipment prescription and evaluation are being developed as part of the package of reforms to centralise the administration of PADP. These new processes have recently been piloted at one rural/regional and one metropolitan lodgement centre.[352]

Other factors influencing the quality of prescriptions

6.5 Concerns regarding the quality of prescriptions were also raised by participants to this Inquiry. While acknowledging that inadequate training and experience contributed to poor quality prescriptions, participants also suggested that inadequate program funding and the shortage of therapists, especially in rural and regional areas, contributed to the problems afflicting the prescription process.

6.6 The Australian Association of Occupational Therapists NSW suggested that underfunding of PADP had a highly detrimental effect on the prescription process. Poor funding, they argued,

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350 PricewaterhouseCoopers, 'Review of the Program of Appliances for Disabled People', June 2006, pp 145-146. Throughout the chapter this report will be referred to as the PwC Review

351 Submission 72, NSW Health, p 14

352 Submission 72, p 10. This project is known as the *Common Equipment Prescriber Guidelines Project.*

encourages therapists to prescribe to equipment availability instead of client need,[353] and that faced with a long wait for equipment, clients are more inclined to be offered and to accept inappropriate 'ex stock' or 'standard' items equipment.[354]

6.7 Mr Malcolm Turnbull, the Managing Director of SDL, also commented on the distortion of the prescription process caused by underfunding:

> It has become increasingly apparent that therapists are taking on the role of "gatekeepers" to an underfunded scheme. Decisions on equipment provision are being made on "available funds" consideration, rather than clinical necessity.[355]

6.8 Several inquiry participants commented on the delay in receiving a prescription due to the shortage of experienced prescribers. Ms Wendy Hall, Senior Manager of Client Programs for Northcott Disability Services told the Committee that:

> …. to prescribe some of the equipment, you need a lot of experience and a supervisor. We do not always have that available. We are struggling to employ enough therapists for our services now, particularly therapists with that specific experience. … we do not have a lot of senior therapists who are available to support the more junior therapists.[356]

6.9 Mr Raul Osbich, a full time carer to his wife who has multiple sclerosis, described his frustrating attempts to schedule an assessment with an occupational therapist:

> My wife goes through the MS Society. At last count it had 1,300 clients in the northern sector and two OTs that are specialised enough. So even going to see them every day, they would have to see two every day for the whole year, and they are still not going to see everybody. Trying to make an appointment for these evaluations, they are not 15 minutes. They are usually a couple of hours and there is a report to be written, so the poor OTs are inundated with paperwork ....[357]

Need for a 'client centred' approach

6.10 It is widely held that an effective disability equipment prescription process is 'client-focussed'. In other words the client is able to participate fully in the decision regarding the equipment they receive. According to Ms Cathrine Lynch, Director, Primary Health and Community Partnerships, NSW Health, failing to take clients' views into account can lead to inappropriate prescriptions and the eventual abandonment of the equipment.[358]

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353 Submission 37, Australian Association of Occupational Therapists NSW, p 2

354 Submission 37, p 5

355 Submission 4, SDL (Seating Dynamics), p 2

356 Ms Wendy Hall, Senior Manager Client Programs, Northcott Disability Services, Evidence, 2 October 2008, p 7. See also Submission 52, Disability Council of NSW, p 3.

357 Mr Raul Osbich, Evidence, 1 October 2008, p 16

358 Ms Cathrine Lynch, Director, Primary Health and Community Partnerships, NSW Health, Evidence, 24 October 2008, p 4

6.11 The importance of a client-focussed approach in prescribing disability equipment was highlighted by the Executive Officer of the Disability Council of NSW, Mr Dougie Herd:

> I have 25 years' experience of being a C5-6 quad. I know what works and does not work for me. I think I have something to offer to the prescription process. I think the system needs to listen to me and to give me the backup support so that I will use the equipment that I receive well.[359]

6.12 This view was reiterated by the Chairman of the Disability Council of NSW, Mr Andrew Buchanan:

> I think Dougie's point in looking at and listening to the voice of the person with a disability should not be underestimated. …. If you have lived with a disability, you know if a wheelchair fits or if a calliper fits et cetera. That should not be misunderstood. [360]

6.13 Mr Sean Lomas, Policy and Information Manager for Spinal Cord Injuries Australia, argued that the current prescription process is insufficiently client focussed:

> Often I hear stories from our members that when it comes to being prescribed an item of equipment they have very little say in it … I have one case … a lady who was stuck outside while the OT went off with the lodgement centre manager; three hours later came back and said. "You're having this chair" and that was it.[361]

6.14 Mr Lomas believes that the shortage of therapists and their concomitant workloads discourage therapists from considering clients' view point in prescribing aids:

> … there are not enough OTs out there … So they may well drive four hours in regional New South Wales to get to a house, to then assess and then need to drive another four hours back. All of that time spent on one application; they just want to get there and get it done. But in the process of doing that you have marginalised the person who you are there to work for. You are there to support that person and make sure they get the right item because 12 months, 18 months down the track they will be calling you up again saying, "I'm having a lot of problems with this."[362]

6.15 Dr Matthews, Deputy Director General, Strategic Development, NSW Health, acknowledged the problems with the prescription process posed by the broad issue of an insufficient rural workforce in isolated towns: 'I cannot begin to say that I have the answer to the question of appropriate equitable access to all health services … in rural New South Wales'.[363]

6.16 Mr Herd told the Committee that he was hopeful that the revised prescription guidelines will address concerns about the role of clients in the this process:

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359 Mr Dougie Herd, Executive Director, Disability Council of NSW, Evidence, 1 October 2008, p 37

360 Mr Andrew Buchanan, Chairperson, Disability Council of NSW, Evidence, 1 October 2008, p 38

361 Mr Sean Lomas, Policy and Information Manager, Spinal Cord Injuries Australia, Evidence 1 October 2008, p 45

362 Mr Lomas, Evidence 1 October 2008, p 46

363 Dr Richard Matthews, Deputy Director General, Strategic Development, NSW Health, Evidence, 24 October 2008, p 11

> … if I understand correctly, the changes that have been proposed to the prescription arrangements are intended to give the client more say and influence over what it is that has been prescribed so that there is not under-or-overprescription, and clients understand their equipment needs and can feel confident that … their view will be listened to.[364]

6.17 Ms Lynch confirmed that under the new prescription processes clinicians were being asked to engage more closely with clients. For example, clients are required to sign off on their equipment and therapists are expected to follow up with clients and evaluate whether the prescribed equipment is meeting their goals.[365]

Committee comment

6.18 The Committee welcomes the steps taken by NSW Health to ensure the prescription of disability aids is more client-focussed. However none of the initiatives identified by the Department to improve these arrangements address one of the key factors impeding effective prescriptions, that is, inadequate program funding.

6.19 As many inquiry participants have noted, inadequate recurrent funding is at the heart of most of the problems that beset PADP. Their comments underline the need for the Government to implement our earlier Recommendation 1, that the recurrent funding for the PADP be increased significantly, so that decisions about equipment would be based on need rather than budget.

6.20 The Committee also notes that another major contributor to the problems with the prescription process is the shortage of occupational therapists and other qualified health professionals, particularly in rural and regional areas. Increasing these numbers is a key challenge for the Government to tackle – not just for PADP, but for all of NSW.

Equipment trials

6.21 It is considered best practice for a clinician to trial equipment with clients before issuing a prescription to ensure it is safe and effective and suits the client's needs.[366]

6.22 In cases involving high cost equipment where a prescriber must obtain three quotes, these trials are mandatory.

6.23 While acknowledging the importance of trials to ensure the correct prescription of equipment, suppliers expressed concern about the cost of such trials. For example, the Independent Rehabilitation Suppliers Association advised that equipment trials, which are often performed free of charge, cost suppliers on average between $300-$700 (including travel time and administration), stating:

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364 Mr Herd, Evidence, 1 October 2008, p 37

365 Ms Lynch, Evidence, 24 October 2008, p 11. The new prescription guidelines have been developed in partnership with the Lifetime Care and Support Agency

366 Email correspondence from Ms Bronwyn Scott to the Committee Director, 27 November 2008

> When PADP insists on 3 quotations to be submitted per client, the cost to industry escalates to $900-$2,100 per assessment with no guarantee to any supplier of eventually receiving an order.[367]

6.24 It was suggested that three trials may not always be necessary, such as where an outcome can be predetermined. Mr George Ajaka, an occupational therapist employed by a supplier, stated '[f]or example there is no point trialling a wheelchair for a client who has had a chair for 15 years and wants a replica'.[368]

6.25 The Committee heard that there is increasing pressure on suppliers to loan equipment for extended periods, who are unable to charge for equipment on loan beyond three days. The cost to the supplier includes set up costs, delivery and pick up, reconfiguration, as well as the opportunities lost from not having the equipment available for demonstration.[369] According to the Independent Rehabilitation Suppliers Association: '[i]t is commercially unsustainable to have such pieces of equipment out on extended trials'. [370] Several inquiry participants requested that suppliers be able to charge for extended equipment trials.[371]

6.26 Northern Rivers Surgical Supplies expressed their reluctance to loan valuable equipment for extended periods:

> As a supplier, we are not prepared to loan a $15,000 power wheel chair to a client for a week's trial, with the possibility that the equipment will return in a damaged condition, unless there is adequate insurance/compensatory cover.[372]

6.27 According to NSW Health, under the revised Enable prescription guidelines, clinicians will be required to document the number of trials they have undertaken with individual clients. While the number of trials will be adjusted according to the cost of the equipment and the complexity of the equipment or the clients' condition, the expectation is that even low cost equipment will need to be trialled. Replacement equipment may only require investigation to ascertain that an equivalent model is available. The Department also pointed out that equipment for trials is most often sourced from equipment loan pools located in hospital and community health centres.[373]

6.28 Commenting on the revised guidelines under which all equipment must be trialled, Mr Terry Gallagher, the Managing Director of Otto Bock stated that:

> While this may assist in reducing incorrect prescription of equipment, suppliers would need to charge additional amounts for trial equipment, or incorporate the costs of this trial equipment into their quotes …[374]

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367 Submission 43, Independent Rehabilitation Suppliers Association of NSW, p 9

368 Submission 55, Mr George Ajaka, p 4

369 Submission 55, p 4

370 Submission 43, p 10

371 Submission 43, p 10; Submission 45, Otto Bock Australia, p 4; Submission 55, p 3

372 Submission 9, Northern Rivers Surgical Supplies, p 3

373 Email correspondence from Ms Bronwyn Scott to the Committee Director, 27 November 2008

374 Submission 45, p 4

6.29 Dr Matthews advised that NSW Health is looking at placing complex PADP aids and appliances in Equipment Loan Pools (ELPs) for use in extended trials.[375] ELPs were examined in chapter 3.

Committee comment

6.30 The Committee is genuinely sympathetic to the concerns of suppliers regarding the costs associated with trials, however we are of the view that equipment trials are essential to ensure that clients are prescribed the most appropriate equipment. Trials also assist prescription processes to be appropriately client-focussed.

6.31 We note that NSW Health will be contributing complex equipment to loan pools for use in equipment trials, and believe that this will ease some of the financial costs and burdens associated with suppliers loaning equipment on extended trials.

Repairs and maintenance

6.32 PADP equipment is owned by health services through PADP, and lodgement centres are responsible for the servicing and repair of this equipment.

6.33 The maintenance and repair of disability equipment by PADP was a major issue raised during the Inquiry. Two main problems were identified by participants. First, that PADP does not fund a preventative equipment maintenance program and second, that the system for making minor repairs or adjustments to PADP appliances is highly inefficient.

Need for a preventative maintenance program

6.34 According to the PADP policy directive: 'Assistance is provided through PADP to meet the cost of regular service, maintenance and reasonable repairs to PADP supplied items.'[376] Despite the directive, several inquiry participants, including People with a Disability Australia (PWD) commented on the lack of routine maintenance. [377]

6.35 Participants, including Mr Greg Kline, the Managing Director of GTK Rehab were concerned about the implications of a lack of routine maintenance:

> If we did that to our cars we would void our warranty. The first we hear from the PADP is when the chair is broken down. For instance, electric motors on wheelchairs have brushes; it is like in your car. If you drive around with no brake pads you will damage the disc and it will cost you a lot more money. Wheelchairs are no different. If you do preventative maintenance your overall costs in the long run will be cheaper. But currently PADP will not fund preventative maintenance.[378]

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375 Dr Matthews, Evidence, 24 October 2008, p 13

376 Program of Appliances for Disabled People – NSW Health Policy, PD2005_ 563, NSW Health, p 9

377 Submission 47, People with a Disability Australia, p 2

378 Mr Gregory Kline, Owner, GTK Rehab, Evidence, 2 October 2008, p 25

6.36 Northcott Disability Services suggested that a routine maintenance program would reduce the need for emergency repairs:

> A regular follow up and maintenance schedule for equipment would also assist in maintaining equipment in good working order and avoid emergency situations where equipment breaks down and requires urgent repairs.[379]

6.37 Mr George Ajaka, an occupational therapist employed by GTK Rehab, told the Committee that in the absence of a routine maintenance program, there is an expectation that suppliers will repair equipment at no cost.[380]

Maintenance and repair of donated equipment

6.38 People who secure their equipment through charitable donations rather than PADP face even greater challenges in relation to the repair and maintenance of disability equipment. While the PADP policy directive states that 'PADP may also assist with the cost of repairing an item supplied by another organisation',[381] it would seem this occurs infrequently. According to Ms Wendy Hall, Senior Manager of Client Programs, Northcott Disability Services:

> If they get their equipment through another funding source, PADP often does not take responsibility for maintenance. Sometimes that is what parents weigh up: If we get equipment funded through a charity, who is going to maintain the equipment for us? Often it is very costly replacing and maintaining equipment.[382]

6.39 National Disability Services NSW also argued that PADP should fund repairs to equipment secured by non-government organisations or charities. They suggest that undertaking these repairs will provide savings to the program by ensuring equipment is kept in good working order, thus preventing the need for new equipment to be provided under PADP.[383]

Committee comment

6.40 In chapter 3 the Committee discussed its concerns regarding the significant contribution being made by charitable organisations in supplying equipment to people with disabilities who are not able to access or wait for equipment through PADP. It is hoped that additional recurrent funding provided to the program may reduce the need for people to go outside of PADP for their equipment, in which case the responsibility for repairs and maintenance will rest squarely on the shoulders of PADP.

6.41 In the meantime NSW Health must ensure that lodgement centres are able to adhere to their own guidelines in relation to the repair of items supplied by other organisations. Additional program funding recommended by this Committee will no doubt assist in this regard.

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379 Submission 49, Northcott Disability Services, p 6

380 Submission 55, p 3

381 NSW Health Policy, PD2005_ 563, p 9

382 Ms Hall, Evidence, 2 October 2008, p 3

383 Submission 54, National Disability Services NSW, p 14

Recommendation 10

That NSW Health ensure that EnableNSW assist with the cost of repairing items supplied by non-government or charitable organisations, as per the NSW Health Policy on PADP.

Inefficient repairs and modifications

6.42 Inquiry participants commented generally on the inadequacy of PADP's approach to repairs and modifications of equipment supplied through the program.

6.43 Ms Fiona Anderson, the mother of an adolescent boy with a significant physical disability, told the Committee that PADP's management of equipment repairs and modifications is in dire need of reform. Ms Anderson cited an example from her own experience to illustrate her claim.

6.44 When Ms Anderson's son was 13 he experienced a significant growth spurt and outgrew his powered wheelchair. In order to receive funding for the necessary modifications, Ms Anderson was required to arrange for multiple reports from an occupational therapist over a two month period, after which she was advised that there would be a further two to three month wait for approval for chair modifications. During this period her son was in considerable discomfort because his wheelchair was simply too small.[384] Ms Anderson questioned why there was a need for extensive involvement from therapists in what should have been a straightforward exercise:

> I know when he has grown out of a chair. It does not take rocket science. I am the expert on my son's condition, nobody else. I should have just been able to say we need these modifications. If it were complicated, of course I would go to an OT for input. As it was, I said what we needed and the OT wrote the report. Then the merry-go-round started. It is needlessly complicated and now we are going to take months and months to try to redress the problem.[385]

6.45 Ms Anderson pointed out that a similar level of intervention would be required to repair something as simple as a broken foot plate. She believes the process should be streamlined so that if PADP has already funded equipment, all modifications or adjustments should be automatically approved without need for 'OT waitlist, report, applications, time off work with no pay to attend appointments, time away from school etc'.[386]

> I could send a photograph to PADP and say "This is the situation. We need a new seat" or this needs to happen, we need a new footplate, whatever, that should be it. The response should be, "Yes go and get it done and send us the invoice." [387]

6.46 Ms Anderson's experience with PADP contrasts with that of the approach adopted by the Motor Neurone Disease Association to organising routine repairs or modifications:

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[384] Submission 17, Ms Fiona Anderson, p 4

[385] Ms Fiona Anderson, Evidence, 1 October 2008, p 14

[386] Submission 17, p 4

[387] Ms Anderson, Evidence, 1 October 2008, p 18

> … when it comes to maintenance of equipment the requests are sent straight to our office and we go straight to wherever the repair person is and it is done directly. We know our equipment and we know what is out there and we get it fixed. We have a good relationship with the suppliers in New South Wales. If they say something is wrong, then we know something is wrong and we get it fixed.[388]

6.47 Ms Lynch advised the Committee that in future, most routine repairs will not need to go back to the prescriber, although she noted that if there is a change in equipment because the child has grown it will need to go back to the therapist.[389]

Initiatives to address concerns about repairs and maintenance

6.48 Dr Matthews acknowledged the problems concerning the maintenance and repair of PADP equipment. He advised the Committee of several initiatives designed to address these concerns including:

- The establishment of a business processes working group that is developing a process for both routine maintenance and unscheduled repairs.
- Incorporation of an asset management module in the new IT system which will identify when a particular piece of complex equipment is due for routine maintenance and keep a record of unscheduled repairs (see chapter 7)
- The development of a system to address the need for urgent repairs to be arranged quickly and, if necessary, out of hours.[390]

Committee comment

6.49 The Committee welcomes the various initiatives being introduced by NSW Health to improve routine maintenance and unscheduled equipment repairs. It is essential that experiences such as that of Ms Anderson and her son are not repeated. Again we note that additional recurrent funding will be required to ensure the system for repair and maintenance of PADP is effective.

Access to equipment for people with sensory disabilities

6.50 Several peak organisations representing people with vision or hearing disabilities noted that communication aids to assist people with sensory disabilities are either not available under PADP, or are very difficult to access, compared with aids that meet clinical and mobility needs. According to Northcott Disability Services:

> Feedback from therapists that we support often describes the difficulties in obtaining ANY type of communication aid through the PADP scheme. In some case therapists

388 Mr Graham Opie, Chief Executive Officer, Motor Neurone Disease Association of NSW, Evidence, 1 October 2008, p 30

389 Ms Lynch, Evidence 24 October 2008, p 12

390 Dr Matthews, Evidence, 24 October 2008, p 12

> will not apply to PADP as they consider that PADP would not be able to fund devices of such low priority.[391]
>
> We would like to see a greater recognition of communication as being a basic human need, and for the provision of adequate funding to allow clients to be provided with whatever device is suitable for them.[392]

6.51 Ms Luisa Ferronato, the National Program Manager, Equipment Solutions, Vision Australia, pointed out that some technologies slip under the radar of PADP because there is a heavy focus on physical disability.[393] Ms Ferronato did not want to single out one particular disability group for special consideration:

> Our preference is for everyone to be on an equal playing field, to not compare apples with oranges. The impact of someone with a physical disability and their access to everyday life is just as difficult to someone who has a sensory disability but in different ways. The technology and equipment that is available to enable a better quality of life and better access to society.[394]

6.52 The General Manager of the Spastic Centre, Mr Chris Campbell acknowledged that while some of the technology to assist people with communication disabilities is expensive, and may make a significant demand on the PADP budget, we need to confront the fact that:

> … technology and communication devices are a key to many of our client groups. It is also going to be something that the next generation of younger people with disabilities, especially cerebral palsy, are going to expect to be the benchmark and baseline that will enable them to integrate into mainstream school and to communicate with their families and interact with their peers. Unlike the situation with the previous generation of adults for whom that level of technology was not available, there will be a demand coming quickly down the track that will increase the pressure on the existing budget unless there is a significant increase in the level of funding.[395]

6.53 While the needs of their client group are considerable, Vision Australia acknowledged recent welcome developments, noting that PADP 'has better provided for the needs of people who are blind or have low vision'.[396]

6.54 Northcott Disability Services also expressed hope that centralisation will increase the equity of communication device provision across all areas of the State, especially regional areas.[397]

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391 Submission 49, Northcott Disability Services, p 2

392 Submission 49, p 7

393 Ms Luisa Ferronato, National Program Manger, Equipment Solutions, Vision Australia, Evidence, 2 October 2008, p 51

394 Ms Ferronato, Evidence, 2 October, 2008, p 52

395 Mr Christopher Campbell, General Manager, Services, The Spastic Centre, Evidence, 1 October, 2008, p 47

396 Submission 64, Vision Australia, p 5

397 Submission 49, p 7

Provision of feeding sets

6.55 Some people with certain types of medical conditions receive all or most of their nutrition and hydration via feeding tube sets. At present, PADP supplies two feeding sets per week to allow such people to feed themselves at home, despite guidelines from the Therapeutic Goods Administration stipulating that single use feeding devices should be used (which therefore should be changed daily).[398]

6.56 The re-use of tubes can result in serious health consequences:

> … enteral feeding equipment is often cleaned and reused for several days before being replaced with fresh equipment due to patients being supplied less than adequate feeding sets. This practice is often associated with microbial contamination of the feed, which is of great concern. Studies have shown that colonisation, infection, and septicaemia can occur in adults using contaminated enteral feeds …[399]

6.57 The insufficient supply of feeding sets is a cause of concern for feeding tube users and their families, adding 'to the financial and general stress of the household'.[400] Matthew and Belinda Hooley, whose two and a half year old son requires feeding tubes, stated in their submission that 'PADP tell us they cannot supply more because of funding'.[401]

6.58 The funding allocated to the supply of feeding sets is inadequate to meet current and future demand. Ms Janet Bell, Head Dietitian, Dietitians Association of Australia, informed the Committee that in 2005/06, an estimated 3,330 people were not appropriately supplied with feeding sets. Ms Bell further indicated that current figures would greatly exceed the 2005/06 statistics.[402]

6.59 Dr Matthews advised the Committee that the Therapeutic Goods Administration (TGA) was responsible for determining standards for feeding equipment and noted that some feeding tubes are labelled 'single use only' and there are others that are labelled 'single patient use only', which means that they can be used more than once by the same patient. He also noted that TGA guidelines cover health workers but do not cover people using that equipment themselves.

> So in many cases it is not absolutely clear-cut where the safety issues begin and end in terms of reusing and how they might be cleaned and sterilised, so we obviously have to rely on TGA guidelines. But we have made submissions and we will make a submission on the basis of this anomaly. We have not done so as yet but we will.[403]

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398 Ms Janet Bell, Head Dietician, Dieticians Association of Australia, Central Hospital Network, South East Sydney Illawarra Area Health Service, Evidence, 2 October 2008, p 13

399 Submission 48, Nutricia Australia Pty Ltd, p 1

400 Submission 58, Mrs Alison Simpson, p 1. See also Submission 6

401 Submission 5, Matthew and Belinda Hooley, p 1

402 Ms Bell, Evidence, 2 October 2008, p 14

403 Dr Matthews, Evidence, 24 October 2008, p 5

6.60 TGA policy states that it is the responsibility of the manufacturer to determine the usage of a device.[404]

Committee comment

6.61 The Committee considers that provision by PADP of two single use feeding sets per week is inadequate, and unnecessarily jeopardises the health and wellbeing of people who require nutritional support. Additional recurrent program funding would allow PADP to supply one feeding set per day to people who require tube feeding, in line with the recommendations by the manufacturer and TGA policy.

Recommendation 11

That NSW Health immediately commence supplying one single use feeding set per day to PADP clients who require tube feeding, as per Therapeutic Goods Administration policy.

6.62 We also support the undertaking by Dr Matthews to make a submission to the TGA, and recommend that this occur as a matter of priority. Further, we recommend that the NSW Minister for Health initiate a national review on the guidelines and policy for equipment reuse, including enteral feeding tubes, through the Council of Australian Governments.

Recommendation 12

That the NSW Minister for Health:

- initiate through the Council of Australian Governments process a national review on the guidelines and policy for equipment use, including enteral feeding tubes; and
- make a submission to the Therapeutic Goods Association on this specific issue.

Home modifications

6.63 In 2003, approximately 395,700 Australians living in private dwellings made modifications to their home to enable them to cope with restrictions to their activity levels or to continue to live in their homes.[405]

6.64 The Association for Children with a Disability estimated that home modifications can cost anywhere between $30,000 to $180,000.[406] These are clearly significant costs on already stretched family incomes. Many families can not afford this additional expense. The Committee was advised that this is particularly the case with many Aboriginal people with a

404 Therapeutic Goods Administration, *ARGMD Single Use Devices (SUDs) and the reuse of SUDs draft as at 15 October 2008*, p 1, accessed 1 December 2008, < http://www.tga.gov.au/devices/argmd-drsud.pdf>

405 Submission 54, p 4

406 Submission 53, Association for Children with a Disability NSW, p 4

disability, some of whom are left with no option but to undertake their own modifications: '… so people build their own ramps or pull down walls. That is really what happens out there, particularly in remote parts of the State.[407]

6.65 Assistance with home modifications is available through the DADHC's Home and Community Care (HACC) program. Linkages to this and other DADHC programs are discussed in chapter 7.

Vehicle modifications

6.66 Likewise, many families also need to undertake vehicle modifications in order to accommodate a wheelchair. There are currently no provisions to assist with vehicle modifications through NSW Health or DADHC.

6.67 The limits placed on clients and their families by not having an accessible vehicle were observed by Northcott Disability Services:

> Without a modified vehicle, families are very limited in what they can do together. Unless they stay at home all the time, they are forced to lift heavy children into car seats, a twisting and stretching manoeuvre that causes considerable back strain. Using modified taxis is a very tedious, time-consuming and inflexible option that does not fit in with family life.[408]

6.68 The cost of taxis was also raised by Ms Jordana Goodman, a Policy Officer from the Physical Disability Council of NSW, who utilises a wheelchair: 'Speaking for myself, I am driving now but I have been catching cabs for the past 18 months and spending $8,000 per annum just getting to work'.[409]

6.69 Inquiry participants called for PADP to either support families to pay for an accessible vehicle,[410] or make accessible vehicles or vehicle modifications tax deductible.[411]

6.70 One option, suggested by Northcott Disability Services, is to implement something similar to the new Victorian Government motor vehicle modification scheme.[412] The $2.5 million scheme subsidises private vehicle modifications, with a maximum subsidy of up to $10,000 available to assist people with a disability to convert their car for wheelchair access.[413]

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407 Mr Damian Griffis, Executive Officer, Aboriginal Disability Network, Evidence, 2 October 2008, p 64

408 Submission 49, p 6

409 Ms Jordana Goodman, Policy Officer, Physical Disability Council of NSW, Evidence, 1 October 2008, p 56

410 Submission 49, p 6

411 Ms Anderson, Evidence, 1 October 2008, p 12; Submission 53, p 5

412 Ms Hall, Evidence, 2 October 2008, p 3

413 Vehicle Modification Subsidy Scheme, < http://www.dhs.vic.gov.au/disability/supports_for_people/ living_in_my_home/aids_and_ equipment_ program/whats_new#vehiclemodification> (accessed 27 November 2008)

6.71 In an answer to a question on notice as to whether the Department had considered funding a scheme similar to that in Victoria, NSW Health advised that the Victorian scheme is funded as part of the Aids and Equipment Program which provides subsidies towards the cost of some equipment rather than full funding.[414]

Case Study: Mrs Heike Fabig*

Heike is a mother of three children, two of whom have an early onset, non-degenerative and as yet unidentified form of autosomal recessive hereditary spastic paraplegia.

Heike's daughter Billie was two and a half years old when her occupational therapist suggested that she would greatly benefit from a power wheelchair. The therapist showed Heike and their PADP extensive research showing that introducing Billie to powered mobility may avoid developmental delays, as at her age children normally acquire independent movement. PADP refused the request, stating that it does not fund power wheelchairs for very young children.

Heike became disillusioned with PADP processes. She was upset that decisions based on budgetary constraints were impeding the wellbeing of her son and daughter. Luckily, Heike's grandfather came forward and offered to fund the wheelchair for Billie.

Over the years Heike has spent a considerable amount of money to purchase other aids and appliances to assist her children to function in everyday life, such as wheelchairs, special seating, walkers, orthopaedic shoes and handrails. She has also purchased a wheelchair accessible vehicle and portable ramp. Her expenses for this essential equipment have totalled over $175,735.

Additionally, Heike's home has needed to undergo major renovations to be made wheelchair accessible such as making the floor flush, building a ramp to the front door and widening the doors. The expenses for these modifications have all come on top of a $300,000 mortgage.

Heike said that she is willing to bear these costs as they are critical to the wellbeing of her children, however she would greatly appreciate government assistance in the form of a tax break on disability related purchases.

* Submission 16, Heike Fabig

Committee comment

6.72 The Committee agrees that people with a disability should be supported to make necessary vehicle modifications in order to drive a vehicle or travel as a passenger in a vehicle. We are aware that the NSW Government generally pays a higher contribution toward PADP equipment than the Victorian Government,[415] nonetheless we believe that assistance should be provided for vehicle modifications.

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414 Answers to questions on notice taken during evidence 24 October 2008, Dr Richard Matthews, NSW Health, Question 7, p 4

415 Submission 72, p 21

6.73 We recommend that the NSW Government implement a vehicle modification subsidy scheme, similar to that operating in Victoria.

Recommendation 13

That the NSW Government implement a vehicle modification subsidy scheme for people with a disability.

Conclusion

6.74 An effective prescription process for disability aids focuses firmly on the needs of the client. While the Committee welcomes recent reforms to the prescription process, these initiatives will not be successful unless accompanied by adequate funding.

6.75 The apparent lack of a routine maintenance program and an efficient system to repair aids and appliances, is a problem for PADP clients, as well as those who have secured their equipment from a non-government agency or charitable organisation. While NSW Health acknowledges the problems regarding the maintenance and repair of disability equipment, and is introducing various initiatives to address these concerns, the Committee is mindful yet again of the need for adequate funding to ensure these reforms are properly implemented.

6.76 The significant financial costs of living with a disability has been a recurrent theme during this Inquiry. In addition to aids and appliances, many people with a disability need to modify their homes and vehicles in order to live as productive a life as possible. At present, financial assistance is not available for vehicle modification. The Committee urges the NSW Government implement a vehicle modification subsidy scheme, similar to that operating in Victoria.

Chapter 7 Administration of PADP

As outlined in chapter 2 and demonstrated throughout this report and the PwC Review, there are significant inefficiencies and inconsistencies inherent in the administrative arrangements of PADP. Many of the reforms being implemented by NSW Health to address these problems have already been considered in previous chapters. This chapter will examine some of the broader reforms relating to centralisation, information systems and procurement strategies. It will also consider improvements to customer service and access to program information.

Administrative reforms

Overview

7.1 In order to overcome the inconsistencies in the provision of PADP identified across the State, the PwC Review made a key recommendation to centralise the administration of the program.[416] This entails transferring all PADP administrative functions from the current 22 Lodgement Centres to a single state-wide service.[417]

7.2 As discussed throughout this report, NSW Health has agreed to implement this recommendation, and has established EnableNSW to serve as the central administrative body.[418]

7.3 EnableNSW will streamline and simplify access to NSW Health disability support programs, namely PADP, the NSW Artificial Limb Service, Ventilator Dependent Quadriplegia program, Home Oxygen Service and the Children's Home Ventilation program.[419] NSW Health expressed the view that EnableNSW would have the effect of eliminating the 'separate fiefdoms' that had developed under the previous system.[420]

7.4 NSW Health has also established the EnableNSW Advisory Council, comprising of key stakeholders including clinicians and consumers, to develop strategic policies, plans and initiatives for Enable.[421]

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416 PricewaterhouseCoopers, *NSW Health – Review of the Program of Appliances for Disabled People*, June 2006, p 19. Throughout the chapter this report will be referred to as the PwC Review.

417 Submission 72, NSW Health, p 4

418 Submission 72, p 13

419 NSW Health, *Disability Equipment – EnableNSW* <http://www.health.nsw.gov.au/initiatives/disabilityequipment/index.asp> (accessed 30 October 2008)

420 Dr Richard Matthews, Deputy Director General, Strategic Development, NSW Health, Evidence, 24 October 2008, p 7

421 Submission 72, p 23

Benefits

7.5 There are a number of significant benefits expected from the centralisation of PADP, not least of which include standardising application and prioritisation processes, waiting lists, and types of equipment provided:

> EnableNSW will apply one set of financial eligibility criteria, clinical criteria and prioritisation process to ensure that people with disabilities and equivalent clinical need receive the same level of assistance regardless of where they live in NSW.[422]

7.6 Centralisation is also expected to achieve administrative efficiencies and improved client outcomes. As outlined in chapter 4, through the streamlining of record keeping and administration, and through better information systems, NSW Health hopes to increase the proportion of the PADP budget spent on equipment from 80 per cent to 84 per cent.[423]

7.7 Another key benefit of rationalisation is that it will provide a single point of access and redress for clients. This point was raised by Dr Richard Matthews, Deputy Director General, Strategic Development, NSW Health: 'I am talking about central coordination and, most importantly, a known central place to which you can go if, for any reason, you believe that you are being unfairly treated'.[424] Information about the complaints process is considered at 7.75.

7.8 Importantly, inconsistencies with prioritisation will also be addressed by the reforms. Under the new system, applicants will be prioritised according to the clinical urgency of their need. Under the current system there have been significant variances in prioritisation practices across lodgement centres. The new tool will allow applications to be considered on the basis of 'clinical expertise in categories of equipment rather than a geographic basis'.[425]

Concerns about centralisation

7.9 Inquiry participants generally welcomed the move for a more consistent, efficient and transparent system that will free up more funds for equipment,[426] however many also held some reservations about centralisation.

7.10 One of the common concerns raised regards the loss of personal contacts and relationships.[427] This point was illustrated by Mr Alfred Alexander de Leeuw from Disability Enterprises:

> As a person who puts the submissions together I lost the personal contacts that could help me solve problems easier and quicker for the clients I work with. Now my client and I are just a number on a list and the communication is gone which makes the

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422 Submission 72, p 13

423 Dr Richard Matthews, Deputy Director General, Strategic Development, NSW Health, Evidence, 1 October 2008, p 2

424 Dr Matthews, Evidence, 1 October 2008, p 6

425 Submission 72, p 13

426 See for example Submissions 18, 25, 51, 52, 54, 64, 68 and 75

427 See for example Submissions 3, 54, 56 and 71

> whole process less transparent for the client which does not help the frustration level.[428]

7.11 A similar statement was made in the Spinal Injury Practitioner Group submission:

> The effect of centralisation may remove the personal element for recipients wishing to advocate for themselves or health professionals advocating on their behalf. A lack of personal contact may result in recipients being disempowered to make an impact or have their needs heard for both repairs and replacement.[429]

7.12 This was a particular concern for inquiry participants from Areas with shorter waiting lists and better program administration, such as Hunter New England (recently assessed as 'the most highly functioning unit in the state').[430] The submission from the Social Issues Committee of the Country Women's Association of NSW declared:

> Once centralised … efficiency in the Hunter will drop dramatically – with no personal contact with the assessment board and no contact with local charities. This, no doubt, will result in long waiting times for requested items.[431]

7.13 While acknowledging that local centres can be advantageous to clinicians and clients with a good working relationship with their PADP coordinator, the NSW Government noted that on the other side people who have not developed these relationships are disadvantaged. They maintained that rationalisation of lodgement centres remains the best option, as it will enable a more equitable distribution of resources.[432]

7.14 Another concern, raised by Mr Alexander de Leeuw, is that '[c]entralising the lodgement centres has formed one big waiting list. Area's with less demand now have to wait as long as everybody else'.[433]

7.15 Concern was also raised that clients in rural and regional areas would be disadvantaged and further isolated as a result of centralisation.[434] These concerns have been acknowledged by NSW Health, who have assured that the changes to the program will be 'fair to everyone, no matter where they live'.[435]

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428 Submission 3, Disability Enterprises, p 1

429 Submission 56, Spinal Injury Practitioner Group NSW, p 3

430 Submission 22, Social Issues Committee, Country Women's Association of NSW, p 2

431 Submission 22, p 2

432 NSW Health, 'NSW Government response to the Review of the Program of Appliances for Disabled People', November 2007, p 4

433 Submission 3, p 1

434 Submission 27, Southern Prosthetics and Orthotics, p 2; Submission 52, Disability Council of NSW, p 4

435 Submission 72, p 12

7.16 Ms Bronywn Scott, Director of EnableNSW, emphasised that clients and therapists and suppliers 'will be ringing the same number and … will have access to the same trained staff', and that everyone from rural and metropolitan areas will receive the exact same support.[436]

7.17 Another common concern raised by inquiry participants regarding centralisation is the loss of local assessment, supply and maintenance services. There was a strong view prevalent among equipment suppliers that centralisation would effectively eradicate local businesses and services.[437] This will be considered later in this chapter.

7.18 Mr Dougie Herd, Executive Director, Disability Council of NSW, suggested that '[a] flexible system delivered locally, and administered centrally seems to everybody to be desirable…'.[438]

7.19 NSW Health assured that this would be the case, advising that only the 'back office' functions of PADP would be centralised. The clinical services used to assess, prescribe, measure and train around equipment will remain local, as will Equipment Loan Pools (ELPs) (discussed in chapter 3). The Department also advised that repairs and maintenance will continue to be provided locally 'where ever practicable'.[439]

Committee comment

7.20 The Committee wholly supports the move to centralisation of PADP. We acknowledge the concerns raised in evidence regarding these reforms, however believe that many of these concerns may not actually eventuate given that clinical services will be remaining local. The centralisation of PADP's 'back office' functions is long overdue and we welcome the efficiencies and cost savings that this will bring.

Rollout period

7.21 In response to the PwC Review, the NSW Government gave an undertaking to implement two stages of reforms. The first stage is to streamline equipment services for people with a disability through centralisation, improved procurement strategies and information management initiatives. The second stage will look at integrating some or all NSW Government disability equipment services 'to further streamline and simplify client access and maximise program efficiency'.[440]

7.22 Stage 1 (which commenced on 6 August 2007)[441] was initially to be rolled out over an eighteen-month period. However this has since been extended, and is now not expected to be completed until early 2011.[442] NSW Health explained the reason for this being that they want the transition to be as seamless as possible: 'Detailed planning undertaken since the release of

436 Ms Bronwyn Scott, Director, EnableNSW, Evidence, 1 October 2008, p 7

437 Submission 9, Northern Rivers Surgical Supplies, p 2

438 Mr Dougie Herd, Executive Director, Disability Council of NSW, Evidence, 1 October 2008, p 38

439 Submission 72, p 12

440 NSW Government response, November 2007, p 3

441 NSW Government response, November 2007, p 4

442 Submission 72, p 4

the Review has identified the need for longer time frames to ensure that client services are not disrupted'.[443]

7.23 The Department advised that the reforms around prescription processes, supply policies and financial management systems will be implemented before that date, however the centralisation of lodgement centres will take time.[444]

7.24 In evidence, Dr Matthews outlined some of the tasks involved in transitioning lodgement centres to a single service:

> We will need to extract the client data from the existing databases and transfer it to the new system. We need to allocate stock equipment to clients, equipment loan pools and web recycling. We need to deal with the issues of relocation and redeployment of staff – employees of area health services who may need to be relocated in other jobs within the area. [445]

7.25 Inquiry participants, while appreciative of the care and caution taken by the Department with regard to the transition, nonetheless felt that the extension of time was too long: 'While appropriate consultation, a pilot and thorough consideration is important, the current review of PADP to centralise and improve the service is rolling out far too slowly'.[446]

7.26 Likewise, Mr Herd declared: 'You do not need to be a rocket scientist to work out that it ought not to have taken this length of time to get us to here and we need to move quickly'.[447]

7.27 The practical impact of the longer rollout period was observed by Mr Sean Lomas, Policy and Information Manager, Spinal Cord Injuries Australia, who stated:

> That is all great and well, but for the person who requires a piece of equipment who is languishing in a hospital bed or at home or, like we have seen on the waiting list data, the young child who has been waiting 18 months for a back brace out in Western Sydney. If you turn around and say to them, "In 2011 it will probably be about right and you can put your application in again after being reassessed, of course, and we will start to move forward with you." The opportunity has been there for a long time. It has not been grasped.[448]

7.28 In response to questioning from the Committee regarding the rollout timeframe, Dr Matthews explained that the process for transitioning lodgement centres involves a two-person implementation team to train clinicians and implement the changes at each centre. This is expected to take several weeks for each centre.[449] However, Dr Matthews was optimistic that the rollout would not take as long as anticipated:

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443 Submission 72, p 4

444 Ms Scott, Evidence, 1 October 2008, pp 3-4

445 Dr Matthews, Evidence, 24 October 2008, pp 1-2

446 Submission 49, Northcott Disability Services, p 5

447 Mr Herd, Evidence, 1 October 2008, p 34

448 Mr Sean Lomas, Policy and Information Manager, Spinal Cord Injuries Australia, Evidence, 1 October 2008, p 43

449 Dr Matthews, Evidence, 24 October 2008, p 2

> We are hopeful that we will be able to improve on that timetable because we think that the first centre and its transition will be a learning process. What they learn from the first one or two [transitions] will hopefully shorten the process and shorten the timetable.[450]

7.29 The only other possible option to speed up the process would be to run two implementation teams in tandem. Dr Matthews stated: 'I think there are some concerns about doing that, but what I will do is undertake to go away and have a look at that'.[451]

Committee comment

7.30 Given that the PwC Review was completed in 2006, and the NSW Government agreed to centralise PADP in 2007, we believe that a completion date of 2011 to finalise these reforms is too long.

7.31 We understand that there is a considerable amount of work involved in the transitions, and appreciate that NSW Health is ensuring that the transitions are as smooth as possible to minimise disruptions to clients, staff and therapists. Nonetheless we believe that it is still possible to bring forward the completion date while ensuring minimal disruption to stakeholders.

Recommendation 14

That to improve the efficiency of the equipment assessment and delivery process, NSW Health complete Stage 1 of PADP reforms by the end of 2009.

Supplier consultations

7.32 One of the concerns expressed during the Inquiry was that suppliers were not consulted during the PwC Review. This was raised by Mr Christopher Sparks, Executive Officer, Independent Rehabilitation Suppliers Association of NSW:

> We are a major stakeholder and critical part of the entire equipment supply process, yet until now we have been effectively shut out of any debate with little chance to contribute in formation of policy. Frankly, we were stunned when we were not properly consulted in any way in the formation of the PricewaterhouseCoopers report. In our view this report is fundamentally flawed due to its abject failure to consult with equipment suppliers, yet this report has become the basis of the Government's reform agenda.[452]

7.33 Suppliers commented on an apparent negative perception of them as being 'money hungry, greedy and constantly wanting to 'rip off the system''.[453] They argued that this perception is

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450 Dr Matthews, Evidence, 24 October 2008, p 10

451 Dr Matthews, Evidence, 24 October 2008, p 10

452 Mr Christopher Sparks, Executive Officer, Independent Rehabilitation Suppliers Association of NSW, Evidence, 2 October 2008, p 22

453 Submission 9, p 2

unjustified and far from the truth, and emphasised that their industry has considerably low profit margins compared to other medical sectors.[454]

7.34 They contended that consultation was important to help maintain the future viability of their industry, not only for their sake but for clients too:

> The fallout of business failures in our industry sector will have a devastating impact on the lives of those will disabilities and the elderly who depend on our products and services. It is incumbent upon Government at every level to ensure they conduct themselves so as to stimulate and support our industry whilst achieving best value for the public dollar.[455]

Committee comment

7.35 The Committee agrees that major reforms involving PADP should include input from suppliers, in order to provide an holistic understanding of the program from people 'on the ground'. We understand that clinicians and consumers will be provided with the opportunity for input through the EnableNSW Advisory Council, and believe that a similar opportunity for input should be made available to suppliers.

Recommendation 15

That NSW Health ensure there is supplier representation on the EnableNSW Advisory Council.

Procurement

7.36 At present, individual lodgement centres are responsible for purchasing their own equipment. As a part of the proposed reforms to PADP, procurement functions will also be centralised. The aim of the standardised procurement program, currently being developed by EnableNSW, is to purchase products in the most cost effective manner:

> Centralised procurement functions will allow bulk purchase of equipment for the entire state, thereby gaining optimal unit prices for equipment and subsequently releasing more funds for equipment purchase.[456]

7.37 Dr Matthews told the Committee that bulk buying would be limited to non-complex items such as continence aids, adding: 'Clearly, pieces of equipment or aids that need to be designed for an individual, because of that individual's unique needs, cannot be the subject of bulk purchase'.[457]

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454 For example, see Submissions 9, 30, 43

455 Submission 43, Independent Rehabilitation Suppliers Association of NSW, p 4

456 Submission 72, p 8

457 Dr Matthews, Evidence, 24 October 2008, p 15

7.38 NSW Health advised that standardised, centralised procurement functions would be achieved through the use of Preferred Suppliers Agreements, Tenders and State-wide Contracts.[458]

7.39 This proposal has been met with considerable protest from suppliers, who expressed concerns that rural and regional suppliers would be run out of business: 'Centralisation would mean the mass closure of all regional rehabilitation supplier outlets for lack of viability'.[459]

7.40 Mr Christopher Sparks, Executive Officer, Independent Rehabilitation Suppliers Association of NSW, illustrated this point in evidence to the Committee:

> … there are smaller rural dealers and they feed their families by selling half a dozen rollators, a couple of standard wheelchairs and the odd scooter and perhaps a slightly complex power chair once a month. All of a sudden you say you are going to buy all your standard products from company X based in Sydney ... That business collapses and next thing the disabled people in that community have no access to local service.[460]

7.41 Inquiry participants also stressed that the cheapest product does not necessarily mean that it is the most suitable.[461] For example, the Social Issues Committee of the Country Women's Association talked about one PADP that changed nappy suppliers in a bid to save money:

> The new nappies have proved to be of inferior quality, forcing the mothers to use many more than previously, making the mothers run out of credit with PADP. They then have to top up supplies with their own purchases. Surely, a false economy.[462]

7.42 The Committee also received evidence of an 'OfficeMax trial', where standard healthcare equipment has been provided through OfficeMax. There have been reports of equipment being 'dropped off on the front porch of an elderly or disabled person by a courier', with no assistance provided to set it up or train the user in its proper use.[463] Mr George Ajaka commented on this situation:

> Consider the 75 year old female who lives alone and has recently returned home following a hospital stay. This person may require a $500 wheelchair, which is deemed a low cost item and non-complex in nature. Now consider the wheelchair turns up delivered in a box from a courier company. Is she expected to unpack the wheelchair and assemble it? Who is responsible in showing her how to operate the wheelchair? The local therapist could be 2-4 hours away. A local provider of the same chair may sell it for $50 more but will deliver it and ensure safe use.[464]

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458 Submission 72, p 8

459 Submission 9, p 2

460 Mr Sparks, Evidence, 2 October 2008, p 28

461 Submission 35, Multicultural Disability Advocacy Association, p 7; Submission 55, Mr George Ajaka, p 2

462 Submission 22, p 3

463 Submission 43, p 12; Submission 45, Otto Bock Australia, p 7

464 Submission 55, p 2

Committee comment

7.43 The Committee supports a cost-effective procurement strategy that will free up more funds for the direct purchase of PADP equipment. We note that bulk buying will be limited to purchases of non-complex items.

7.44 The Committee notes the concerns raised regarding the viability of rural and regional suppliers, and agree that centralised procurement should not come at the expense of these businesses. We recognise that there is a balance to be made between cost savings through bulk purchases and supporting local industry. We suggest that this be considered as part of the new procurement strategy.

Recommendation 16

That EnableNSW consider the viability of equipment suppliers in rural and regional areas as part of its new procurement strategy.

Information systems

7.45 There was significant criticism in evidence regarding the adequacy of the PADP information system and data collection across the State.

PADPIS

7.46 Inquiry participants expressed frustration with the lack of information regarding waiting lists: 'Information about the status of applications, once made, is very difficult to obtain, which increases frustration and exasperation with the program from clients and allied health staff'.[465]

7.47 Vision Australia staff commented 'it is difficult to find out if people are on the waiting list and if so how long they are likely to wait'.[466] The Physical Disability Council of NSW suggested that current and accessible information regarding waiting lists would assist with the assessment, coordination and processing of applications.[467]

7.48 The lack of information regarding waiting lists stems from the incapacity of the program's current information system, the Program of Appliances for Disabled People Information System (PADPIS) to record this information. PADPIS also lacks the ability to plan for routine maintenance or replacement of equipment.[468]

7.49 Additionally, PADPIS is unable to interface with other NSW Health information systems and databases. This has resulted in multiple databases and duplication of data entry.[469] In its

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465 Submission 68, MS Australia, p 9

466 Submission 64, Vision Australia, p 2

467 Submission 51, Physical Disability Council of NSW, p 8

468 PwC Review, p 139

469 Dr Matthews, Evidence, 24 October 2008, p 15

consideration of the system, the PwC Review found that PADPIS was 'outdated, prone to error and software failure'.[470] The Review recommended that a new information system be implemented as a matter of urgency.[471]

7.50 NSW Health agreed to this, and is planning to implement the new information system by March 2009. The new system will include up-to-date information on the length and monetary value of waiting lists and the status of applications, and will collect information for equipment tracking and maintenance purposes[472] (as discussed in chapter 3).

Data collection

7.51 There has been inadequate data collection on the number of people with a disability and their equipment requirements.[473] This issue is not only confined to PADP, but affects disability programs across NSW and Australia.[474] For instance, the 2006 Census was the first to contain any disability related questions.[475]

7.52 The Australian Institute of Health and Welfare commented on the inconsistency of disability equipment services in a 2006 report on disability and disability services in Australia:

> Equipment services in Australia are somewhat fragmented, being provided by a mosaic of services, generally through the health or veteran's systems or the non-government sector. No national data on these various programs are compiled.[476]

7.53 Collection of disability data in NSW is necessary to determine unmet need and future demand for the program (as discussed in chapter 4), which will in turn enable planners to ascertain how much funding is actually required. This point was noted by Mr Greg Killeen:

> … although NSW Health has agreed more funding is required, it has always maintained that it requires appropriate data on the demand for PADP before it could approach the NSW Government and NSW Treasury to seek an increase in PADP funding.[477]

7.54 Vision Australia commented in their submission that 'the collection and publication of these statistics will give a clearer picture as to the adequacy of funding for the program'.[478]

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470 PwC Review, p 139

471 PwC Review, p 21

472 NSW Government response, November 2007, p 11

473 Submission 68, p 4

474 Submission 52, p 2

475 Australian Bureau of Statistics 2007, '2006 Census of Population and Housing: Media Releases and Fact Sheets', Cat. No. 2914.0.55.002, ABS, Canberra

476 Submission 52, p 2

477 Submission 63, Mr Greg Killeen, p 1

478 Submission 64, p 2

7.55 In addition to robust data collection to determine unmet and future demand, the National Disability Services submission suggested that data on the current usage of PADP is also inadequate: '[T]he accuracy of waiting list data is questionable and unreliable'.[479]

7.56 Inquiry participants urged for the immediate state-wide collection of data on current use, unmet need and projected need of disability equipment, in order to accurately determine the full extent of current demand and to assist in the prediction of future demand.[480] At the same time however, many acknowledged the difficulty in doing so: 'Trying to get an accurate snapshot of absolute demand for those who have a requirement for equipment under the PADP is virtually impossible'.[481]

7.57 While some areas of unmet need are undoubtedly difficult to measure, it was noted that other areas are relatively easy to ascertain. For example, Mr Herd highlighted in evidence:

> If a child is born with a disability and that child requires, let us say, a motorised wheelchair for her entire life, we know that that child will grow and will need a wheelchair as time develops. We know how many people have a spinal cord injury every year, and an acquired brain injury is a consequence of a road traffic accident … We know with cast-iron guaranteed certainty that we will need more incontinence pads in the future because we have an ageing population and incontinence is associated with that.[482]

7.58 Similarly, the General Manager of Services from the Spastic Centre, Mr Chris Campbell also commented on the ability to forecast future demand, noting that this has already been done in other areas:

> … you can predict reasonably accurately the types of equipment that someone is going to use and if you factor in it has a lifespan of X, you can then start to build up an idea of what your future demand is going to be over that time. Again, that is the same sort of process that John Walsh went through with the lifetime care scheme, and recently we engaged Access Economics to look at the broader effect of the person with cerebral palsy on the economy.[483]

7.59 It was emphasised that it is not only important to understand current needs, but it is equally essential to have the predictive capability to plan for the future: 'We need the ability to see what is happening now in unmet need, waiting times and waiting lists, but we also need to be able to look forward and see what we will need'.[484]

7.60 In its submission, NSW Health stated that 'further work on demand projections will be undertaken following consolidation of the program and enhancements to data management'.[485]

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479 Submission 54, National Disability Services NSW, p 15

480 Submission 52, p 2; Submission 54, p 15; Submission 64, p 4

481 Submission 75, Spinal Cord Injuries Australia, p 2

482 Mr Herd, Evidence, 1 October 2008, p 39

483 Mr Chris Campbell, General Manager, Services, the Spastic Centre, Evidence, 1 October 2008, p 47

484 Mr Herd, Evidence, 1 October 2008, p 39

485 Submission 72, p 7

Committee comment

7.61 The Committee agrees that data capture is essential to measure the program's ability to meet current and unmet demand, and to forecast future demand. This is essential for future funding and planning reasons, and we are significantly concerned about the lack of disability and PADP data capture to date.

7.62 We note that the PwC Review did not make a recommendation regarding data collection for measuring unmet and future demand.

7.63 The Committee believes that data on disability equipment requirements should be collected on a state-wide basis as a matter of priority, in order to assist the NSW Government to fully determine funding and planning requirements for its disability programs.

Recommendation 17

That the NSW Government collect data on current, unmet and future demand for disability equipment in New South Wales as a matter of priority.

Program information and customer service

7.64 Inquiry participants have experienced difficulties in accessing program information and contacting PADP staff. Even once staff have been contacted, issues have arisen regarding the quality of service provided.

Information and access

7.65 The Committee received evidence that general information regarding PADP has been difficult to obtain. The Physical Disability Council of NSW stated:

> In the past both written and electronic information about PADP, including eligibility criteria, wait lists, the availability of equipment, complaint mechanisms and contact information has been difficult to obtain. Current information on the NSW Health website is limited to the PADP policy, information about this review and out of date information about lodgement centres.[486]

7.66 The difficulty in even finding out contact information was raised by Vision Australia, who told the story of one client being 'referred to 4 different hospital services before finally obtaining the correct phone number for the PADP contact, which was an answering machine'.[487]

7.67 Another issue is that the available information is difficult to understand. Ms Ruth Robinson, Executive Officer, Physical Disability Council of NSW, suggested that there are a number of ways in which this could be improved:

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486 Submission 51, p 8

487 Submission 64, pp 3-4

> [The program needs] clear information about really basic things – what is it about? Am I eligible? How do I apply? How long will I have to wait? What is the opportunity I might actually get something? Where do I complain if none of these things happen?[488]

7.68 Inquiry participants also viewed the limited opening hours of lodgement centres as a significant barrier to information about the program. In evidence, Ms Scott acknowledged that some lodgement centres are only accessible to clients 'for only a few hours each day, or on two or three days a week, which is … not acceptable'.[489]

7.69 The impact that these hours can have on a client was illustrated by Spinal Cord Injuries Australia:

> There was a lack of 24/7 assistance. This was highlighted with the story of a gentlemen whose batteries ceased working on Good Friday and was unable to leave the house until the following Tuesday when his batteries were replaced. In this instance the lodgement centre was helpful although all they could do was leave a phone message for their sub-contracted repairer to pick up when they returned to work on Tuesday.[490]

7.70 Northcott Disability Services suggested that an after hours emergency contact number would assist clients who need urgent equipment support.[491]

7.71 Recognising these issues, the PwC Review recommended that more information be made available regarding PADP policies and lodgement centre operations,[492] and that this information be made available on a website and via a 1800 number.[493]

7.72 This was supported by NSW Health, who have begun implementing these recommendations. The 1800 helpline has been operating since September 2007 to provide general information regarding eligibility and application processes.[494] The Department also advised that EnableNSW will be open for standard business hours, and they will also be running a trial of extended hours into the early evening.[495]

7.73 The Committee heard evidence however that although the 1800 number has been up and running for over a year, 'nobody knows about it'.[496] In response to questioning from the Committee as to what can be done to remedy this situation, Dr Matthews replied:

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488 Ms Ruth Robinson, Executive Officer, Physical Disability Council of NSW, Evidence, 1 October 2008, p 52

489 Ms Scott, Evidence, 1 October 2008, p 6

490 Submission 75, p 10

491 Submission 49, p 6

492 PwC Review, p 20, Recommendation 5

493 PwC Review, p 23, Recommendation 17

494 NSW Government response, November 2007, pp 13-14

495 Submission 72, p 14

496 Mr Lomas, Evidence, 1 October 2008, p 44

> … I will go out on a limb here and say, I will ask the team to develop a simple business card or something that can be distributed to all the relevant clinicians that contains the contact details for Enable and the website and the single 1800 number and try and get it disseminated and distributed as widely as possible.[497]

Committee comment

7.74 The Committee believes that better advertising of the new PADP website and 1800 number is required to improve awareness of the new system, which will facilitate better access to program information. We thank Dr Matthews for his undertaking to widely distribute a business card to stakeholders with this information, however believe that still more needs to be done.

Recommendation 18

That EnableNSW conduct a public awareness campaign informing PADP stakeholders of its website and 1800 number before June 2009.

Complaints

7.75 The Committee also heard that information regarding complaints procedures and mechanisms is difficult to obtain.[498] The Physical Disability Council of NSW stated that '[c]urrent information on the NSW Health website is limited to the PADP policy, information about this review and out of date information about lodgement centres'.[499]

7.76 The Multicultural Disability Advocacy Association commented in their submission:

> … the experience of MDAA consumers and advocates when trying to make complaints is that they are not informed of the internal and external compliments and complaints procedures. MDAA views this as being unacceptable. Particularly as people from NESB often fear the repercussions of complaining directly to a service provider. Details of the mechanisms for complaints and compliments procedures should be readily available to all.[500]

7.77 The PwC Review agreed that people with a disability need better access to information about the program, particularly in regard to appeals (see chapter 5) and complaints.[501] This was accepted by NSW Health, which has given an undertaking to provider clearer information regarding both.[502] In order to achieve this, EnableNSW will be developing clear communication templates and processes which include advice about how to make a

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[497] Dr Matthews, Evidence, 24 October 2008, p 13

[498] See for example Submissions 35, 51 and 54

[499] Submission 51, p 8

[500] Submission 35, p 8

[501] PwC Review, p 149

[502] NSW Government response, November 2007, p 6

complaint. These will be sent to clients with letters about their application. The Department advised that the new system will begin running in early 2009.[503]

Access for vision and hearing impaired clients

7.78 Access to information for vision and hearing impaired clients was another issue raised during the Inquiry. One witness stated: 'It is currently pretty much impossible for a person who is blind or has low vision to access the program independently as the information and the application forms are not accessible'.[504]

7.79 Vision Australia suggested that information on PADP be made more accessible through a variety of formats, such as Braille and audio.[505] In addition to these two formats, the Disability Council of NSW added that information should also be made available via a W3C compliant website and large print.[506]

7.80 As part of its reforms to improve access to program information, NSW Health advised that it will 'support access by people with sensory disabilities such as vision impairment'.[507] Dr Matthews advised that feasible options to support vision impaired clients include attaching audio information to a website and enlarging text on web pages.[508]

Committee comment

7.81 The Committee supports the availability of PADP information in different formats to assist hearing and vision impaired people. We believe that this is essential given the scope of the program.

7.82 We note that NSW Health have stated that they will support people with sensory disabilities, and that they provided examples of how they can support people that are vision impaired. However it was not clear to the Committee as to what assistance is currently in place, and what (or when) other sensory assistance will be made available. Therefore we recommend that access to PADP information be made available to sensory impaired people by March 2009.

Recommendation 19

That EnableNSW ensure that access to PADP information is made available to people with sensory impairments by March 2009.

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503 Answer to additional question on notice 24 October 2008, Dr Richard Matthews, NSW Health, Tab C, p 9

504 Ms Susan Crane, Administration and Research Officer, Vision Australia, Evidence, 2 October 2008, p 48

505 Submission 64, p 3

506 Submission 52, p 5

507 NSW Government response, November 2007, p 13

508 Answers to questions on notice taken during evidence 24 October 2008, Dr Richard Matthews, NSW Health, Question 8, p 5

Access for people from culturally different backgrounds

7.83 There is also a lack of accessible PADP information for people from Culturally and Linguistically Diverse backgrounds and Indigenous people.[509] The Multicultural Disability Advocacy Association informed the Committee that:

> Many services centres seem unable to accommodated linguistic and cultural diversity of consumers. The most basic mechanisms for people from NESB [Non-English Speaking Backgrounds] such as the use of interpreters or the publication of material in languages other than English are often neglected.[510]

7.84 The Association emphasised the impact this has on its clients, noting that '[a]ccess to information is often the first step towards people making meaningful choices to participate in the community'.[511]

7.85 The Disability Council of NSW recommended that PADP information be made available in a variety of community languages.[512]

7.86 Aboriginal people also face access barriers to program information, many of whom have never even heard of PADP.[513] This is of particular concern given the high proportion of the Indigenous community that has some form of disability.[514] Further, the Aboriginal Disability Network claimed:

> … the 1800 line will do nothing to improve access to the program by Aboriginal people - many of whom would not have ready access to a phone in any event … There ought to be specific culturally sensitive and accessible information available to Aboriginal persons about PADP.[515]

Committee comment

7.87 It is clear from the evidence that access to PADP information for people from culturally different backgrounds is an issue. The Committee believes that providing PADP information in a range of community languages will go some way in addressing this issue.

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509 Submission 54, p 14

510 Submission 35, p 8

511 Submission 35, p 4

512 Submission 52, p 5

513 Mr Damian Griffis, Executive Officer, Aboriginal Disability Network, Evidence, 2 October 2008, p 58

514 Submission 70, Aboriginal Disability Network NSW, p 1

515 Submission 70, pp 6-7

Recommendation 20

That EnableNSW ensure that PADP information is made more accessible to people from culturally different backgrounds, including being made available in a variety of community languages.

Customer service

7.88 A related issue to the provision of program information is customer service. Evidence received by the Committee revealed frustrations with the quality of the program's customer service, with some inquiry participants complaining of rude service from staff.[516] The adequacy of PADP staff training was also questioned.[517] One submission author commented:

> I hope that in the future PADP could be made more "user friendly", dealing with applications in a timely manner, managed by well-trained and efficient staff who are able to accurately assess the needs of the applicants, without the applicants feeling like unworthy recipients of charity.[518]

7.89 A similar request was made by National Disability Services, who recommended that all PADP staff undergo disability awareness training in line with the Disability Service Standards and the Disability Discrimination Act.[519]

7.90 Not all consumers were dissatisfied with the service. One carer stated: 'All my dealings with the PADP have been good except for the delays, the service is good, the staff are helpful and polite'.[520]

7.91 Ms Scott told the Committee that she was aware of these issues, and that EnableNSW will be addressing them as part of their reforms:

> Regrettably, I am aware of situations where clients or their family members have not received a reasonable standard of customer service ... As part of our reforms we want to ensure that all clients are treated with the courtesy and respect that they deserve, that they are provided with information that is helpful to them, and that they are provided with it in a timely way.[521]

7.92 In order to facilitate this, Ms Scott informed the Committee that all EnableNSW staff will be required to complete Certificate III or IV level training in customer service, which will be tailored specifically for staff working in disability services.[522]

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516 Submission 10, Name suppressed, p 2; Submission 57, Ms Jackie Kay AM JP, p 1

517 Submission 75, p 7

518 Submission 57, p 1

519 Submission 54, p 3

520 Submission 15, Mr Ian Justice, p 1

521 Ms Scott, Evidence, 1 October 2008, p 6

522 Ms Scott, Evidence, 1 October 2008, p 6

7.93 In addition to customer service training, EnableNSW will ensure that senior staff members are available to support junior staff. The lack of senior support for staff in the existing system was also recognised as a problem by Ms Scott: 'Often their jobs are difficult and stressful and we also need to support our staff more effectively. To date they have not been provided with that support'.[523]

7.94 Further, the new information system (discussed earlier) is also expected to improve customer service through better maintenance of client records:

> It will ensure that, when customer service officers respond to a call, they will have at their fingertips current information about that person, about any inquiries or complaints that they have previously made, and about the progress of those inquiries and complaints.[524]

Departmental responsibilities

7.95 PADP is currently administered by NSW Health. However questions have been raised as to whether or not the program would be better located within the Department of Ageing, Disability and Home Care (DADHC).

Health or DADHC?

7.96 The Committee heard mixed views in evidence. For example, the Spastic Centre highlighted that PADP was established in the early 1980's, before DADHC existed and when NSW Health was wholly responsible for disability services. They therefore argued that responsibility for PADP should be transferred to DADHC for the following reasons:

- DADHC has a greater awareness of the care, community support and equipment needs for children and adults with disabilities;
- DADHC has stronger links and relationships with government and non government disability service providers and advocacy groups;
- The majority of people with disabilities would not relate directly with a health service in their daily lives but have greater links with a disability service;
- DADHC would have a greater commitment to community integration and participation for people with disabilities.[525]

7.97 The MS Society also supported departmental change, noting that at a recent meeting of National and State/Territory Disability Ministers in May 2008, the Ministers agreed 'to work towards greater consistency in equipment schemes across Australia'. The MS Society argued that this undertaking necessitated the need for the DADHC Minister to take responsibility for PADP.[526]

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523 Ms Scott, Evidence, 1 October 2008, p 7

524 Ms Scott, Evidence, 1 October 2008, p 7

525 Submission 38, The Spastic Centre of NSW, pp 6-7

526 Submission 68, p 111

7.98 Additionally, Spinal Cord Injuries Australia contended that the clinical focus of NSW Health is too narrow for PADP clients, and expressed the view that the more holistic approach of DADHC is better suited:

> DADHC will look at this from a person centred approach as they do across all of their disability services. This approach will look at contribution to society and their community. Ease of access to shops and employment. A person with a disability does not necessarily have an illness it's a situation they live with.[527]

7.99 However, there were equal arguments the other way. For example, Ms Jordana Goodman, Policy Officer, Physical Disability Council of NSW declared that PADP 'is not just a disability program. We are talking about people with health conditions who are living in the community'.[528]

7.100 Another argument for NSW Health to retain PADP, raised by the Greater Metropolitan Clinical Taskforce, is that the majority of clinicians prescribing equipment are employed by the Department, which also has 'the capacity, established clinical networks and the operational experience to address important workforce issues'.[529]

7.101 Also in support of keeping the status quo was the Disability Council of NSW, who stated:

> Indeed, we have been impressed by the commitment shown and effectiveness demonstrated by Enable NSW to date. We believe that Enable NSW is best placed to carry forward the reform agenda for PADP and allied equipment programs.[530]

7.102 PwC considered departmental responsibility for the program as part of its Review. It recommended that NSW Health retain responsibility for PADP, and that DADHC contribute to the development of policy through 'an appropriate governance mechanism'.[531]

7.103 NSW Health and DADHC both supported this recommendation. Both departments agreed that a key component of PADP is the role of clinicians in prescribing appropriate equipment, and that the most effective way to support this is to keep the program within NSW Health which has responsibility for clinical services and clinical practice.[532]

7.104 DADHC also highlighted to the Committee that it has senior representation on the EnableNSW Advisory Council, which will enable it to contribute disability policy expertise to NSW Health.[533] Further, the Department added:

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527 Submission 75, p 9

528 Ms Jordana Goodman, Policy Officer, Physical Disability Council of NSW, Evidence, 1 October 2008, p 53

529 Submission 46, Greater Metropolitan Clinical Taskforce, NSW State Spinal Cord Injury Service Summary Paper, p 4

530 Submission 52, p 5

531 PwC Review, p 20, Recommendation 8

532 Submission 66, Department of Ageing, Disability & Home Care, p 2; Submission 72, p 23

533 Submission 66, p 2

> The consolidation of equipment schemes operated within NSW Health and the Area Health Services has resulted in a service that is significantly larger in scope and size than PADP. A significant proportion of the aids and equipment to be made available through EnableNSW are for the specific health-related purposes of clients of NSW Health.[534]

Committee comment

7.105 The Committee notes that there are strong arguments either way regarding which department should be responsible for administering PADP, however we agree with the finding of the PwC Review that departmental responsibility for PADP should remain with NSW Health. We are confident in the role of EnableNSW in implementing the PADP reforms and improving the program, and we support the vital role of DADHC on the Advisory Council.

Integration of disability programs and services

7.106 In evidence to the Committee, the Director of the Council of Social Services of NSW, Ms Alison Peters, suggested that the question as to which department should be responsible to PADP is somewhat irrelevant, as ideally both departments are responsible:

> It really is not about replicating the particular administration of the programs within a particular silo area. It is about moving beyond that way of looking at the delivery of services, particularly with PADP. What you want to get, the sort of outcomes that you would like to achieve is a full coordination of the health, disability and non-government organisation sectors in providing comprehensive quality services to individuals to facilitate their full participation in society.[535]

7.107 Other inquiry participants, noting the range of interrelated programs across NSW Health and DADHC, agreed that '[t]he imperative is for cross program linkages, so location is only part of this equation'.[536]

7.108 As outlined earlier, EnableNSW has now taken responsibility for an integrated approach to managing PADP, the NSW Artificial Limb Service, Ventilator Dependent Quadriplegia program, Home Oxygen Service and the Children's Home Ventilation program.

7.109 However there are also a number of related disability support programs run through DADHC, including the Home and Community Care (HACC) program, Attendant Care program, Home Modification and Maintenance Services (HMMS), Group Homes and the NSW Younger People in Residential Aged Care program (YPIRAC).[537]

7.110 The Aboriginal Disability Network NSW commented on this plethora of programs in its submission:

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534 Submission 66, p 2

535 Ms Alison Peters, Director, Council of Social Services of NSW, Evidence, 1 October 2008, p 61

536 Submission 68, p 11

537 Department of Ageing, Disability and Home Care, 'People with a disability', <http://www.dadhc.nsw.gov.au/dadhc/People+with+a+disability/> (accessed 2 November 2008)

> In our view there is great inefficiency and injustice associated with maze created by this multiplicity of programs. It is essential that these programs are integrated and harmonised so as to eliminate administrative inefficiency, ensure that the maximum possible resources are deployed to service delivery, and improve visibility and access.[538]

7.111 Mr Killeen stressed the importance of a whole of government approach to disability services, contending that there have been occasions in the current system when people have tried to access services, only for there to be 'a dispute between the services as to which one has the responsibility for providing the specific service'.[539]

7.112 One problem, raised by the Greater Metropolitan Clinical Taskforce, is that there have apparently been cases where clients have received PADP equipment, but have been unable to secure assistance with home modifications in time to facilitate use of the equipment. They recommended that EnableNSW review PADP links with programs such as the home modifications scheme in order to prevent these situations.[540]

7.113 These problems were acknowledged by Dr Matthews, who advised that there are discussions regarding the integration of disability programs at a national level through the Council of Australian Governments. However, until and unless any changes are made, Dr Matthews agreed that the two departments 'need clearly to work in partnership'.[541]

7.114 With regard to integration of NSW Health and DADHC services, the PwC Review made a specific recommendation to transfer the Aids for Individuals in DADHC Accommodation Services (AIDAS) to PADP.[542] AIDAS is funded by DADHC to provide disability aids and equipment to clients living in DADHC operated residential facilities. There is considerable overlap between AIDAS and PADP, however clients in receipt of funding from one program are not eligible for funding from the other.[543]

7.115 The NSW Government agreed to give this recommendation further consideration after completion of Stage 1 reforms to PADP.[544] The Department advised that integration of NSW Government disability equipment services are to be considered as part of the Stage 2 reforms.

Committee comment

7.116 The Committee agrees that there must be better coordination and integration of disability services between NSW Health and DADHC. We note that the NSW Government has undertaken to consider this during Stage 2 of its reforms. However we believe that this is an important area that should be considered sooner rather than later, and are of the view that the

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538 Submission 70, p 4

539 Submission 63, p 4

540 Submission 46, Greater Metropolitan Clinical Taskforce, GMCT Brain Injury Rehabilitation Program Summary Paper, p 1

541 Dr Matthews, Evidence, 24 October 2008, p 16

542 PwC Review, p 25

543 PwC Review, p 164

544 NSW Government response, November 2007, p 17

EnableNSW Advisory Council are in a position to do this, beginning at its first meeting on 4 December 2008.[545]

Recommendation 21

That the EnableNSW Advisory Council consider ways to improve coordination and integration of NSW Health and Department of Ageing, Disability and Home Care disability support services, beginning immediately.

Conclusion

7.117 For many years PADP has been marred by inconsistencies and administrative inefficiencies, the effects of which have taken a major toll on clients and their carers, and impacted on suppliers and therapists. Centralisation of the program's administrative functions should go a long way in addressing these issues, and importantly it will assist in ensuring that the program is delivered equitably to all clients regardless of where they live in NSW.

7.118 While there are notable concerns that centralisation will impact local services, NSW Health has assured that clinical assessment and prescription services for the program will remain local, along with repair and maintenance services where possible.

7.119 The Committee's main concern regarding centralisation is the extended timeframe to rollout the reforms. We believe that change must ensue quickly to better help clients who are already in dire need of assistance.

7.120 There is significant work ahead for EnableNSW. To assist it in achieving its tasks, improvements will need to be made to data collection and information dissemination. While most stakeholders are broadly aware of the reforms, many have been unable to ascertain details of what (or when) these changes will affect them. Clear information and communication will be critical during the rationalisation of lodgement centres to ensure as smooth a transition as possible.

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545 Answers to questions on notice taken during evidence 1 October 2008, Ms Bronwyn Scott, NSW Health, Question 5, p 4

Appendix 1 Submissions

No	Author
1	Mrs Jennifer de Ville
2	Mr Paul Said
3	Mr Alfred Alexander de Leeuw
4	SDL (Seating Dynamics)
5	Matthew and Belinda Hooley
6	Ms Beverley Horner
7	Mr Evan Starling
8	Mr Barry Bryan
9	Northern Rivers Surgical Supplies
10	Name suppressed
11	Occupational Therapy Department Cessnock/Kurri Kurri and Singleton Health Services
12	Mr Ralph Hasna
13	Mr Bruce Ellison
14	Invacare Australia
15	Mr Ian Justice
16	Ms Heike Fabig
17	Ms Fiona Anderson
18	Motor Neurone Disease Association of NSW
19	Mrs Gail Martin
20	Specialised Wheelchair Company
21	Name suppressed
22	Social Issues Committee County Women's Association of NSW
23	GTK Rehab
24	Hunter Lymphoedema Support Group
25	CNC Dysphagia Clinic
26	The Health Services Association of NSW
27	Southern Prosthetics and Orthotics
28	The Concerned Australian Family Action Group Incorporated
29	Coffs Harbour and Bellingen Local Disability Advisory Committee
30	Mr George King

No	Author
31	Muscular Dystrophy Association NSW
32	Paraplegic and Quadriplegic Association of NSW (ParaQuad NSW)
33	Ms Joy Ryder
34	Ms Amy Bjornson
35	Multicultural Disability Advocacy Association
36	Norman and Chris Mackenzie
37	Australian Association of Occupational Therapists NSW
38	The Spastic Centre of NSW
39	Name suppressed
40	Department of Paediatric Occupational Therapy The John Hunter Children's Hospital
41	Mrs Katalin Eben
42	Gastronomy Information and Support Society NSW
43	Independent Rehabilitation Suppliers Association of NSW
43a	Independent Rehabilitation Suppliers Association of NSW
44	Dieticians Association of Australia
45	Otto Bock Australia
46	Greater Metropolitan Clinical Taskforce
47	People with Disability Australia
48	Nutricia Australia PTY Ltd
49	Northcott Disability Services
50	Mr Don Howe
51	Physical Disability Council of NSW
52	Disability Council of NSW
53	Association for Children with a Disability NSW
54	National Disability Services NSW
55	Mr George Ajaka
56	Spinal Injury Practitioner Group NSW
57	Ms Jackie Kay AM JP
58	Mrs Alison Simpson
59	Mr Morris Malouf
60	Mr Mark Stallard
61	Council of Social Service of NSW
62	Mr Mark Malouf

No	Author
63	Mr Greg Killeen
64	Vision Australia
65	Ms Patricia Manderson
66	Department of Ageing, Disability and Home Care
67	Mrs Kay Brooks
68	MS Australia
69	Ms Christine Hughes
69a	Confidential
70	Aboriginal Disability Network NSW
71	Spinal Pressure Care Clinic
72	NSW Department of Health
73	The Cancer Council NSW
74	Confidential
75	Spinal Cord Injuries Australia
76	Coles Orthotics Pty Ltd
77	Ms Faye Galbraith

Appendix 2 Witnesses

Date	Name	Position and Organisation
1 October 2008, Jubilee Room Parliament House	Dr Richard Matthews	Deputy Director General, Strategic Development, NSW Department of Health
	Ms Cathrine Lynch	Director, Primary Health and Community Partnerships, NSW Department of Health
	Ms Bronwyn Scott	Director, EnableNSW, NSW Department of Health
	Ms Heike Fabig	
	Ms Fiona Anderson	
	Mr Raul Osbich	
	Mr Barry Bryan	Coordinator, Lymphoedema Support Group
	Mr Greg Killeen	
	Mr Graham Opie	Chief Executive Officer, Motor Neurone Disease Association of NSW
	Mr Andrew Buchanan	Chairperson, Disability Council of NSW
	Mr Dougie Herd	Director, Disability Council of NSW
	Mr Sean Lomas	Policy and Information Manager, Spinal Cord Injuries Australia
	Mr Chris Campbell	General Manager – Services, The Spastic Centre
	Ms Ruth Robinson	Executive Officer, Physical Disability Council of NSW
	Ms Jordana Goodman	Policy Officer, Physical Disability Council of NSW
	Ms Alison Peters	Director, Council of Social Service of NSW
	Ms Kristie Brown	Senior Policy Officer, Health, Council of Social Service of NSW
2 October 2008, Jubilee Room Parliament House	Ms Wendy Hall	Senior Manager, Client Programs, Northcott Disability Services
	Ms Rebecca Philips	Manager, Service Development and Government Relations, Northcott Disability Services
	Mr Peter Talbot	Dietician, Dieticians Association of Australia
	Ms Janet Bell	Dietician, Dieticians Association of Australia
	Mr Shaun Jenkinson	General Manager, Invacare Australia
	Mr Greg Kline	Managing Director, GTK Rehab
	Mr Chris Sparks	Executive Officer, Independent Rehabilitation Suppliers Association of NSW
	Mr David Jack	Chief Executive Officer, Muscular Dystrophy Association NSW
	Ms Catherine Nowlan	Operations Manager, Eastern Cluster, Greater Western Area Health Service

Date	Name	Position and Organisation
	Ms Melanie Tobin	Manager, Bathurst Seating Clinic
	Mr Jim MacWhinnie	Senior Seating Technician, Bathurst Seating Clinic
	Ms Sue Crane	Administration and Research Officer, Vision Australia
	Ms Louisa Ferronato	National Program Manager, Equipment Solutions, Vision Australia
	Mr Max Bosotti	Chief Executive Officer, ParaQuad NSW
	Mr Martin Gardiner	General Manager, Corporate Services, ParaQuad NSW
	Mr Damien Griffis	Executive Officer, Aboriginal Disability Network
24 October 2008, Room 814/815 Parliament House	Dr Richard Matthews	Deputy Director General, Strategic Development, NSW Department of Health
	Ms Cathrine Lynch	Director, Primary Health and Community Partnerships, NSW Department of Health

Appendix 3 Tabled documents

Wednesday 1 October 2008
Public Hearing, Jubilee Room, Parliament House

1. Opening statement – *tendered by Ms Heike Fabig*
2. Opening statement – *tendered by Ms Fiona Anderson*
3. Looking Towards Best Practice in Equipment Provision by Australian MND Associations – Final Report 2008 – *tendered by Mr Graham Opie*
4. Financial, Compliance and performance related audits of AHS Lodgement Centres, PADP, For Enable NSW, June 2008 – *tendered by Mr Ian Cohen MLC*

Thursday 2 October 2008
Public Hearing, Jubilee Room, Parliament House

1. HEN supply and delivery models in Australia and overseas paper and GMCT Hen recommendations paper – *tendered by Ms Janet Bell*
2. Equipment supplied by Invacare Australia – *tendered by Mr Shaun Jenkinson*
3. Powerpoint presentation: Muscular Dystrophy NSW perspectives on the Inquiry into PADP – *tendered by Mr David Jack*
4. Folder with several documents concerning the Bathurst Seating Clinic – *tendered by Ms Melanie Tobin*

Friday 24 October 2008
Public Hearing, Room 814/815, Parliament House

1. Document clarifying aspects of the evidence provided by witnesses at earlier hearings – *tendered by Dr Richard Matthews*

Appendix 4 Minutes

Minutes No. 16
Thursday 26 June 2008
Members Lounge, Parliament House at 1:05 pm

1. **Members present**
Ms Robyn Parker (Chair)
Mr Greg Donnelly
Mr Tony Catanzariti
Ms Marie Ficarra
Dr Gordon Moyes
Ms Lee Rhiannon
Ms Christine Robertson

2. **Previous minutes**
Resolved, on the motion of Ms Robertson: That draft Minutes No.15 be confirmed.

3. **Correspondence**
The Committee noted the following items of correspondence received:
Inquiry into the Program of Appliances for Disabled People
- 24 June 2008 – From three members of GPSC 2 regarding proposed terms of reference for an inquiry into the Program of Appliances for Disabled People (PADP)

4. ***

5. **Consideration of proposed self reference – the Program of Appliances for Disabled People (PADP)**
Ms Ficarra moved: That the Committee adopt the following terms of reference:

That General Purpose Standing Committee No 2 inquire into and report on the Program of Appliances for Disabled People (PADP), and in particular:

a. Adequacy of funding for present and projected program demand
b. Impact of client waiting lists on other health sectors
c. Effects of centralising PADP Lodgement Centres and the methods for calculating and implementing financial savings from efficiency recommendations
d. Appropriateness and equity of eligibility requirements
e. Future departmental responsibility for the PADP
f. Any other related matter.

Question put.

The Committee divided.

Ayes: Ms Parker, Ms Ficarra, Ms Rhiannon, Dr Moyes.

Noes: Ms Robertson, Mr Catanzariti, Mr Donnelly.

Question resolved in the affirmative.

Resolved, on the motion of Ms Ficarra: That the inquiry and the call for submissions be advertised on 9 July 2008, in the metropolitan and relevant regional papers.

Resolved, on the motion of Ms Ficarra: That the closing date for submissions be 3 September 2008.

Resolved, on the motion of Ms Ficarra: That the Committee hold two hearings on either Wednesday 1, Thursday 2 or Friday 3 October 2008.

6. Adjournment
The Committee adjourned at 1:25pm until Tuesday 1 July 2008 at 10.00am.

Merrin Thompson
Clerk to the Committee

Minutes No. 19
Tuesday 22 July 2008
Room 814/815, Parliament House, 10.00am

1. Members present
Ms Robyn Parker *(Chair)*
Mr Greg Donnelly
Mr Tony Catanzariti
Ms Marie Ficarra
Ms Lee Rhiannon
Ms Christine Robertson (*Deputy Chair*)

2. Apologies
Dr Gordon Moyes

3. ***

4. ***

5. Deliberative meeting
5.1 Previous minutes
Resolved, on the motion of Ms Rhiannon: That draft Minutes No.17 (site visit) and 18 be confirmed.

5.2 ***

5.3 ***

5.4 PADP Inquiry
Resolved, on the motion of Ms Ficarra: That the Committee hold public hearings in relation to its inquiry into the PADP on Wednesday 1 and Thursday 2 October 2008.

5.5 ***

6. ***

7. ***

8. Adjournment
The Committee adjourned at 4:54pm until Monday 28 July (public hearing).

Beverly Duffy
Clerk to the Committee

Minutes No. 20
Monday 28 July 2008
Room 814/815, Parliament House, 9.10am

1. **Members present**
   Ms Robyn Parker *(Chair)*
   Mr Greg Donnelly
   Mr Tony Catanzariti
   Ms Marie Ficarra
   Ms Lee Rhiannon
   Ms Christine Robertson (*Deputy Chair*)

2. **Apologies**
   Dr Gordon Moyes

3. ***

4. **Deliberative meeting**
   4.1 Previous minutes
   Resolved, on the motion of Mr Donnelly: That draft Minutes No.19 be confirmed.
   4.2 ***

   4.3 ***

   4.4 ***

   4.5 ***

   4.6 ***

   4.7 PADP Inquiry
   Resolved, on the motion of Ms Rhiannon: That, according to section 4 of the Parliamentary Papers (Supplementary Provisions) Act 1975 and standing Order 223(1), the Committee authorise the publication of Submissions No. 1 - 4.

5. ***

6. **Adjournment**
   The Committee adjourned at 5.15pm until Monday 22 September (deliberative meeting).

Beverly Duffy
Clerk to the Committee

Minutes No. 21
Friday 29 August 2008
Members Lounge, Parliament House, 1.00pm

1. **Members present**
   Ms Robyn Parker *(Chair)*
   Mr Tony Catanzariti
   Mr Greg Donnelly

Ms Christine Robertson (*Deputy Chair*)

2. Apologies
Ms Marie Ficarra
Ms Lee Rhiannon
Dr Gordon Moyes

3. Previous minutes
Resolved, on the motion of Mr Catanzariti: That draft Minutes No.20 be confirmed.

4. ***

5. PADP inquiry
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 Submissions No 5 to 15.

6. ***

7. ***

8. Adjournment
The Committee adjourned at 1.27pm until Monday 22 September (deliberative meeting).

Beverly Duffy
Clerk to the Committee

Minutes No. 22
Wednesday 1 October 2008
Jubilee Room, Parliament House, 9.15am

1. Members present
Ms Robyn Parker *(Chair)*
Ms Christine Robertson (*Deputy Chair*)
Mr Tony Catanzariti
Mr Ian Cohen
Mr Greg Donnelly
Ms Marie Ficarra
Rev Dr Gordon Moyes

2. Previous minutes
Resolved, on the motion of Ms Robertson: That draft Minutes No.21 be confirmed.

3. Correspondence
The Committee noted the following items of correspondence received:

Received

- 16 July 2008 - Email from Ms Rhiannon to the Committee advising that Mr Cohen will be her substitute for the duration of the PADP inquiry

4. ***

5. Inquiry into the Program of Appliances for Disabled People

5.1 Publication of submissions

Resolved, on the motion of Ms Robertson: 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 s Nos 16 to 20, 22 and 23, 25 to 38, 40 to 68, 70-73, 75-77

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. 21, 24 and 39 with names and other identifying information suppressed.

Resolved, on the motion of Ms Robertson: That, according to section 4 of the Parliamentary Papers (Supplementary Provisions) Act 1975 and Standing Order 223(1), the Committee authorises the partial publication of Submission No. 69 with adverse mentions removed.

Resolved, on the motion of Mr Donnelly: That the Committee keep Submissions No. 69a confidential.

Resolved, on the motion of Mr Donnelly: That the Committee keep Submission No. 74 confidential.

6. Public hearing – Inquiry into the Program of Appliances for Disabled People

Witnesses, the public and media were admitted.

The Chair made an opening statement regarding the broadcasting of proceedings and other matters.

The following witnesses were sworn and examined:

- Dr Richard Matthews, Deputy Director General, NSW Department of Health
- Ms Cathrine Lynch, Director, Primary Health and Community Partnerships, NSW Department of Health
- Ms Bronwyn Scott, Director, Enable NSW, NSW Department of Health

The evidence concluded and the witnesses withdrew.

The following witnesses were sworn and examined:

- Ms Fiona Anderson
- Mr Raul Osbich
- Ms Heike Fabig

Ms Fabig tabled her opening statement.

Ms Anderson tabled her opening statement.

The evidence concluded and the witnesses withdrew.

The following witnesses were sworn and examined:

- Mr Greg Killen
- Mr Barry Bryan

The evidence concluded and the witnesses withdrew.

The following witness was sworn and examined:

- Mr Graham Opie, Chief Executive Officer, Motor Neurone Disease Association NSW

Mr Opie tabled 'Looking Towards Best Practice in Equipment Provision by Australian MND Associations – Final Report 2008'.

The evidence concluded and the witnesses withdrew.

Lunch break 12:45 pm

The following witnesses were sworn and examined:
- Mr Dougie Herd, Executive Director, Disability Council of NSW
- Mr Andrew Buchanan, Chairperson, Disability Council of NSW

The evidence concluded and the witnesses withdrew.

The following witness was sworn and examined:
- Mr Sean Lomas, Policy and Information Manager, Spinal Cord Injuries Australia

The evidence concluded and the witness withdrew.

The following witness was sworn and examined:
- Mr Chris Campbell, General Manager – Services, The Spatic Centre

The evidence concluded and the witness withdrew.

Mr Cohen tabled a document entitled: Financial, Compliance and performance related audits of AHS Lodgement Centres, PADP, For Enable NSW, June 2008

The following witnesses were sworn and examined:
- Ms Ruth Robinson, Executive Officer, Physical Disability Council of NSW
- Ms Jordana Goodman, Policy Officer, Physical Disability Council of NSW

The evidence concluded and the witnesses withdrew.

The following witnesses were sworn and examined:
- Ms Alison Peters, Director, Council of Social Services of NSW
- Ms Kristie Brown, Senior Policy Officer, Health, Council of Social Services of NSW

The evidence concluded and the witnesses withdrew.

The public hearing concluded at 4:45 pm.

The public and the media withdrew.

7. Adjournment

The Committee adjourned at 4.45pm until Thursday 2 October (PADP public hearing).

Beverly Duffy
Clerk to the Committee

Minutes No. 23
Thursday 2 October 2008
Jubilee Room, Parliament House, 9.00am

1. **Members present**
Ms Robyn Parker *(Chair)*
Ms Christine Robertson (*Deputy Chair*)
Mr Tony Catanzariti
Mr Ian Cohen
Mr Greg Donnelly
Ms Marie Ficarra
Rev Dr Gordon Moyes

2. **Public hearing – Inquiry into the Program of Appliances for Disabled People**
Witnesses, the public and media were admitted.

The Chair made an opening statement regarding the broadcasting of proceedings and other matters.

The following witnesses were sworn and examined:
- Ms Wendy Hall, Senior Manager - Client Programs Northcott Disability Services
- Ms Rebecca Philips, Manager, Service Development and Government Relations Northcott Disability Services

The evidence concluded and the witnesses withdrew.

The following witnesses were sworn and examined:
- Mr Peter Talbot, Dietitians Association of Australia
- Ms Janet Bell, Dietitians Association of Australia

Ms Janet Bell tabled two documents including, HEN supply and delivery models in Australia and overseas paper and GMCT Hen recommendations paper

The evidence concluded and the witnesses withdrew.

The following witnesses were sworn and examined:
- Mr Shaun Jenkinson, General Manager, Invacare Australia
- Mr Greg Kline, Managing Director, GTK Rehab
- Mr Chris Sparks, Executive Officer, Independent Rehabilitation Suppliers Association NSW

Mr Shaun Jenkinson tabled a document outlining the equipment supplied by Invacare Australia.

The evidence concluded and the witnesses withdrew.

The following witness was sworn and examined:
- Mr David Jack, Chief Executive Officer, Muscular Dystrophy Association NSW

Mr David Jack tabled a powerpoint presentation in relation to Muscular Dystrophy NSW perspectives on the Inquiry into PADP.

The evidence concluded and the witness withdrew.

The public and the media withdrew.

3. Deliberative meeting

Resolved, on the motion of Ms Christine Robertson: That documents tabled at today's hearings that have not already been published, be published.

Resolved, on the motion of Ms Christine Robertson: That the Committee hold a two-hour hearing commencing at 9.30am on 24 October 2008 to invite the representatives from NSW Health to reappear before the Committee.

Resolved, on the motion of Ms Christine Robertson: That the Committee hold a deliberative meeting to discuss the Chair's draft PADP report on the afternoon of Monday 24 November.

Lunch break 12:00 pm

The public hearing resumed.

Witnesses, the public and media were admitted.

The following witnesses were sworn and examined:

- Mr Jim MacWhinnie,
- Ms Melanie Tobin,
- Ms Catherine Nowlan,

Ms Tobin tabled a folder with several documents concerning the Bathurst Seating Clinic.

The evidence concluded and the witnesses withdrew.

The following witnesses were sworn and examined:

- Ms Sue Crane, Administration and research officer, Vision Australia
- Ms Luisa Ferronato, National Program Manager Equipment Solutions, Vision Australia

The evidence concluded and the witnesses withdrew.

The following witness was sworn and examined:

- Mr Max Bosotti, Chief Executive Officer, ParaQuad NSW
- Mr Martin Gardiner, General Manager Corporate Services, ParaQuad NSW

The evidence concluded and the witness withdrew.

The following witness was sworn and examined:

- Mr Damien Griffis, Executive Officer, Aboriginal Disability Network

The evidence concluded and the witness withdrew.

The public hearing concluded.

The public and the media withdrew.

4. Adjournment

The Committee adjourned at 4.00pm

Beverly Duffy
Clerk to the Committee

Minutes No. 31
Friday, 24 October 2008
Room 814/815, Parliament House, Sydney, at 9.30 am

1. **Members present**
   Ms Robyn Parker *(Chair)*
   Ms Christine Robertson (*Deputy Chair*)
   Mr Ian Cohen (Rhiannon)
   Mr Greg Donnelly
   Ms Marie Ficarra
   Ms Kayee Griffin (Catanzariti)

2. **Apologies**
   Rev Dr Gordon Moyes

3. **Substitute members**
   The Chair advised that she had received written advice that the following members would be substituting for the purposes of this hearing:
   - Ms Griffin to substitute for Mr Catanzariti

4. ***

5. **Public hearing: Inquiry into the Program of Appliances for Disabled People (PADP)**
   Witnesses, the public and media were admitted.

   The Chair made an opening statement regarding the broadcasting of proceedings and other matters.

   The following witnesses were examined on former oath:
   - Dr Richard Matthews, Deputy Director General of Strategic Development, NSW Department of Health
   - Ms Cathrine Lynch, Director of Primary Health and Community Partnerships, NSW Department of Health

   Dr Matthews tabled a document clarifying aspects of the evidence provided by witnesses at earlier hearings.

   The evidence concluded and the witnesses withdrew.

   The public hearing concluded at 11:30 am. The public and media withdrew.

6. **Adjournment**
   The Committee adjourned at 11.30 am

Beverly Duffy
Clerk to the Committee

Minutes No. 32
Wednesday 12 November 2008
Members' Lounge, Parliament House, Sydney, at 10.30 am

1. **Members present**
   Ms Robyn Parker *(Chair)*
   Ms Christine Robertson (*Deputy Chair*)
   Mr Tony Catanzariti

Mr Greg Donnelly
Ms Marie Ficarra
Dr John Kaye (Rhiannon)
Revd Dr Gordon Moyes

2. Minutes
Resolved, on the motion of Ms Ficarra: That draft minutes no. 31 be confirmed.

3. Correspondence
The Committee noted the following items of correspondence:

Received
- 28 October 2008 – Letter from Ms Melanie Tobin, Manager PADP Seating Clinic, Bathurst Base Hospital, to the Committee, providing answers to questions taken on notice
- 29 October 2008 – Letter from Ms Heike Fabig, to the Committee, providing answers to questions on notice
- 30 October 2008 – Letter from Ms Melanie Tobin, Manager PADP Seating Clinic, Bathurst Base Hospital, to the Committee, providing additional information and clarification of evidence given on 2 October 2008
- 31 October 2008 – Letter from Mr Sean Lomas, Policy and Information Officer, Spinal Cord Injuries Australia, to the Committee, providing funding calculations of the PADP program
- 3 November 2008 – Letter from Dr Richard Matthews, Deputy Director General, Strategic Development, NSW Health, to the Committee, attaching responses to questions on notice from evidence provided on 1 October 2008.
- 7 November 2008 – Letter from Ms Natasha Layton, Occupational Therapist, Independent Living Centre Victoria, to the Chair, providing clarification of evidence given on Wednesday 24 October 2008

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 the answers to questions on notice provided by:
- Ms Melanie Tobin, PADP Seating Clinic
- Ms Heike Fabig
- Dr Richard Matthews, NSW Health.

Resolved, on the motion of Mr Catanzariti: That, according to section 4 of the *Parliamentary Papers (Supplementary Provisions) Act 1975* and Standing Order 223(1), the Committee authorise the publication of the correspondence provided by:
- Ms Melanie Tobin, PADP Seating Clinic, providing additional information and clarification of her evidence
- Mr Sean Lomas, Spinal Cord Injuries Australia, providing PADP funding calculations
- Ms Natasha Layton, Independent Living Centre Victoria, to the Chair, providing clarification of her evidence.

4. ***

5. Inquiry into the program of appliances for disabled people (PADP)
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 43a

6. ***

7. Adjournment

The Committee adjourned at 10.57 am.

Madeleine Foley
Clerk to the Committee

Minutes No. 33
Wednesday 19 November 2008
Members' Lounge, Parliament House, Sydney, at 9.05 am

1. Members present

Ms Robyn Parker *(Chair)*
Ms Christine Robertson (*Deputy Chair*)
Ms Catherine Cusack (Ficarra) (from 9.15 am)
Mr Greg Donnelly
Dr John Kaye (Rhiannon)
Revd Dr Gordon Moyes
Ms Helen Westwood (Catanzariti) (from 9.15 am)

2. Substitutions

The Chair advised that she had received written advice that the following members would be substituting for the purposes of this hearing:

- Ms Cusack for Ms Ficarra
- Dr Kaye for Ms Rhiannon
- Ms Westwood for Mr Catanzariti.

3. Minutes

Resolved, on the motion of Mr Donnelly: That draft minutes no. 32 be confirmed.

4. Correspondence

The Committee noted the following item of correspondence:

Received

- 12 November 2008 – From Ms Alison Peters, Director, Council of Social Service of New South Wales, to the Chair, providing responses to questions taken on notice during the hearing on 1 October 2008.

Resolved, on the motion of Ms Robertson: That, according to section 4 of the *Parliamentary Papers (Supplementary Provisions) Act 1975* and Standing Order 223(1), the Committee authorise the publication of the answers to questions on notice provided by Ms Alison Peters, Council of Social Service of NSW.

5. ***

6. ***

7. ***

8. ***

Madeleine Foley
Clerk to the Committee

Minutes No. 36
Friday 5 December 2008
Room 1102, Parliament House, Sydney, at 9:35 am

1. Members present
Ms Robyn Parker *(Chair)*
Ms Christine Robertson (*Deputy Chair*)
Mr Tony Catanzariti
Mr Ian Cohen (Rhiannon)
Ms Marie Ficarra
Mr John Robertson (Donnelly)

2. Apologies
Revd Dr Gordon Moyes

3. Substitutions
The Chair advised that she had received written advice that the following member would be substituting for the purposes of this deliberative:

- Mr Robertson to substitute for Mr Donnelly.

4. Minutes
Resolved, on the motion of Ms Ficarra: That draft minutes nos. 33. 34 and 35 be confirmed.

5. Correspondence
The Committee noted the following items of correspondence received:

- 27 November 2008 – Email from Ms Bronwyn Scott, Director EnableNSW, to the Secretariat, outlining PADP procedures for equipment trials and quotes

6. Publication of answers to questions on notice
Resolved, on the motion of Ms Robertson: That, according to section 4 of the Parliamentary Papers (Supplementary Provisions) Act 1975 and Standing Order 223(1), the Committee authorise the publication of the answers to questions on notice provided by NSW Health on 20 November 2008.

5. Consideration of Chair's draft report
The Chair submitted her draft report titled: 'The Program of Appliances for Disabled People' which having been previously circulated was taken as being read.

The Committee proceeded to consider the draft report in detail.

Summary of key issues read.

Resolved, on the motion of Mr Cohen: That paragraph 1.1 be amended by omitting 'spasticity' and inserting instead 'cerebral palsy'.

Resolved, on the motion of Ms Robertson: That paragraph 1.3 be amended by inserting at the end of the paragraph the words 'Much of the evidence from the NSW Department of Health and some representatives of interest groups related to the current implementation processes for the majority of the recommendations in the PwC Review.'

Resolved, on the motion of Ms Robertson: That paragraph 1.5 be amended by omitting 'while waiting for PADP equipment' and inserting instead 'and had still not received their PADP equipment'

Resolved, on the motion of Mr Cohen: That paragraph 1.6 be amended by inserting 'on the hospital system' after '$100,000'.

Resolved, on the motion of Mr Catanzariti: That paragraph 1.11 be amended by omitting 'is a direct consequence of inadequate program funding. This was' and inserting instead 'is a consequence of the structural issues identified by this and other inquiries, and ongoing and long-term inadequate program funding. Inadequate funding was'

Resolved, on the motion of Ms Ficarra: That Recommendation 1 be adopted.

Resolved, on the motion of Ms Ficarra: That paragraph 1.18 be amended by omitting 'which NSW Health has agreed to implement.' and inserting instead 'NSW Health has agreed to implement a new information system by March 2009. The Committee supports the expeditious implementation of that system.'

Resolved, on the motion of Mr Cohen: That paragraph 1.24 be amended by omitting 'But this does not mean that we say or do nothing about what is admittedly a vexed policy challenge.' and inserting instead 'However this does not excuse the NSW Government from taking action on what is admittedly a vexed policy challenge.'

Resolved, on the motion of Mr Cohen: That Recommendation 2 be adopted.

Resolved, on the motion of Ms Robertson: That the Secretariat incorporate paragraph 7.20 into the 'Centralisation' section in the Summary of key issues.

Resolved, on the motion of Mr Cohen: That paragraph 1.41 be amended by omitting 'centralisation may' and inserting instead 'the reform agenda will'.

Resolved, on the motion of Ms Robertson: That the Summary of key issues be adopted as amended.

Chapter 1 read.

Resolved, on the motion of Ms Robertson: That the last sentence of paragraph 1.26 be omitted.

Resolved, on the motion of Ms Robertson: That Chapter 1 as amended be adopted.

Chapter 2 read.

Resolved, on the motion of Mr Cohen: That Chapter 2 be adopted.

Chapter 3 read.

Resolved, on the motion of Ms Ficarra: That Recommendation 3 be adopted.

Resolved, on the motion of Mr Robertson: That Recommendation 4 be adopted.

Resolved, on the motion of Mr Cohen: That paragraph 3.41 be amended by omitting 'may' and inserting instead 'should'

Resolved, on the motion of Mr Catanzariti: That Recommendation 5 be adopted.

Resolved, on the motion of Ms Robertson: That the heading 'Cost shifting' above paragraph 3.70 be omitted and inserted instead 'Impact of the waiting lists on other health sectors'.

Resolved, on the motion of Ms Robertson: That paragraph 3.107 be amended to refect the evidence provided by Dr Matthews in relation to recycling PADP equipment.

Resolved, on the motion of Mr Cohen: That Chapter 3 as amended be adopted.

Chapter 4 read.

Resolved, on the motion of Mr Cohen: That paragraph 4.10 be amended by inserting 'being totally funded by the Area Health Service PADP budget' after 'people with a disability', and by omitting the word 'however' and inserting instead 'Dr Matthews'.

Resolved, on the motion of Ms Robertson: That after paragraph 4.10 the Secretariat inserts a paragraph on the oxygen scheme.

Resolved, on the motion of Ms Ficarra: That Recommendation 6 be adopted.

Resolved, on the motion of Mr Cohen: That Chapter 4 as amended be adopted.

Chapter 5 read.

Resolved, on the motion of Mr Cohen: That Recommendation 7 be adopted.

Resolved, on the motion of Ms Ficarra: That Recommendation 8 adopted.

Resolved, on the motion of Mr Robertson: That Recommendation 9 be amending by omitting all words after 'That' and inserting instead 'NSW Health examine the evidence received by General Purpose Standing Committee No. 2 regarding the abolition of the $100 co-payment in its proposed review of the financial eligibility criteria for PADP.'

Resolved, on the motion of Mr Robertson: That the order of Recommendations 8 and 9 be reversed.

Resolved, on the motion of Mr Cohen: That Chapter 5 as amended be adopted.

Chapter 6 read.

Resolved, on the motion of Mr Cohen: That Recommendation 10 be adopted.

Resolved, on the motion of Mr Cohen: That Recommendation 11 be adopted.

Resolved, on the motion of Ms Robertson: That paragraph 6.61 be amended by inserting a statement regarding NSW Health's submission to the TGA regarding enteral feeding equipment.

Resolved, on the motion of Ms Robertson: That the following Recommendation be inserted after Recommendation 11 'That the NSW Minister for Health:

- initiate through the Council of Australian Governments process a national review on the guidelines and policy for equipment use, including enteral feeding tubes; and
- make a submission to the Therapeutic Goods Association on this specific issue.'

Resolved, on the motion of Mr Cohen: That paragraph 6.67 be amended by omitting the words 'is wheelchair bound' and inserting instead 'utilises a wheelchair'.

Ms Ficarra moved: That Recommendation 12 be adopted

Resolved, on the motion of Mr Cohen: That Chapter 6 as amended be adopted.

Chapter 7 read.

Resolved, on the motion of Ms Roberston: That the heading 'Centralisation reforms' above paragraph 7.1 be omitted and inserted instead 'Administrative reforms'

Resolved, on the motion of Mr Catanzariti: That Recommendation 13 be adopted.

Resolved, on the motion of Mr Cohen: That Recommendation 14 be adopted.

Resolved, on the motion of Ms Ficarra: That Recommendation 15 be adopted.

Resolved, on the motion of Mr Robertson: That Recommendation 16 be adopted.

Resolved, on the motion of Mr Cohen: That Recommendation 17 be adopted.

Resolved, on the motion of Mr Catanzariti: That Recommendation 18 be adopted.

Resolved, on the motion of Mr Robertson: That Recommendation 19 be adopted.

Resolved, on the motion of Ms Ficarra: That Recommendation 20 be adopted.

Resolved, on the motion of Mr Cohen: That Chapter 7 as amended be adopted.

Resolved, on the motion of Mr Cohen: That the draft report, as amended, be the report of the Committee.

Resolved, on the motion of Mr Cohen: That the Committee present the report to the House, together with transcripts of evidence, submissions, tabled documents, answers to questions on notice, minutes of proceedings and correspondence relating to the inquiry, except for documents kept confidential by resolution of the Committee.

The Secretariat undertook to distribute the Chairs' forward via email.

6. Adjournment

The Committee adjourned at 12:00 pm until Thursday 26 February 2009 *(Inquiry into governance of NSW universities)*

Beverly Duffy
Clerk to the Committee