

Standing Committee on Law and Justice

**Fourth Review of the
Lifetime Care and Support
Authority and the Lifetime
Care and Support Advisory
Council**

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Terms of reference

1. That, in accordance with section 68 of the *Motor Accidents (Lifetime Care and Support) Act 2006*, the Standing Committee on Law and Justice be designated as the Legislative Council committee to supervise the exercise of the functions of the Lifetime Care and Support Authority of New South Wales and the Lifetime Care and Support Advisory Council of New South Wales under the Act.
2. That the terms of reference of the Committee in relation to these functions be:
 - (a) to monitor and review the exercise by the Authority and Council of their functions,
 - (b) to report to the House, with such comments as it thinks fit, on any matter appertaining to the Authority or Council or connected with the exercise of their functions to which, in the opinion of the committee, the attention of the House should be directed, and
 - (c) to examine each annual or other report of the Authority and Council and report to the House on any matter appearing in, or arising out of, any such report.
3. That the committee report to the House in relation to the exercise of its functions under this resolution at least once each year.
4. That nothing in this resolution authorises the Committee to investigate a particular participant, or application for participation, in the Lifetime Care and Support Scheme provided for by the *Motor Accidents (Lifetime Care and Support) Act 2006*.

These terms of reference were referred to the Committee by resolution passed LC Minutes No 17 (14/6/2011), Item 15

Committee membership

| | | |
|---------------------------------|------------------------|-----------------------|
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| The Hon Peter Primrose MLC | Australian Labor Party | <i>(Deputy Chair)</i> |
| The Hon Scot MacDonald MLC | Liberal Party | |
| The Hon Sarah Mitchell MLC | The Nationals | |
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Chair's foreword

This is the Committee's Fourth Review of the Lifetime Care and Support Authority and the Lifetime Care and Support Advisory Council since the Scheme's 2006 inception. The report highlights that overall the Scheme is working very well to provide support to people who are catastrophically injured in motor vehicle accidents.

Previous reviews have noted that the Scheme is its infancy. While this remains true, I have been pleased to observe that as the Scheme matures, fewer new issues of concern have been brought to the Committee's attention. In the present review, the Committee has noted a distinct stabilisation of the Scheme's operation. It is also becoming apparent that several of the areas in which ongoing points of contention arise are in fact symptomatic of foundational aspects of the Scheme itself.

This year, as in previous reviews, the Committee has heard from a range of stakeholders including medical professionals, legal specialists and advocacy groups. A number of these groups have commended the LTCSA for its ongoing work to improve its processes and for operating in a spirit of collaboration with other stakeholders. Nevertheless, stakeholders have raised a number of concerns that the Committee has sought to address through constructive recommendations.

I would like to thank all of those who have contributed to the conduct of this year's review. I am especially grateful to those stakeholders who participated in this review through the preparation of submissions and participation in hearings. The considered views of stakeholders have permitted the Committee to conduct a thorough examination of the key issues affecting the Scheme and develop recommendations for improvement.

With the recent change of Government has come a change in Committee membership. I express my thanks to my colleagues for their thoughtful contributions to this year's review. I also thank the staff of the Committee secretariat for their ongoing professional support.



Hon David Clarke MLC

Committee Chair

Executive summary

Chapter 1 Introduction

The Lifetime Care and Support (LTCS) Scheme is a NSW Government initiative established to provide for the treatment and care of people who have been catastrophically injured as a result of a motor accident, irrespective of who was at fault. The LTCS Scheme is administered by the Lifetime Care and Support Authority (LTCSA) and the Lifetime Care and Support Advisory Council (LTCSAC).

Chapter 1 outlines the role of the Committee in reviewing the LTCSA and the LTCSAC. Section 68 of the *Motor Accidents (Lifetime Care and Support) Act 2006* provides that a committee of the Legislative Council is to be designated to supervise the exercise and functions of the LTCSA and the LTCSAC. On 30 May 2007, the Standing Committee on Law and Justice (the Committee) was appointed to fulfill this function.

In relation to future reviews, Chapter 1 recommends that the Committee conduct its review of the LTCSA and LTCSAC on a biennial rather than an annual basis.

Chapter 2 Overview of the Scheme and past reviews

Chapter 2 includes an outline of the operation of the Scheme to date including its object and purpose and key provisions of the legislation which underpins its operation. It also discusses the issues and recommendations that arose in previous reports.

Eligibility into the LTCS Scheme is described, including what happens procedurally when a person first enters the Scheme. Dispute resolution arises most commonly in relation to eligibility to enter the Scheme and decisions related to a participant's treatment and care. The processes for resolving such disputes are outlined in this Chapter (and stakeholder concerns about dispute resolution are considered in Chapter 4). The Chapter moves on to consider the day to day operation of the LTCS Scheme including a description of the role of LTCS Coordinators and case managers.

The Chapter concludes with a brief description of the proposed National Injury Insurance Scheme (NIIS), as proposed in the Productivity Commission's report on a national scheme for disability care and support. The NIIS would facilitate the establishment of nationally consistent, state-based, no fault schemes for people who have suffered catastrophic injuries, whatever the cause. At the time of writing, the Productivity Commission's recommendations had not been adopted by the state governments or the federal Government.

Chapter 3 Scheme operation and performance

This Chapter outlines the operation of the LTCS Scheme to date including its relationship with the Motor Accidents Scheme. It includes statistical data detailing the number of people in the Scheme, both children and adults, and the type of accidents in which they were injured. It outlines the cost of the Scheme and the mechanisms employed by the LTCSA to forecast future costs.

Chapter 3 also outlines the progress of the LTCS Scheme including what was an overall positive review from most stakeholders who gave evidence to the Committee. The results of the most recent participant satisfaction survey are canvassed, which show that more than 83 per cent of respondents were satisfied with how the Scheme meets their needs.

Currently there are no participant members of the LTCSAC, although during the Second and Third Reviews, the Committee recommended their inclusion, which was broadly supported by stakeholders including the LTCSA itself. Thus, the present review recommends a stand-alone legislative amendment to enable participant involvement on the Council.

Chapter 4 Entry into the Scheme, opting-out of the Scheme and dispute resolution

That there should be an option for participants not to participate in the Scheme, and instead receive a lump sum payment to manage their own care, has been raised by stakeholders in previous reviews and also the present. Chapter 4 outlines the forthcoming staged implementation of an option in respect of periodic payments for self-management of attendant care. This includes a brief discussion of a relevant ruling by the Australian Taxation Office that such payments shall not be taxed as ‘income’, subject to certain specific conditions.

Chapter 4 describes the medical eligibility criteria and assessment tools, and outlines amended eligibility criteria for people who have had amputations as a result of a motor vehicle accident. It recommends that the LTCSA evaluate the current medical assessment tools and investigate alternatives to avoid inequity in Scheme eligibility

The Chapter concludes with consideration of participant access to independent legal advice and advocacy and outlines stakeholders concerns in relation to dispute resolution under the LTCS Scheme.

Chapter 5 Administration of the Scheme

The administrative burden of the LTCS Scheme on stakeholders, and in particular medical professionals, has been a regular concern which stakeholders have again raised in the present review. Clinicians have noted that attending to the paperwork generated by the LTCS Scheme limits the time they can spend with patients. In this regard, possible efficiencies in the LTCS Scheme to reduce the administrative burden of the Scheme were suggested by some stakeholders.

Chapter 5 also canvasses stakeholder views about delays in approval by the LTCSA of rehabilitation, care and support services. This issue arose both in evidence to the Committee and in the participant satisfaction survey. This Chapter also discusses related concerns about the role and expertise of LTCS Coordinators and problems with communication between stakeholders.

The LTCS Scheme priorities have shifted towards greater focus on community based care as more participants move out of acute care and back into the community. This focus is likely to become permanent in the longer term as participant numbers increase.

Chapter 6 Treatment, rehabilitation and care services

Chapter 6 canvasses a number of issues directly related to the treatment, rehabilitation and care services received by participants in the LTCS Scheme. The Chapter commences with discussion of what constitutes ‘reasonable and necessary’ treatment services pursuant to the legislation. It moves on to discuss the tension between LTCSA treatment decisions and the desire to respect participant choice in the context of the move towards ‘person-centred’ approaches in the disability sector. Some evidence of LTCS Coordinators ‘second-guessing’ of clinician decisions is also discussed.

Accessible housing was considered in depth as part of the Committee’s Third Review. In the present review, stakeholders raised particular concerns with delay and accessibility of transitional

accommodation for participants who are ready to leave hospital but have not yet secured, or had appropriate modifications to, a more permanent residence.

This Chapter discusses the impact of the passage into law of the *Carers Recognition Act 2010*. It also outlines stakeholder support for financial payments to be made to suitably qualified family members for the provision of voluntary care. Some concerns with such an arrangement are also considered.

Some stakeholders again expressed the view that the LTCSA should provide greater support to facilitating participants' recreation and leisure activities, including reasonable transportation costs to and from such activities. The physical benefits of such activities were emphasised and the LTCSA acknowledged that the issue was a difficult one.

The adequacy of educational support for children in the Scheme was questioned by the Children's Hospital at Westmead. The Hospital commended the LTCSA on recent efforts to work with schools to support education initiatives but also expressed the view that more could be done.

Summary of recommendations

- Recommendation 1** **4**
That the Legislative Council amend the resolution designating the Standing Committee on Law and Justice with responsibility for supervising the Lifetime Care and Support Authority and the Lifetime Care and Support Advisory Council, so that the Committee will be required to report to the House in relation to the exercise of its functions under that resolution at least once every two years.
- Recommendation 2** **29**
That the Government pursue a stand-alone amendment to section 45 of the *Motor Accidents (Lifetime Care and Support) Act 2006* to include two participant representatives on the Lifetime Care and Support Advisory Council.
- Recommendation 3** **39**
That the Lifetime Care and Support Authority evaluate the current medical assessment tools used to assess eligibility criteria, and investigate and report on any alternative and/or additional tools or strategies that may be appropriately used to avoid inequity in Scheme eligibility. The Authority should consult with stakeholders during this process.
- Recommendation 4** **42**
That the Lifetime Care and Support Authority should review the adequacy of the Accident Advice Support Grant on an annual basis and at minimum annually increase the grant to meet increases in the Consumer Price Index.
- Recommendation 5** **47**
That the Lifetime Care and Support Authority work with the Brain Injury Rehabilitation Directorate and other stakeholders to examine the feasibility of a more robust and independent dispute resolution process for disputes concerning eligibility and treatment.
- Recommendation 6** **53**
That the Lifetime Care and Support Authority collaborate with the Brain Injury Rehabilitation Directorate, the State Spinal Cord Injury Service, the Children’s Hospital at Westmead and other service providers to simplify and standardise forms with a view to minimising the duplication of information and limiting the administrative burden on service providers.
- Recommendation 7** **65**
That the Lifetime Care and Support Authority work with the State Spinal Cord Injury Service and the Brain Injury Rehabilitation Directorate directly to develop methods for improved communication between clinicians and the Authority and to act on the concerns of service providers and to put in place a system whereby clinicians receive meaningful responses to the concerns they raise.
- Recommendation 8** **67**
That the Lifetime Care and Support Authority develop and then employ effective mechanisms to better inform both general practitioners and acute treating teams of the Lifetime Care and Support Scheme and report to the Committee on these mechanisms in its next review.

- Recommendation 9** 76
That the Lifetime Care and Support Authority ensure that it provides, as part of its induction training for Lifetime Care and Support Coordinators, information on respect for expert clinician decisions and treatment recommendations notwithstanding Coordinators' previous skills and experience.
- Recommendation 10** 76
That the Lifetime Care and Support Authority consult with the Children's Hospital at Westmead to develop an agreed protocol to enable discussion of a participant's appropriate treatment options with clinicians prior to any discussion with a participant's family.
- Recommendation 11** 79
That the Lifetime Care and Support Authority investigate options for permitting participants to be discharged from hospital to interim accommodation, prior to long-term accommodation having been secured.
- Recommendation 12** 88
That the Lifetime Care and Support Authority clarify its guidelines and consider the extent to which the Authority will pay for treatment and care services while a participant is on holiday or overseas in order to balance the needs of participants with the scope and capacity of the Scheme.
- Recommendation 13** 89
That the Lifetime Care and Support Authority publish its guidelines on recreation and leisure activities and clarify its policy on funding for the transport of participants and carers to and from recreation and leisure activities.
- Recommendation 14** 92
That the Lifetime Care and Support Authority liaise with the Department of Education and Training and review the issues raised by the Children's Hospital Westmead as set out in paragraph 6.112 of this Report to improve and clarify the process of obtaining educational support for child participants in the Scheme, with a view to accepting and implementing those recommendations as appropriate.

Glossary

| | |
|----------------|---|
| ADHC | Ageing, Disability and Home Care within the NSW Department of Family and Community Services |
| ALA | Australian Lawyers Alliance |
| AMA | Australian Medical Association (NSW) Ltd |
| ATO | Australian Taxation Office |
| BIRD | Brain Injury Rehabilitation Directorate |
| CTP | Compulsory Third Party |
| FIM | Functional Independence Measure |
| LTCS | Lifetime Care and Support |
| LTCSA | Lifetime Care and Support Authority |
| LTCSAC | Lifetime Care and Support Advisory Council |
| MAA | Motor Accidents Authority |
| MCIS | Medical Care and Injury Services |
| NDIS | National Disability Insurance Scheme |
| NDS | National Disability Services |
| NIIS | National Injury Insurance Scheme |
| PCANS | Paediatric Care and Needs Scale |
| SCIA | Spinal Cord Injuries Australia |
| SSCIS | State Spinal Cord Injury Service |
| The Act | <i>Motor Accidents (Lifetime Care and Support Act) 2006</i> |

Chapter 1 Introduction

In this Chapter, the Committee outlines its role in reviewing the Lifetime Care and Support Authority and the Lifetime Care and Support Advisory Council and describes the process of the Committee's Fourth Review.

The Lifetime Care and Support Scheme

- 1.1 The Lifetime Care and Support (LTCS) Scheme is a NSW Government initiative that provides for the lifetime treatment and care of people who have suffered a catastrophic injury as a result of a motor accident, regardless of who was at fault. The Scheme operates pursuant to the *Motor Accidents (Lifetime Care and Support) Act 2006* and is administered by the Lifetime Care and Support Authority. It commenced operation on 1 October 2006 for children under the age of 16 and 1 October 2007 for people aged 16 and over. A levy is collected through Compulsory Third Party (CTP) insurance for the purpose of covering the Scheme's costs.¹
- 1.2 The LTCS Scheme is described in further detail in Chapter 2.

The Committee's role

- 1.3 Section 68 of the *Motor Accidents (Lifetime Care and Support) Act 2006* provides that a committee of the Legislative Council is to be designated to supervise the exercise and functions of the LTCSA and the LTCSAC. On 30 May 2007, the Standing Committee on Law and Justice (the Committee) was appointed to fulfill this function. The Committee reports its findings to the House annually.² The present review considers the need for reporting at this frequency. The Committee's consideration of biennial reporting is outlined later in this Chapter.
- 1.4 Information on the Committee's previous reviews, including reports, can be found on the Committee's website at: www.parliament.nsw.gov.au/lawandjustice.

Conduct of the Inquiry

- 1.5 The Committee resolved to commence this Fourth Review on 22 June 2011. The Review was conducted concurrently with the Committee's Eleventh Review of the Motor Accidents Authority and the Motor Accidents Council which is the subject of its own report.

Submissions

- 1.6 The Committee called for submissions through advertisements in major newspapers with distribution in NSW. The terms of reference and the call for submissions were also placed on the Committee website. At the Committee's request, the LTCSA advertised the review through its E-Newsletter and the Committee wrote to stakeholders inviting submissions on issues of relevance to the present review.

¹ LTCSA, *Annual Report 2009-2010*, p 22.

² *LC Minutes (30/05/2007)* 81.

- 1.7 The Committee received a total of 19 submissions from a range of stakeholders. These included individual participants, their families, peak disability services groups, medical service providers and representatives from the legal sector. A list of submissions is provided at Appendix 1.

Public hearings

- 1.8 The Committee held two public hearings on 10 and 17 October 2011 for the reviews of the LTCSA and also the Motor Accidents Authority. On the first day, the Committee heard from representatives of the Law Society of NSW, the Australian Lawyers Alliance, the NSW Bar Association, the Insurance Council of Australia, the Motorcycle Council of New South Wales, and the Children's Hospital at Westmead.
- 1.9 On the second day of hearings, the Committee heard from Spinal Cord Injuries Australia as well as a panel of witnesses representing the NSW Agency for Clinical Innovation: Dr Adeline Hodgkinson, Director, Brain Injury Rehabilitation Directorate, Dr Joe Gurka, Director, of the Brain Injury Program and Associate Professor James Middleton, Director of the State Spinal Cord Injury Service.
- 1.10 The Lifetime Care and Support Authority gave evidence at the conclusion of the final day of hearings.
- 1.11 A full list of witnesses is provided in Appendix 2.

Questions on notice

- 1.12 The Committee forwarded questions on notice to the LTCSA for answer prior to the commencement of the hearings, as has been the Committee's practice in all of its previous reviews of the LTCSA. Asking the Authority to answer pre-hearing questions allows the Committee to obtain an understanding of the work of the LTCSA in the past year and facilitates a more informed, efficient, and targeted hearing process. The questions on notice were developed in consideration of previous review reports, information provided in submissions and the LTCSA's 2009-2010 Annual Report.
- 1.13 The LTCSA's response to the questions on notice was received by the Committee on 29 September 2011. The answers were put to use in the hearing, witnesses were asked to respond to the Authority's statements, and in turn, those witnesses responses were put to the LTCSA representatives when they provided evidence.

Consideration of biennial review of the LTCSA and LTCSAC

- 1.14 For the first time, this year the Committee canvassed stakeholders' views on whether its review of the LTCSA and LTCSAC should be conducted biennially rather than annually. Stakeholder responses to this idea were mixed.
- 1.15 In support of annual reviews, Ms De Paoli, a member of the Law Society of NSW Law Injury Compensation Committee, stated that in the Law Society's view, there are sufficient issues being raised in reviews of the LTCS Scheme to warrant annual consideration by the

Committee. The Australian Lawyers Alliance also supported an annual review on the basis that more frequent review will permit stakeholder concerns to be answered more promptly.³

- 1.16** Conversely, Carers NSW supported the idea of a biennial review, noting the time and resources involved in conducting and participating in the review.⁴
- 1.17** The potential introduction of a National Injury Insurance Scheme (discussed further in Chapter 2) was provided by stakeholders as a reason both for and against biennial review of the LTCSA. For example, National Disability Services supported biennial review of the LTCSA on the basis of the potential forthcoming changes to the national disability system.⁵
- 1.18** To the contrary, Mr Sean Lomas, Policy and Advocacy Manager at Spinal Cord Injuries Australia (SCIA), stated that annual review of the LTCSA is ‘very important’ in the context of possible forthcoming changes in the national approach. He noted that the operation of the LTCS Scheme is being used to inform the national model and accordingly ‘[g]etting the Lifetime Care Scheme right is so utterly important because it is [potentially] going to go from hundreds of people in NSW to thousands of people Australia-wide’.⁶
- 1.19** The Authority expressed no particular preference for annual or biennial review. Mr David Bowen, Executive Director of the LTCSA, explained that the Authority was ‘happy’ to attend hearings and provide evidence either biennially or annually as the Committee saw fit.⁷

Committee comment

- 1.20** The Committee did not receive a great deal of evidence for or against the idea of biennial review. It notes the concerns expressed by some stakeholders that contributing to annual review of the LTCS Scheme can be burdensome.
- 1.21** However, the Committee also acknowledges the comments of other stakeholders that the Scheme is in a stage of relative infancy and important issues continue to be raised. Moreover, in the context of the potential implementation of a National Injury Insurance Scheme it will be worthwhile for the Committee to remain abreast of developments.
- 1.22** On balance, the Committee considers that biennial review of the LTCSA is preferable. The Committee acknowledges the resource burden that assisting the Committee in its review in appearing at hearings and preparing submissions places on stakeholders and notes that, overall, the Scheme is running smoothly. Accordingly, the Committee recommends that the Legislative Council amend the resolution designating the Standing Committee on Law and Justice with responsibility for supervising the LTCSA and the LTCSAC, so that the Committee will be required to report to the House in relation to the exercise of its functions under that resolution at least once every two years.

³ Answers to supplementary questions 3 November 2011, Jnana Gumbert, NSW Branch President, Australian Lawyers Alliance, Question 4, p 5.

⁴ Carers NSW, answers to post-hearing questions on notice, q 5, p 6.

⁵ National Disability Services, answers to post-hearing questions on notice, q 7, p 8.

⁶ Mr Sean Lomas, Policy and Advocacy Manager, Spinal Cord Injuries Australia, Evidence, 17 October 2011, pp 15-16.

⁷ Mr David Bowen, Executive Director, LTCSA, Evidence, 17 October 2011, p 66.

- 1.23** This would not prevent the Committee from reviewing the LTCSA and the LTCSAC on an annual basis if particular concerns were raised, such as the imminent implementation of the national disability insurance scheme.

Recommendation 1

That the Legislative Council amend the resolution designating the Standing Committee on Law and Justice with responsibility for supervising the Lifetime Care and Support Authority and the Lifetime Care and Support Advisory Council, so that the Committee will be required to report to the House in relation to the exercise of its functions under that resolution at least once every two years.

The Committee's report

- 1.24** This report is underpinned by the hard work of the submission makers and witnesses in preparing and providing evidence to the Committee. It is enriched by a process which enables the Committee to ask questions of the LTCSA and LTCSAC and, in turn, put the responses to those questions to stakeholders directly. This discursive process enables a thorough analysis of the issues.
- 1.25** As in previous reviews, the Committee's process has generated a significant amount of information through the experience and analysis of stakeholders as provided in submissions and in evidence at the hearings. Some issues in relation to which only a very small amount of information was received have not been substantively examined in this report but may be considered in future reviews.

Structure of the report

- 1.26** This report is comprised of 6 chapters. This first chapter outlines the Committee's role in reviewing the LTCSA and the LTCSAC and sets out the process undertaken by the Committee during this Review.
- 1.27** Chapter 2 provides an overview of how the LTCSA and LTCSAC operates, including in relation to eligibility, dispute resolution and the day to day operation of the Scheme. The chapter then outlines key considerations in the Committee's previous reviews of the LTCSA and LTCSAC and concludes by outlining a recent Productivity Commission Report recommending a National Injury Insurance Scheme.
- 1.28** Chapter 3 considers the LTCS Scheme performance to date, including statistical information such as the number of participants in the Scheme and financial matters. This is followed by consideration of the relative success of the Scheme and the results of the LTCSA's participant satisfaction survey. Finally, the chapter outlines the relationship of the LTCS Scheme to the Motor Accidents Scheme and discusses membership of the LTCSAC.
- 1.29** Chapter 4 outlines issues raised by stakeholders about opting-out of the Scheme and the possibility of improved LTCS Scheme capacity to facilitate participants' management of their own care through periodic payments. An important decision by the Australian Taxation

Office is outlined in this regard. The chapter moves on to consider issues related to the medical eligibility criteria and assessment and it concludes with consideration of participants access to legal advice and advocacy and the resolution of disputes regarding eligibility and treatment and care under the LTCS Scheme.

- 1.30** In Chapter 5, the report focuses on the administration of the LTCS Scheme. The first issue considered is the administrative burden the Scheme places on clinicians and participants and the availability of workforce. The approval process for treatment, rehabilitation and care services is discussed in the context of delay. The chapter then delineates issues related to participant privacy and confidentiality, and the function of LTCS Coordinators, including training and communication. The renewed focus of the LTCSA on community based care concludes the chapter.
- 1.31** Chapter 6 reflects on treatment, rehabilitation and care services provided for under the LTCS Scheme. It considers participant choice in treatment decisions and the alleged second-guessing of clinician decisions by LTCS Coordinators. The chapter canvasses problems with access to appropriate housing for participants leaving acute care, and also looks at support for carers including the implementation of the *Carers Recognition Act 2010*. Stakeholder views on funding for recreation and leisure activities and educational support for children are also considered.

Chapter 2 Overview of the Scheme and past reviews

This chapter provides a brief overview of the Lifetime Care and Support Scheme and its administering body, the Lifetime Care and Support Authority as well as the Lifetime Care and Support Advisory Council and the Committee's past three reviews. This chapter also describes the Australian Productivity Commission's recommendations for a national disability long-term care and support scheme and the implications of the *Carers (Recognition) Act 2010* (NSW) for the Lifetime Care and Support Scheme.

An overview of the Scheme

- 2.1** The Lifetime Care and Support (LTCS) Scheme aims to ensure 'participants are treated with respect and dignity and given the best possible opportunities and choices in achieving quality of life. In achieving this, the Authority seeks to be an international leader in the delivery and development of disability services'.⁸ The LTCS Scheme has been operating for five years, having commenced on 1 October 2006 for children under the age of 16 and on 1 October 2007 for people aged 16 and over.⁹
- 2.2** The Scheme provides 'lifelong treatment, rehabilitation and attendant care for people severely injured in a motor vehicle accidents in NSW, regardless of who was at fault' in the accident. It applies in respect of people who have suffered catastrophic injuries including spinal cord injury, moderate to severe brain injury, multiple amputations, severe burns or permanent blindness.¹⁰
- 2.3** The LTCS Scheme is governed by the *Motor Accidents (Lifetime Care and Support) Act 2006* ('the Act') which is divided into eight parts:
- Part 2 sets out the care, treatment and support to be paid by the Authority, the Scheme's eligibility criteria, its application and acceptance processes, provisions for the approval of treatment and care providers, and the effect of the Scheme on motor accidents compensation claims
 - Part 3 deals with dispute resolution processes
 - Part 4 governs treatment and care needs assessment
 - Part 5 governs payment to hospitals, doctors and other medical services
 - Part 6 deals with the administration of the LTCS Scheme and the roles of the Lifetime Care and Support Authority and Lifetime Care and Support Advisory Council
 - Part 7 sets out how the Scheme is funded
 - Part 8 makes miscellaneous provisions, including for a Committee of the Legislative Council to supervise the Scheme, Authority and Advisory Council.

⁸ LTCSA, *Annual Report, 2009-2010*, p 3.

⁹ LTCSA, *Annual Report, 2009-2010*, p 4.

¹⁰ LTCSA, *Annual Report, 2008-2009*, p 4.

- 2.4** An important distinction between the LTCS Scheme and other similar arrangements, such as the Motor Accidents Scheme, is that the Scheme does not pay compensation to individuals.¹¹ Instead, the Scheme pays for medical treatment, rehabilitation and attendant care services that are ‘reasonable and necessary’ to meet the needs of each participant. Medical treatment services may include doctors, hospitals and medication. Rehabilitation may include physiotherapy, occupational therapy, speech pathology, social work, psychology, equipment to assist in daily living and home and vehicle modification. Attendant care services means personal or respite care, childcare, domestic assistance and educational or vocational support.¹²
- 2.5** Pursuant to Part 7 of the Act, funding for the LTCS Scheme is obtained through the Medical Care and Injury Services (MCIS) levy paid by motorists when they purchase a Compulsory Third Party (CTP) green slip insurance policy. Licensed insurers collect the levy on behalf of the Motor Accidents Authority (MAA). Levy contributions are adjusted over time in order to remain sufficient to fund the full cost of providing lifetime care and treatment to Scheme participants, and meet other Scheme expenses.¹³

The Lifetime Care and Support Authority and the Advisory Council

- 2.6** The Lifetime Care and Support Authority (LTCSA) is responsible for the day to day administration of the Scheme. It ensures the effective coordination and funding of care, treatment and rehabilitation and other services for participants. In carrying out its functions the LTCSA is subject to the oversight of the Lifetime Care and Support Advisory Council (LTCSAC). The functions of both the LTCSA and the LTCSAC are set out in the Act.¹⁴
- 2.7** The responsibilities of the LTCSA include to:
- monitor the operation of the Scheme and conduct research and collect statistics in relation to its operation
 - advise the Minister on the administration, efficiency and effectiveness of the Scheme and publicise and disseminate information
 - provide administrative support, advice and recommendations to the LTCSAC, and
 - monitor and provide support and funding for research and education services relating to care, treatment, rehabilitation and lifetime support for people who are catastrophically injured in motor accidents.¹⁵
- 2.8** The LTCSAC Board of Directors determines the administrative policies of the LTCSA and ensures that, as far as practicable, the activities of the Authority are carried out properly and efficiently.¹⁶ The Board is chaired by its Chief Executive Officer and is made up of four part-time directors and the chair.¹⁷

¹¹ 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*, Report 37, October 2008, p 5.

¹² Standing Committee on Law and Justice, Report 37, p 9.

¹³ LTCSA, *Annual Report, 2008-2009*, p 4.

¹⁴ *Motor Accidents (Lifetime Care and Support) Act 2006*, ss 43 and 46.

¹⁵ *Motor Accidents (Lifetime Care and Support) Act 2006*, s 43.

¹⁶ *Motor Accidents (Lifetime Care and Support) Act 2006*, s 39.

¹⁷ *Motor Accidents (Lifetime Care and Support) Act 2006*, s 34.

- 2.9 In contrast, the primary functions of the LTCSAC are to monitor the operation of the services provided by the Scheme and to review the *Lifetime Care and Support Guidelines* and advise the LTCSA in relation to them. The Council can also provide advice to the Minister on any matter relating to the Scheme that it considers appropriate.¹⁸

The process of entering the Scheme

- 2.10 This section briefly outlines eligibility for the Scheme, what it covers, the process for people to become participants in the Scheme and the dispute resolution mechanisms. These were described in detail in the Committee's *First Review Report*.¹⁹

Eligibility

- 2.11 For a person to be eligible to participate in the LTCS Scheme, his or her injury must result from an accident involving a motor vehicle insured under the NSW Motor Accidents Scheme.²⁰ The LTCS Scheme does not cover injuries arising from the use or operation of a motor vehicle that is not capable of registration, or the use or operation of an unregistered and uninsured vehicle on private property.²¹
- 2.12 The Scheme covers people with serious injuries requiring lifelong care. Accordingly, eligibility will depend on the type and severity of injury and is determined on the basis of medical assessment. There are different eligibility criteria in respect to spinal cord injuries, brain injuries, severe burns, multiple amputations and permanent blindness.²²
- 2.13 Recently the LTCSA has reviewed its eligibility criteria for people with amputations in order to resolve ambiguity in the wording of the current criteria and specify the types of amputations that are eligible for the Scheme. The revisions also proposed expansion of the eligibility criteria for specific types of unilateral amputations that give rise to an ongoing high care need that were not previously eligible for participation in the Scheme.²³
- 2.14 Eligibility for lifetime participation in the Scheme is a two-stage process: first there is an 'interim' participation period, which is followed by 'lifetime' participation in eligible cases. Eligibility for interim participation is assessed soon after injury and continues for a maximum of two years for people over three years of age. Interim participation for children under this age will continue until they reach the age of five years, after which their eligibility for lifetime participation will be assessed. The interim participation period exists to take into account possible improvements to the individual's health.²⁴

¹⁸ Standing Committee on Law and Justice, Report 37, p 13.

¹⁹ Standing Committee on Law and Justice, Report 37, pp 7-12.

²⁰ As prescribed by the *Motor Accidents Compensation Act 1999*.

²¹ Standing Committee on Law and Justice, Report 37, p 7.

²² LTCSA, *Lifetime Care and Support Guidelines 2010* (hereafter referred to as 'LTCS Guidelines'), pp 4-6, accessed 29 October 2010, <www.lifetimecare.nsw.gov.au/Guidelines_and_Policies_for_Professionals.aspx>.

²³ Answers to pre-hearing questions on notice 29 September 2011, LTCSA, Question 11, pp 5-6; see also LTCSA, *Draft Eligibility Criteria for Amputations*, accessed 12 October 2011, <www.lifetimecare.nsw.gov.au/Draft_eligibility_criteria_for_amputations/News.aspx>.

²⁴ *LTCS Guidelines*, p 7; *Motor Accidents (Lifetime Care and Support) Act 2006*, s 9(5A).

- 2.15** Lifetime participation is assessed before the interim participation period expires. Upon a person becoming a lifetime participant in the Scheme, the LTCSA will pay for treatment, rehabilitation and care related to the motor accident injury for the rest of the participant's life.²⁵

Initial stages of participation in the Scheme

- 2.16** Hospital staff, brain injury or spinal injury teams, or social workers assisting an injured person will notify the LTCSA where that person's injuries may make them eligible for the Scheme. Notification is provided by a phone call or by sending a completed Severe Injury Advice Form.²⁶
- 2.17** On receipt of this notification, a LTCS Coordinator will meet with the injured person and his or her family to explain the Scheme and the application process. The LTCS Coordinator will provide the injured person and his or her family with a more detailed application form which asks for information about the motor accident, as well as a medical certificate completed by a treating specialist. The application is then assessed and, if eligible, the injured person and treating team are informed of the commencement date for interim participation.²⁷
- 2.18** All participants in the LTCS Scheme are assigned a LTCS Coordinator. The Coordinator is the primary point of contact between the participant, service providers and the LTCSA.²⁸ The Coordinator will help the participant develop two important plans. Firstly, the LTCS Plan which consists of the participant's current and future needs and aspirations. Secondly, the Community Living Plan which outlines necessary services for the ongoing support of the participant.
- 2.19** The *First Review Report* describes the process of being accepted into the Scheme in further detail.²⁹

Dispute resolution under the Scheme

- 2.20** The Act includes provisions for dispute resolution. These apply in circumstances where an applicant or participant does not agree with a decision of the Authority and informal dispute resolution processes have been unsuccessful. The Act requires that the LTCSA appoint qualified assessors³⁰ to review disputed decisions related to a participant's eligibility, treatment, rehabilitation and care as appropriate.³¹ Disputes fall into one of two categories: they are either about eligibility to enter the Scheme or are about treatment, rehabilitation and care services.

²⁵ 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*, Report 45, November 2010, p 7.

²⁶ Standing Committee on Law and Justice, Report 45, p 8.

²⁷ Standing Committee on Law and Justice, Report 45, p 8.

²⁸ Standing Committee on Law and Justice, Report 45, p 8.

²⁹ Standing Committee on Law and Justice, Report 37, pp 9-11.

³⁰ *Motor Accidents (Lifetime Care and Support) Act 2006*, s 24(3).

³¹ *Motor Accidents (Lifetime Care and Support) Act 2006*, Parts 3 and 4.

- 2.21** The LTCSA reported that, since the commencement of the Scheme in 2006, nine disputes about eligibility to the Scheme have been resolved and one dispute is ongoing. The majority of disputes about eligibility have been initiated by participants with traumatic brain injury. In this context, the adequacy of the Scheme's eligibility criteria has been questioned by some stakeholders. This will be further examined in Chapter 4.
- 2.22** Since the inception of the Scheme, nine cases about eligibility have been resolved. Of these, six disputed an initial decision of ineligibility to enter the Scheme and three were an appeal against eligibility to enter the Scheme. In five of the six decisions of ineligibility, the initial decision was overturned. In two of the decisions of eligibility, one of the three was overturned.³²
- 2.23** Since the commencement of the Scheme there have been 24 disputes about participants' treatment and care needs. Twenty of those have been resolved and four are still in progress.³³ Attendant care and equipment are the most disputed care needs with six resolved disputes arising from each. There have been two disputes about home modifications. Of the six remaining resolved disputes, each related to unique matters.³⁴
- 2.24** The outcomes of the 20 resolved disputes about treatment and care are as follows:
- One dispute was withdrawn
 - In seven instances the dispute assessor upheld the Authority's decision
 - In six instances the dispute assessor varied the Authority's decision
 - In a further six instances, the decision of the dispute assessor reversed the Authority's decision.³⁵
- 2.25** The LTCSA stated in its answers to question on notice that in the majority of cases where the Authority's decision was overturned, the dispute assessor obtained additional information from clinical assessment and from other clinicians involved with the participant.³⁶ The Authority stated that, had it received that information earlier, in most cases, it would have altered the Authority's original decision.³⁷
- 2.26** Several stakeholders have criticized the Authority's dispute resolution processes. These concerns are examined further in Chapter 4.

Day to day operation of the Scheme

- 2.27** The day to day operation of the LTCSA and LTCSAC is facilitated by a small secretariat who draft policy guidance and provide administrative support. In addition, LTCSA Coordinators and case managers work directly with Scheme participants. LTCS Coordinators and case

³² Answers to pre-hearing questions on notice 29 September 2011, LTCSA, Question 3, pp 2-3.

³³ Answers to pre-hearing questions on notice 29 September 2011, LTCSA, Question 3, p 3.

³⁴ Answers to pre-hearing questions on notice 29 September 2011, LTCSA, Question 3, p 3.

³⁵ Answers to pre-hearing questions on notice 29 September 2011, LTCSA, Question 3, p 3.

³⁶ Answers to pre-hearing questions on notice 29 September 2011, LTCSA, Question 3, p 3.

³⁷ Answers to pre-hearing questions on notice 29 September 2011, LTCSA, Question 3, p 3.

managers play an important role in the lives of participants and their interaction with the Scheme.

LTCS Coordinators

- 2.28** Among LTCSA staff, LTCS Coordinators are especially important. They are a participant's primary contact and representative within the LTCS Scheme. LTCS Coordinators come from a variety of backgrounds and have extensive experience working with people with disabilities in the community and their families.³⁸
- 2.29** The role of a Coordinator is to monitor and organize care and support for individual participants and to oversee each person's lifelong participation in the Scheme. The LTCS Coordinator is responsible for providing information to individual participants about the Scheme and organizing their injury-related services, including planning for a return to leisure activities and work or school. Specifically, an LTCS Coordinator should understand the individual participant's needs, administer that person's case file and ensure participants are receiving quality services.³⁹
- 2.30** As the link between participants and the Authority, in practical terms, it is usually the Coordinator who will inform participants about whether services or equipment will or will not be paid for by the LTCS Scheme. The Scheme currently employs the full time equivalent (FTE) of 23.6 LTCS Coordinators. This amounts to a ratio of 24.5 participants per FTE.⁴⁰

Case managers

- 2.31** Each participant also has an individual case manager. Whereas the LTCS Coordinator is the long-term link between a participant and the LTCSA, the case manager is the facilitator of a participant's daily needs. The case manager acts as the primary communication portal between service providers and the LTCS Coordinator.⁴¹
- 2.32** Often a participant's case manager will also be a member of their treating team. This occurs especially in the early stages of acute recovery where it may be appropriate for a treating clinician to be the nominated case manager.⁴² The LTCSA has noted that having a member of the treating team also perform the role of case manager has a number of benefits including improved efficiency:

It can reduce reporting and liaison time if a member of the treating team, who has intimate knowledge of the participant's circumstances and needs, assumes the primary

³⁸ For further information see: LTCSA, *Frequently Asked Questions: LTCS Coordinators*, accessed 22 November 2011, <www.lifetimecare.nsw.gov.au//Scheme_Participants_FAQs.aspx>.

³⁹ Standing Committee on Law and Justice, Report 45, p 85.

⁴⁰ Answers to questions taken on notice during evidence 17 October 2011, LTCSA, Question 2, p 1.

⁴¹ Lifetime Care and Support Authority, *Case Management and the Lifetime Care and Support Scheme*, May 2010, p 14, accessed 1 September 2011, <www.lifetimecare.nsw.gov.au//CaseManagement.aspx>.

⁴² Lifetime Care and Support Authority, *Case Management and the Lifetime Care and Support Scheme*, May 2010, p 11, accessed 1 September 2011, <www.lifetimecare.nsw.gov.au//CaseManagement.aspx>.

role of communication between the participant, their family, the treating team and the Authority.⁴³

- 2.33** The Authority will engage only one case manager per participant at any one time, but case managers may change from time to time, in line with the changing needs of the participant.⁴⁴ The LTCSA has stated that when the participant leaves acute rehabilitation, their needs will broaden and it is preferable for a person who is not providing treatment to take over the case management role.⁴⁵ However, the Authority also recognizes that this is not always possible.⁴⁶

The Committee's past Reviews

- 2.34** As outlined in Chapter 1, the Standing Committee on Law and Justice conducts an annual review of the functions of the LTCSA and the LTCSAC. The following section provides an overview of the Committee's past three reviews.

First Review

- 2.35** The Committee reported on its First Review in October 2008. The Committee congratulated the NSW Government on the establishment of the LTCS Scheme and noted the valuable provisions it made for people who are catastrophically injured in motor vehicle accidents.⁴⁷ The Committee acknowledged that its First Review was necessarily preliminary due to the short time that the LTCS Scheme had been operational and noted that future reviews would provide more in-depth assessments as the Scheme matured.⁴⁸
- 2.36** The Committee identified a number of emerging issues relating to accidents not covered by the Scheme, eligibility for the Scheme and entry to it, the evaluation of medical assessment tools used to assess eligibility criteria, opt-out and self purchasing provisions, the provision of services to participants (including supported accommodation and attendant care), support for family carers, administration and paperwork, the role of LTCS coordinators, transparency, accountability and access to information, interface with the Motor Accidents Scheme, estimated financial liabilities, and premiums.⁴⁹
- 2.37** In its First Review, the Committee made two recommendations. The first was that the Act should be amended to provide that children less than three years of age when injured, are not assessed for lifetime participation in the Scheme until they are at least five years old. The objective was to ensure that their injuries fully stabilise before significant decisions are made

⁴³ Lifetime Care and Support Authority, *Case Management and the Lifetime Care and Support Scheme*, May 2010, p 11, accessed 1 September 2011, <www.lifetimecare.nsw.gov.au/CaseManagement.aspx>.

⁴⁴ Lifetime Care and Support Authority, *Case Management and the Lifetime Care and Support Scheme*, May 2010, p 11, accessed 1 September 2011, <www.lifetimecare.nsw.gov.au/CaseManagement.aspx>.

⁴⁵ Lifetime Care and Support Authority, *Case Management and the Lifetime Care and Support Scheme*, May 2010, p 12, accessed 1 September 2011, <www.lifetimecare.nsw.gov.au/CaseManagement.aspx>.

⁴⁶ Lifetime Care and Support Authority, *Case Management and the Lifetime Care and Support Scheme*, May 2010, p 12, accessed 1 September 2011, <www.lifetimecare.nsw.gov.au/CaseManagement.aspx>.

⁴⁷ Standing Committee on Law and Justice, Report 37, p xi.

⁴⁸ Standing Committee on Law and Justice, Report 37, p xi.

⁴⁹ Standing Committee on Law and Justice, Report 37, pp 33-64.

about their projected lifetime care needs. The Government expressed its full support for this recommendation and the Act was amended accordingly.⁵⁰

2.38 The Committee's second recommendation was that the LTCSA, together with the LTCSAC, consider options for the provision of independent review of decisions, advice and advocacy to applicants and participants in the Scheme and develop recommendations as to the most appropriate mechanisms for each.⁵¹

2.39 In its response to this recommendation, the Government commented that a number of mechanisms were already in place to allow for the independent review of decisions regarding an injured person's eligibility for and participation in the Scheme. The Government also noted that, at the time, the LTCSA was preparing a discussion paper on the provision of advocacy services in the Scheme for consultation with advocacy groups.⁵²

2.40 Concerns over access to independent advice, advocacy and review have been expressed in all of the Committee Reviews to date, including the present.⁵³ The development of this issue since the First Review will be examined in detail in Chapter 4.

Second Review

2.41 The Committee reported on its Second Review in September 2009. In that report, the Committee determined that the Scheme was 'functioning effectively'.⁵⁴ The *Second Review Report* identified a number of new issues that had become apparent with the development of the Scheme. These included, among other things a number of issues which were subsequently considered as part of the third and fourth reviews, including membership of the LTCSAC, a participant representative on the Council, and the role of recreation and leisure in participant rehabilitation.⁵⁵

2.42 Other issues raised in the Second Review that have since been (or are being) addressed will not be revisited in the present review. These include people being hit by projectiles while in a registered motor vehicle, the NSW Health review of the impact of the LTCS Scheme on health service resources and community awareness campaigns.

Third Review

2.43 The Committee's *Third Review Report* was tabled in parliament in November 2010. The Report commends the LTCSA and LTCSAC on the Scheme's continued success⁵⁶ and notes that the first participant satisfaction survey showed overall satisfaction with the LTCS Scheme.⁵⁷

⁵⁰ NSW Government, Government Response to the 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*, Report 37, October 2008, p 1.

⁵¹ Standing Committee on Law and Justice, Report 37, p 55.

⁵² Government Response to the Standing Committee on Law and Justice, Report 37, p 1.

⁵³ Submission 7, Australian Lawyers Alliance, pp 2-4; Submission 14, NSW Agency for Clinical Innovation, p 9.

⁵⁴ 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*, Report 40, September 2009, p xv.

⁵⁵ Standing Committee on Law and Justice, Report 40, pp xvi-xvii.

⁵⁶ Standing Committee on Law and Justice, Report 45, p xii.

- 2.44** The Committee made 12 recommendations in total which related to:
- Possible duplication of claims under the LTCS Scheme and the NSW Motor Accidents Scheme
 - The adequacy of methods for determining eligibility into the LTCS Scheme
 - Peer support and legal advocacy groups
 - Administration of LTCS revenue within the public health system
 - Covering the cost of health service system upgrades to meet requirements of the LTCS Scheme
 - Improving the effectiveness of LTCS Coordinators
 - Improving information and language applicable to carers as contained in LTCS publications
 - Improving participant access to recreation and leisure activities.⁵⁸
- 2.45** Some of the issues addressed in recommendations from the Third Review Report have not been resolved. Several of these have again been raised by stakeholders in the present review. These matters include: the adequacy of methods for determining eligibility to enter into the LTCS Scheme, peer support and legal advocacy groups, improving the effectiveness of LTCS Coordinators, improving information resources and improving participant access to recreation and leisure activities. These issues are considered in subsequent chapters of this report.
- 2.46** As outlined in Chapter 1, this Fourth Review of the LTCSA commenced on 14 June 2011. The newly elected Government had not provided its response to the *Third Review Report* before the 10 August 2011 deadline for submissions. This meant that some submissions reiterated concerns from the Third Review.
- 2.47** It is important to ensure that the LTCSA and other relevant government agencies have adequate time to implement the commitments contained in the Government's response. As such, this report will not focus on issues that were addressed by the Government's response to the Third Review. The Committee commits to reviewing those issues again in future, should they arise. An overview of each of these issues is provided below.

A national disability long-term care and support scheme

- 2.48** On 10 August 2011, the Productivity Commission released its final report on a national disability strategy. The draft report recommends the implementation of two new schemes for the provision of disability care in Australia.⁵⁹ The first, and larger of the two, is a National Disability Insurance Scheme (NDIS) which would, among other things, provide referral services for people with disability, maximize the social and economic participation of people with disability and provide individually tailored funding for people with a significant

⁵⁷ Standing Committee on Law and Justice, Report 45, p xii.

⁵⁸ Standing Committee on Law and Justice, Report 45, pp xvi-xvii.

⁵⁹ Productivity Commission, *Disability Care and Support: Inquiry Report*, Report 54, 31 July 2011, Vol 1, pp 63 and 88.

disability.⁶⁰ The second, and more directly relevant to the work of the LTCSA, is the National Injury Insurance Scheme (NIIS).

- 2.49** The NIIS would facilitate the establishment of nationally consistent, state-based, no-fault schemes for the provisions of care to people who have suffered catastrophic injuries, whatever the cause.⁶¹ It would be established and funded by state and territory governments, although the care of people who suffer catastrophic injuries caused by aviation accidents would be paid for by the Australian Government. Thus, if this recommendation were adopted, the LTCS Scheme would remain operated by the NSW Government.
- 2.50** Although the NIIS would function in a similar way to the existing LTCS Scheme, there would be a need to implement substantial changes to the operation of the LTCS Scheme in order to implement the NIIS. In particular, the proposed national scheme would operate more broadly than the current NSW model in that it is not limited to catastrophic injury caused only by motor vehicle accidents. Accordingly, the LTCSA would need to substantially expand the scope of its operation in order to cater for people who suffer catastrophic injuries from all causes, not only motor vehicle accidents. In addition, the Scheme would need to alter its operation in order to conform to nationally consistent criteria.
- 2.51** The Productivity Commission's report was prepared in consultation with other Australian jurisdictions and the LTCSA has played an active role in assisting the Commission in its inquiry, including through meetings and the provision of a considerable volume of information.⁶² Indeed, the Executive Director of the LTCSA, Mr. David Bowen, was appointed as a member of the independent panel providing assistance to the Commission in its deliberations.⁶³
- 2.52** The NIIS is proposed to commence by October 2013 for new cases of catastrophic injury caused by motor vehicle and medical accidents and by the end of 2016 for new cases of catastrophic injury irrespective of cause.⁶⁴
- 2.53** Although the Scheme has received bipartisan support in the Federal Parliament, it is yet to be adopted. Thus, the implementation and establishment of the NIIS is not yet an absolute certainty.
- 2.54** In its submission to the Productivity Commission's Inquiry, the Keneally Labor Government expressed in principle support for a new national disability insurance scheme and outlined a number of social and economic benefits that such a scheme might produce.⁶⁵ These perceived benefits include improved efficiency through administrative cost savings, greater equity in

⁶⁰ Productivity Commission, *Disability Care and Support: Inquiry Report*, Report 54, 31 July 2011, Vol 1, p 63.

⁶¹ Productivity Commission, *Disability Care and Support: Inquiry Report*, Report 54, 31 July 2011, Vol 1, p 88.

⁶² Answers to pre-hearing questions on notice 29 September 2011, LTCSA, Question 1, p 1.

⁶³ Answers to pre-hearing questions on notice 29 September 2011, LTCSA, Question 1, p 1.

⁶⁴ Productivity Commission, *Disability Care and Support: Draft Report*, Vol 1, 2011, accessed 15 July 2011 <www.pc.gov.au/projects/inquiry/disability-support/draft>.

⁶⁵ NSW Government, *The Productivity Commission Inquiry into a National Disability Long Term Care and Support Scheme: Draft NSW Government Submission August 2010*, Submission 536 to the Productivity Commission Inquiry into a National Disability Long Term Care and Support Scheme, pp 51 and 82-83, accessed 8 November 2011 <<http://www.pc.gov.au/projects/inquiry/disability-support/submissions>>.

allocating resources and the fostering of 'needs based approaches'.⁶⁶ However, the Keneally Labor Government recommended that further economic and financial modeling needed to first be undertaken to ensure that such a scheme is feasible.⁶⁷

- 2.55** The Committee is not aware of any public statements made by the current Government as to its views on the proposed National Injury Insurance Scheme.

⁶⁶ NSW Government, *The Productivity Commission Inquiry into a National Disability Long Term Care and Support Scheme: Draft NSW Government Submission August 2010*, Submission 536 to the Productivity Commission Inquiry into a National Disability Long Term Care and Support Scheme, pp 82-83, accessed 8 November 2011 <<http://www.pc.gov.au/projects/inquiry/disability-support/submissions>>.

⁶⁷ NSW Government, *The Productivity Commission Inquiry into a National Disability Long Term Care and Support Scheme: Draft NSW Government Submission August 2010*, Submission 536 to the Productivity Commission Inquiry into a National Disability Long Term Care and Support Scheme, p 83, accessed 8 November 2011 <<http://www.pc.gov.au/projects/inquiry/disability-support/submissions>>.

Chapter 3 Scheme operation and performance

This chapter reviews the Lifetime Care and Support Scheme's performance to date, including the number and demography of participants as well as the Authority's finances. The chapter also considers the success of the Scheme in broad terms, as reported by key stakeholders, and the results of the participant satisfaction survey. The relationship of the Lifetime Care and Support Scheme to the Motor Accidents Scheme is briefly examined before turning to consideration of the membership of the Lifetime Care and Support Advisory Council.

Scheme performance

3.1 This section provides a statistical picture of the operation of the Scheme. It describes the participants in the Scheme, including the number of participants, their sex, age, injury type, where they live and the role they had in the accident that caused their injury, for example, whether they were the driver, passenger or a pedestrian.

Statistics

3.2 Participation in the LTCS Scheme has increased as follows:

- 76 participants at the time of the Committee's First Review in 2008,
- 233 participants during the Committee's Second Review in 2009
- 379 participants at the Scheme's Third Review in 2010⁶⁸
- 536 participants in the Scheme at 30 June 2011.

3.3 Of the 536 participants in the Scheme at 30 June 2011, 378 were male and 158 female. There were 64 children (under 16 years old, also known as 'paediatric participants') and the remaining 472 were adults. Included in the 536 participants are 13 people who are now deceased.⁶⁹

3.4 Of the 46 paediatric participants: 30 were passengers in vehicles at the time of injury, 26 pedestrians, 3 cyclists, 2 drivers, 3 motorcycle riders/other.⁷⁰

3.5 Of the 472 adult participants there were 164 drivers, 107 motorcycle riders, 84 passengers, 91 pedestrians, and 20 cyclists, 3 pillion passengers and 3 other.⁷¹

3.6 As described in Chapter 2, lifetime participation in the Scheme is assessed before the interim period expires. As at June 2011, there were 186 lifetime participants in the Scheme, increased

⁶⁸ 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*, Report 40, September 2009, p 9.

⁶⁹ Answers to pre-hearing questions on notice, LTCSA, 29 September 2011, attachment 1, p 2.

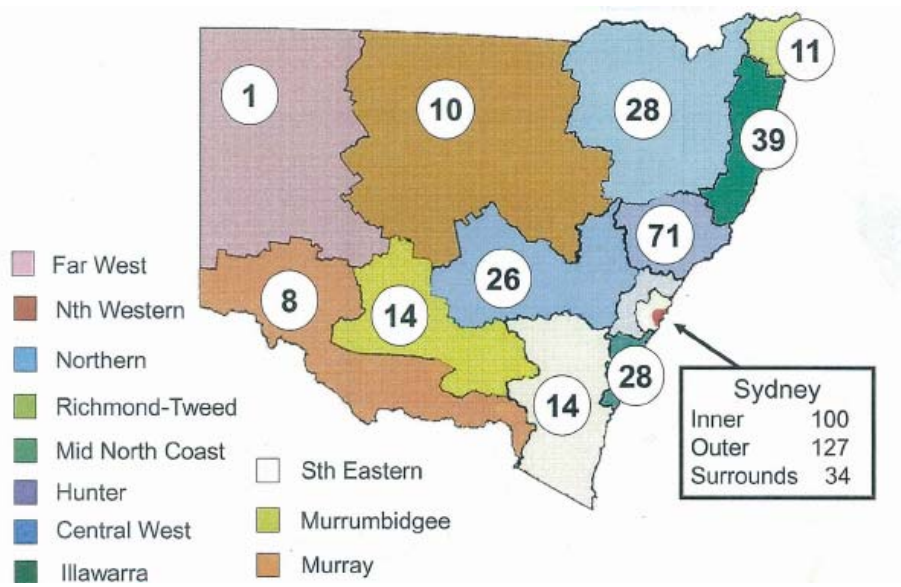
⁷⁰ Answers to pre-hearing questions on notice, LTCSA, 29 September 2011, attachment 1, p 7.

⁷¹ Answers to pre-hearing questions on notice, LTCSA, 29 September 2011, attachment 1, p 7.

from 50 in the previous year.⁷² This number will continue to grow as the majority of participants are likely to remain in the Scheme for life.⁷³

3.7 The map below illustrates where Scheme participants reside.

Figure 1 Scheme participants – geographical breakdown as at June 2011⁷⁴



3.8 The LTCSA provided the Committee with further statistical data in its answers to questions taken on notice during the hearing. The type of injuries sustained by participants is outlined in the table below.

Table 1 Scheme participants – injury type as at 30 September 2011⁷⁵

| Injury type | Paediatric | | Adult | |
|----------------------------------|------------|------|-------|------|
| | No | % | No | % |
| Traumatic brain injury | 61 | 10.6 | 379 | 65.6 |
| Spinal cord injury ⁷⁶ | 7 | 1.2 | 121 | 20.9 |
| Other | 0 | 0 | 10 | 1.7 |

⁷² Answers to pre-hearing questions on notice, LTCSA, 29 September 2011, attachment 1, p 2.

⁷³ 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*, Report 37, October 2008, p 10.

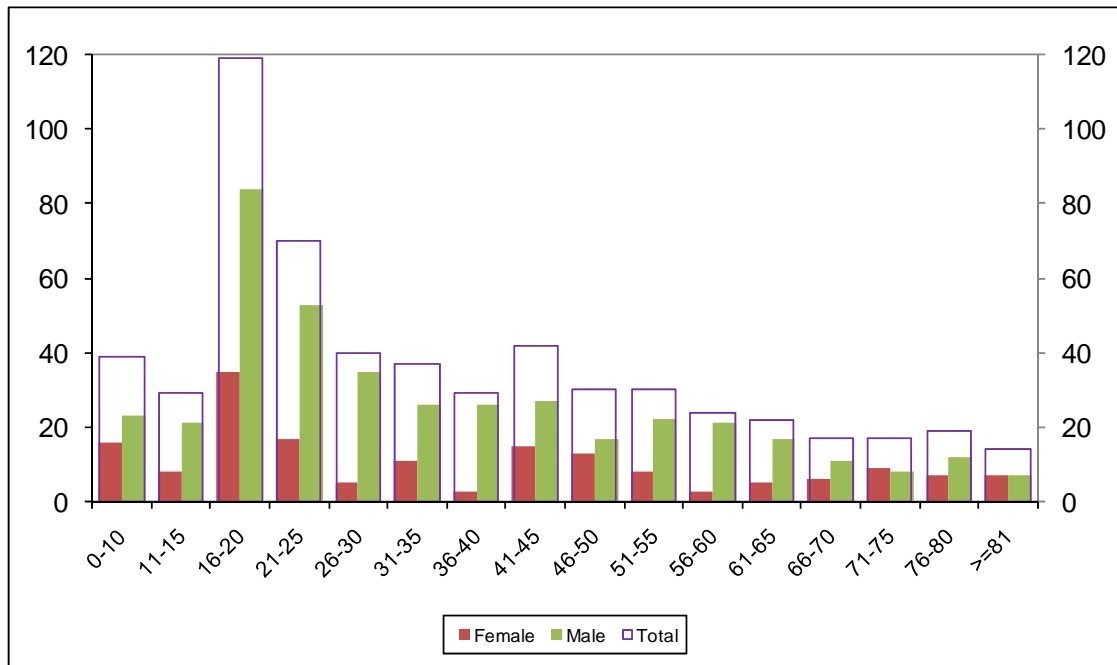
⁷⁴ Answers to pre-hearing questions on notice, LTCSA, 29 September 2011, attachment 1, p 4.

⁷⁵ Answers to questions on notice taken during evidence 17 October 2011, LTCSA, Question 2, p 1.

⁷⁶ Three participants with both brain injuries and spinal cord injuries have been grouped together with spinal cord injuries.

3.9 Below is a graph providing the breakdown of participants by age groups.

Figure 2 Scheme participants – age group as at September 2011⁷⁷



3.10 During the Committee's Third Review, the Authority noted that for the first time, there were more participants in the community than in hospital or rehabilitation.⁷⁸ In the current Review, the Executive Director of the LTCSA, Mr David Bowen, commented that 'the focus of the Authority is on the growing number of participants in the community. I mentioned this last time but it is particularly stark now.'⁷⁹

3.11 Mr Bowen advised the Committee that the number of participants in hospital had now stabilized and that there were about 50 participants in acute care in hospital at any one time.⁸⁰ He also noted that the about 80 per cent of the cost of the Scheme is put towards supporting people to live in the community.⁸¹

Financial matters

3.12 According to its 2009-2010 Annual Report, the financial statements for the LTCSA disclosed a deficit of \$65.133 million, decreasing equity to \$90.86 million.⁸² This is in contrast to the

⁷⁷ Answers to questions on notice taken during evidence 17 October 2011, LTCSA, Question 2, p 12.

⁷⁸ 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*, Report 45, November 2010, p 21.

⁷⁹ Mr David Bowen, Executive Director, Lifetime Care and Support Authority, Evidence, 17 October 2011, p 50.

⁸⁰ Mr Bowen, Evidence, 17 October 2011, p 50.

⁸¹ Mr Bowen, Evidence, 17 October 2011, p 50.

⁸² LTCSA, *Annual Report 2009-2010*, p 25.

deficit of \$4.022 million reported during last year's Review, which formed equity of over \$156 million.⁸³

- 3.13** The Authority previously explained to the Committee that the global financial crisis had impacted on the valuation of its investment assets but that the Scheme remained 'financially healthy'.⁸⁴
- 3.14** In the present Review, the Authority was asked about the possible impact of a gender equity wage claim which is currently before the courts. The LTCSA explained it had provisioned for an increase in care costs above average weekly earnings to account for the impact of a judicial decision. Accordingly, unless the decision was an 'enormous surprise' the Authority was in a 'comfortable position' to cope with any costs that arise from that case.⁸⁵

Life Costing Model

- 3.15** The Life Costing Model is a tool used to estimate costs for providing lifelong treatment, rehabilitation and care services to Scheme participants. It forms part of the Authority's 'Dynamic Financial Management System' whereby actual data is used to improve actuarial assumptions.⁸⁶ The Model allows the Authority to estimate the lifetime cost of individual participants, the cost of all participants, as well as calculating the cash flow requirements of the Authority.⁸⁷
- 3.16** The Committee was first informed of the Life Costing Model in its Second Review. In this regard, the LTCSA advised that it had undertaken a project relating to the financial underpinnings of the Scheme.⁸⁸
- 3.17** As part of the Third Review, the LTCSA advised the Committee that the Life Costing Model had been remodelled throughout 2009-2010 and that, following development and testing, the final model would go into final production release in June 2010.⁸⁹
- 3.18** During the current review, the LTCSA advised the Committee that the latest version of the Life Costing Model was implemented in August 2011.⁹⁰ The Authority stated that it anticipates that as more expense data is collected, the system will become increasingly accurate. The Authority has retained a consultant firm to conduct an annual review of the model to ensure that it reflects 'real' data and expenditure.⁹¹

Medical Care and Injury Services Levy and CTP premiums

- 3.19** As outlined in Chapter 2, the Scheme is funded through the Medical Care and Injury Services (MCIS) levy which a component of the Compulsory Third Party (CTP) green slip insurance

⁸³ LTCSA, *Annual Report 2008-2009*, p 16.

⁸⁴ Standing Committee on Law and Justice, Report 45, p 22.

⁸⁵ Mr Bowen, Evidence, 17 October 2011, p 61.

⁸⁶ Answers to pre-hearing questions on notice 29 September 2011, LTCSA, Question 23, p 11.

⁸⁷ Standing Committee on Law and Justice, Report 45, p 22.

⁸⁸ Standing Committee on Law and Justice, Report 40, p 11.

⁸⁹ Standing Committee on Law and Justice, Report 45, p 23.

⁹⁰ Answers to pre-hearing questions on notice 29 September 2011, LTCSA, Question 23, p 11.

⁹¹ Answers to pre-hearing questions on notice 29 September 2011, LTCSA, Question 23, p 11.

policy purchased by motorists when registering a motor vehicle in NSW. A proportion of the MCIS levy contributes to the LTCS fund, and represents a non-fixed percentage of the insurer premium for each vehicle class and region rating.⁹²

- 3.20** In the last financial year, the Scheme received \$361.683 million in funding through the levy.⁹³
- 3.21** The LTCSA reported the implementation of a 2.5 per cent reduction in the levy on motorists in February 2009 and it had approved a further 3.5 per cent reduction from August 2009.⁹⁴ At the time, the Authority explained that they were able to allow a reduction in the levy because the increase in CTP premiums was delivering a higher income to the LTCSA than was required to maintain full funding.⁹⁵ The levy has not been reduced since 2009.⁹⁶

Progress of the Scheme

- 3.22** In the current Review, as in previous years, most stakeholders expressed the view that overall the Scheme performed important work and was, in general, a successful initiative, although it could be improved. This general perspective echoed those espoused in previous reviews.⁹⁷
- 3.23** For example, a submission to the current review from a number of medical specialists stated that the LTCS Scheme is a model scheme in that it has improved the lives of seriously injured people:

This Scheme has greatly improved the lives of people who sustain extremely severe injuries in motor vehicle accidents in New South Wales. It is recognised as a model scheme and it can form a foundation on which the proposed (Australian) National Injury Insurance Scheme is built.⁹⁸

- 3.24** In its submission, Dare to Do Australia acknowledged that the LTCS Scheme is ‘moving along in a positive way’.⁹⁹ Similarly, the Chair of the Lifetime Care and Support Advisory Council, Mr Douglas Herd, noted that the Scheme is ‘generally regarded as being perhaps the leading scheme of its type in the country, a model that is looked at overseas’.¹⁰⁰ He added that:

The Lifetime Care and Support Authority [is] and authority that is doing the job that Parliament set it and it is doing it very well and the proof of the pudding is the Commonwealth is picking it up and taking it as a model for what might happen in the future.¹⁰¹

⁹² Standing Committee on Law and Justice, Report 45, p 23.

⁹³ LTCSA, *Annual Report 2009-2010*, p 22.

⁹⁴ LTCSA, *Annual Report 2008-2009*, p 11.

⁹⁵ Standing Committee on Law and Justice, Report 45, p 23.

⁹⁶ Answers to pre-hearing questions on notice 29 September 2011, LTCSA, Question 23, p 11.

⁹⁷ Standing Committee on Law and Justice, Report 45, pp 23-28.

⁹⁸ Submission 19, medical specialists, p 2.

⁹⁹ Submission 17, Dare to Do Australia, p 1.

¹⁰⁰ Mr Douglas Herd, Chair, LTCSAC, Evidence, 17 October 2011, p 63.

¹⁰¹ Mr Herd, Evidence, 17 October 2011, p 64.

3.25 The Brain Injury Rehabilitation Directorate acknowledged that, notwithstanding some of the challenges it has faced in relation to the Scheme, it is now the case that because of the introduction of the Scheme ‘more victims of catastrophic injury from motor vehicle accidents have potential to access rehabilitation and care’.¹⁰² However it also noted that there is more work to be done:

...whilst the lifetime care and support is resulting in more patients getting access to rehabilitation and care following catastrophic injury, and we greatly welcome this, we believe much work needs to be done to improve the working relationship between the brain injury program and lifetime care and support. Currently we do not believe that our clients’ needs are being maximally met under the scheme.¹⁰³

3.26 Similarly, the Brain Injury Service at the Children’s Hospital at Westmead stated that their experience with the Scheme:

...has been overall positive. There certainly have been challenges along the way, particularly in working out processes – the difference cultures between our two organizations. But if you look at the outcome for the child, then I would say it has been a positive one.¹⁰⁴

3.27 The Physical Disability Council of New South Wales acknowledged the improvements that have been made to the Scheme since its introduction including in relation to the information provided by the LTCSA about advocacy services, the implementation of case management principles and the opening of new offices outside Sydney:

PDCN commends the LTCSA for recent developments including the provision of information about community based advocacy services that provide service recipients with the ability to seek independent advice, implementation of case management principles, an enquiry into the treatment, care and rehabilitation of service recipients with very high support needs and the opening of offices in Parramatta and Newcastle to assist services users not living directly in Sydney.¹⁰⁵

3.28 Mrs Donna Axiak, a family carer of a participant in the Scheme also commended the Scheme:

The system itself is a magnificent step forward, its conception in 2006 opened doors for young people with acquired catastrophic injuries... [The Scheme] ensures that the claimant should never want for health care resulting from their injury... I don’t feel, especially now living this, that anyone would dispute the benefits under the Act.¹⁰⁶

3.29 One Scheme participant, Mr Greg Moore, expressed his gratitude for the help and support that he receives through the Scheme but expressed frustration with having requests for rehabilitation services denied.¹⁰⁷ These concerns are considered further in Chapter 6.

¹⁰² Dr Adeline Hodgkinson, Rehabilitation Physician, Brain Injury Rehabilitation Unit, Liverpool Hospital, Evidence, 17 October 2011, p 1.

¹⁰³ Dr Hodgkinson, Evidence, 17 October 2011, p 2.

¹⁰⁴ Ms Helene Chew, Coordinator, Brain Injury Service, The Children’s Hospital Westmead, Evidence, 10 October 2011, p 51.

¹⁰⁵ Submission 12, Physical Disability Council of New South Wales, p 5.

¹⁰⁶ Submission 2, Mrs Donna Axiak, p 5.

¹⁰⁷ Submission 9, Mr Greg Moore, p 1.

Participant satisfaction survey

- 3.30** Since 2009, the LTCSA has undertaken an annual participant satisfaction survey. Each participant is invited to respond to the survey a minimum of once every three years but will not necessarily participate every year.¹⁰⁸ The survey is conducted by an external surveyor and participation in the survey is voluntary. The identity of participants surveyed is not disclosed to the LTCSA in order to protect participants' confidentiality.
- 3.31** The survey measures participant satisfaction with the Scheme and its service providers. It also gathers information regarding the Authority's performance in order to foster and direct service improvement.¹⁰⁹
- 3.32** The 2010 participant survey used both qualitative and quantitative methods. The qualitative surveys were conducted in person, while the quantitative surveys were conducted by telephone.¹¹⁰
- 3.33** A total of 188 Scheme participants were invited to take part in the survey in 2010, and 140 interviews took place, with either the participant themselves or their nominated person.¹¹¹
- 3.34** Consistent with the 2009 results, the survey showed an overall satisfaction with the Scheme, with 83 per cent of participants surveyed expressing that they were either satisfied, very satisfied or extremely satisfied with how the Scheme was meeting their needs.¹¹² Also similar to 2009 figures, 13 per cent of participants were dissatisfied, very dissatisfied or extremely dissatisfied with how the Scheme was meeting their needs.¹¹³ The primary reason for dissatisfaction with the Scheme (83 per cent of those dissatisfied) was 'needs not met / service providers inadequate'.
- 3.35** In the 12 months following the 2009 survey, participant satisfaction results largely remained stable although there were a few areas in which there were notable variations. The 2010 survey results showed specific improvement in community participation. The extent to which participants feel part of a community and feel they have enough time with their friends each increased by 13 per cent (to 76 per cent and 73 per cent respectively). Paradoxically, there was an 18 per cent decrease in participants with community living plan goals from 2009 to 2010, down from 71% to 53%.¹¹⁴
- 3.36** The participants were asked about the services they had received through the Scheme in the last three months. The most common services received in that period were case manager services (90 per cent), physiotherapy (69 per cent) and occupational therapy (60 per cent).¹¹⁵

¹⁰⁸ Answers to pre-hearing questions on notice, LTCSA, 29 September 2011, attachment 2, p 20.

¹⁰⁹ Answers to pre-hearing questions on notice, LTCSA, 29 September 2011, attachment 2, p 13.

¹¹⁰ Answers to pre-hearing questions on notice, LTCSA, 29 September 2011, attachment 2, p 15.

¹¹¹ Answers to pre-hearing questions on notice 29 September 2011, LTCSA, Question 8, p 5.

¹¹² Answers to pre-hearing questions on notice, LTCSA, 29 September 2011, attachment 2, p 27. In the 2009 survey, 84% of participants surveyed stated that they were satisfied, very satisfied or extremely satisfied with how the Scheme meets their needs: Standing Committee on Law and Justice, Report 45, p 26.

¹¹³ Answers to pre-hearing questions on notice, LTCSA, 29 September 2011, attachment 2, p 27.

¹¹⁴ Answers to pre-hearing questions on notice, LTCSA, 29 September 2011, attachment 2, p 9.

¹¹⁵ Answers to pre-hearing questions on notice, LTCSA, 29 September 2011, attachment 2, p 31.

At least 80 per cent of participants surveyed reported that they were at satisfied, very satisfied or extremely satisfied with these services.¹¹⁶

- 3.37** Satisfaction results for individual services were as follows: 88 per cent were satisfied with case management services, 93 per cent were satisfied with physiotherapy and 89 per cent with occupational therapy services.¹¹⁷ In addition, 90 per cent of those surveyed were satisfied with attendant care services.¹¹⁸ These results are consistent with those of 2009.¹¹⁹
- 3.38** Suggestions for improvements to the LTCS Scheme were consistent with the 2009 results. In total, 59 per cent of those surveyed in 2010 specified improvements to the Scheme. These improvements fell into two main groups: decreasing delays with approval for access to services and increasing or improving communication.¹²⁰ These issues were also raised in submissions to the Committee's review and are examined in Chapters 6 and 5 respectively.

Committee comment

- 3.39** The Committee acknowledges the valuable work that the LTCSA undertakes to provide lifelong treatment, rehabilitation and care to people who are catastrophically injured in motor vehicle accidents. The Committee continues to support the vision of the Scheme to affirm the rights and dignity of the injured person and ensure a holistic approach to their needs, care and support. In this regard, the Committee commends the LTCSA on the continued success of the Scheme as reflected in both participant satisfaction surveys carried out to date.
- 3.40** The Committee also acknowledges the frustrations that some stakeholders have expressed during the current and previous reviews and considers it is important that their concerns are acknowledged and addressed where possible. The Committee hopes that its ongoing process of review continues to assist stakeholders to address these concerns and that as the Scheme progresses, frustrations diminish.
- 3.41** The Committee remains committed to this ongoing process of public review and values the views and comments of all stakeholders, particularly Scheme participants and their carers.

Relationship with the Motor Accidents Scheme

- 3.42** As described in the Committee's *First Review Report*, the LTCS Scheme and the Motor Accidents Scheme, although separate, do interact. While the LTCS Scheme meets the lifelong treatment, rehabilitation and care needs of a participant, if that participant was injured through the fault of another driver, they may also make a CTP claim for compensation under the Motor Accidents Scheme.¹²¹

¹¹⁶ Answers to pre-hearing questions on notice, LTCSA, 29 September 2011, attachment 2, p 32.

¹¹⁷ Answers to pre-hearing questions on notice 29 September 2011, LTCSA, Question 8, p 5.

¹¹⁸ Answers to pre-hearing questions on notice 29 September 2011, LTCSA, Question 8, p 5.

¹¹⁹ Standing Committee on Law and Justice, Report 45, p 26.

¹²⁰ Answers to pre-hearing questions on notice, LTCSA, 29 September 2011, attachment 2, p 5.

¹²¹ Standing Committee on Law and Justice, Report 37, pp 13-14.

- 3.43** Under the Motor Accidents Scheme, people injured in motor vehicle accidents receive compensation for economic and non-economic losses connected to that injury, such as lost income and pain and suffering. However, LTCS Scheme participants with a concurrent CTP claim cannot claim damages for any treatment and care needs under the Motor Accidents Scheme as these are to be met solely by the LTCS Scheme.¹²²
- 3.44** In the Third Review, the Insurance Council of Australia expressed concern that an ambiguity in the Act could lead to additional claims by participants for further treatment and care under the Motor Accident Scheme for services outside the scope of the LTCS Scheme but also not properly within the Motor Accident Scheme either.¹²³
- 3.45** As part of its Third Review, the Committee noted the concerns of the ICA and recognised that this may be result of ambiguity in the *Motor Accidents Compensation Act 1999*. Accordingly, the Committee recommended:
- That the MAA, in consultation with the Lifetime Care and Support Authority, examine whether Compulsory Third Party claims are being made for treatment, rehabilitation and care expenses that should be claimed under the LTCS Scheme and, if so, whether an amendment is required to the *Motor Accident Compensation Act 1999* to address the potential for duplicating claims and awarded damages.
- 3.46** As yet, the Government response to the recommendations of the Committee in its *Third Review Report* have not been received.

Committee Comment

- 3.47** The Committee did not receive any evidence on this matter in the present review, it was not raised by stakeholders or the Authority. Additionally, the Committee has not heard whether the MAA has resolved its examination of the extent to which duplicate claims between MAA and the LTCS Schemes are occurring. The Committee will remain apprised of this issue in future reviews as the Scheme continues.

Membership of the Lifetime Care and Support Advisory Council

- 3.48** The Lifetime Care and Support Advisory Council (LTCSAC) is comprised of eight members, including the Chief Executive Officer of the LTCSA.¹²⁴
- 3.49** During the Second Review, it was proposed that the membership of the LTCSAC be expanded to include participant and social worker representatives.¹²⁵ In its September 2009 report, the Committee expressed support for this suggestion, and made the following recommendation:

That the Minister for Finance review the membership of the Lifetime Care and Support Advisory Council to consider including representatives of Lifetime Care and

¹²² Standing Committee on Law and Justice, Report 37, p 14.

¹²³ Standing Committee on Law and Justice, Report 45, pp 27-30.

¹²⁴ Standing Committee on Law and Justice, Report 40, p 51.

¹²⁵ Standing Committee on Law and Justice, Report 40, p 51.

Support Scheme participants and allied health workers and professionals and, if necessary, seek an amendment to the *Motor Accidents (Lifetime Care and Support) Act 2006*.

That the Lifetime Care and Support Authority create and facilitate a participant and family carers working group that can support the participant representative on the Lifetime Care and Support Advisory Council.¹²⁶

- 3.50** The NSW Government subsequently advised the Committee that the LTCSA was enthusiastic about having participant representation on the LTCSAC and proposed the inclusion of two participant representatives.¹²⁷
- 3.51** With regard to allied health representation on the Council, the NSW Government indicated that it did not view this recommendation as necessary. It noted that the LTCSAC membership as set out by the Act already includes two health practitioners and two representatives concerned with the treatment, rehabilitation and care of injured people.¹²⁸
- 3.52** In the Third Review, the Chair of the LTCSAC, Mr Douglas Herd, stated that the Scheme was still in its early stage and for many participants it has been a relatively short time since they were injured. It is only now that the participant base was becoming ‘mature enough in their journey... to begin to express a desire to participate in the oversight of the agency’. Mr Herd said that he expected that within approximately 12 months, participants would be directly represented on the Council.¹²⁹
- 3.53** In its *Third Review Report*, the Committee encouraged the LTCSA to commit to the recommendation contained in the *Second Review Report* that the Authority establish a participant working group to support participant and family carer representatives on the Council.¹³⁰
- 3.54** In the current review, Spinal Cord Injuries Australia called for participant representatives to be included on the Council ‘as soon as possible’.¹³¹ Its submission explained that the representation of participants on the Council will likely ‘expedite the resolution of any problems raised by participants in the overall running of the Scheme.’¹³²
- 3.55** The LTCSA has advised the Committee that it supports the plans for participant representation on the Council and that these will be implemented when the Act is next amended.¹³³ This is substantively the same answer as provided by the LTCSAC in last year’s review.¹³⁴

¹²⁶ Standing Committee on Law and Justice, Report 40, p 54.

¹²⁷ NSW Government, Government Response to the Standing Committee on Law and Justice, *Second Review of the Lifetime Care and Support Authority and the Lifetime Care and Support Advisory Council*, Report 40, September 2009, p 2.

¹²⁸ NSW Government response to the Standing Committee on Law and Justice, Report 40, p 2.

¹²⁹ Mr Herd, Evidence, 11 June 2010, p 17.

¹³⁰ Standing Committee on Law and Justice, Report 45, p 32.

¹³¹ Submission 11, Spinal Cord Injuries Australia, p 4.

¹³² Submission 11, p 4.

¹³³ Answers to pre-hearing questions on notice 29 September 2011, LTCSA, Question 5, p 3.

¹³⁴ Mr Herd, Evidence, 11 June 2010, p 57.

- 3.56** In evidence provided to the Committee this year, Mr Herd explained that, given the relative infancy of the Scheme, it could be challenging to find adult participants who are at a stage in their rehabilitation where they are ready to become advocates.

Adults who are going through [the Scheme] with severe spinal cord injury or brain injury may be at the moment little more than, at the most, two or three years away from injury and representation in a democratic forum to present a point of view is not necessarily uppermost in one's mind at that stage on the rehabilitation path.¹³⁵

- 3.57** Nevertheless, Mr Herd also acknowledged that participant representation on the Council is important to pursue because it will establish 'a very direct connection between the advice we give to the Authority' and the participants in the Scheme.¹³⁶

Committee comment

- 3.58** The Committee notes that in order to change the makeup of the LTCSAC, a legislative amendment is required. The LTCSA has confirmed that participant representation would be included when changes are next made to the Act.

- 3.59** However, the Committee notes that the LTCSA provided the same advice in last year's review and there has now been a significant delay in getting participants onto the Council, and acknowledges stakeholder concerns in this regard. The Committee therefore recommends that the Government pursue a stand-alone amendment to the Act in order to expedite participant representation on the Council, which could include a family member or carer of a brain injured participant.

- 3.60** While participant representation has not yet been formalised, the Committee maintains that supporting participant representatives on the Advisory Council through a working group is important. Accordingly, the Committee supports the recommendation contained in the *Second Review Report*, and reiterated in the *Third Review Report*, that the LTCSA establish a support group when participant representatives have, via legislative amendment, been included in the LTCSAC.

Recommendation 2

That the Government pursue a stand-alone amendment to section 45 of the *Motor Accidents (Lifetime Care and Support) Act 2006* to include two participant representatives on the Lifetime Care and Support Advisory Council.

¹³⁵ Mr Herd, Evidence, 11 June 2010, p 57.

¹³⁶ Mr Herd, Evidence, 11 June 2010, p 57.

Chapter 4 **Entry into the Scheme, opting-out of the Scheme and dispute resolution**

This chapter examines a number of issues raised by stakeholders in the current review including entry into and opting out of the Scheme, the assessment tools used to determine medical eligibility for the Scheme and new eligibility criteria for people with amputations. Access to independent advice and legal advocacy, review of decisions and dispute resolution mechanisms are also examined. Some of these issues were raised in the Committee's past reviews and have been identified as issues of ongoing concern.

Opting-out of the Scheme and greater self management of care

- 4.1 A recurring theme in the Committee's past reviews has been consideration of whether participant's should be given the choice to opt-out of the Scheme and instead receive a lump sum payment to cover the cost of their ongoing care. This issue and consideration of methods to provide participants with greater capacity to manage their own care were each raised again in the present review.

Consent

- 4.2 In the First Review, the NSW Law Society suggested that the absence of a provision to enable participants to completely opt-out of the Scheme fails to respect participants' rights.¹³⁷ The Australian Lawyers Alliance (ALA) and the NSW Law Society have recommended that section 8(2) of the *Motor Accidents (Lifetime Care and Support) Act 2006* should be repealed, a step which would effectively make the Scheme voluntary.
- 4.3 In the current Review, the ALA again recommended that section 8(2) be repealed. Although the submission noted that a vote to amend the Act to require a claimant's consent to participate in the Scheme was defeated in the Legislative Council in 2006, the ALA nevertheless urged the Committee to consider again the repeal of the section.¹³⁸

Implementation of an option for participants to opt-out and self-manage care

- 4.4 In its submission to the present review, the NSW Law Society acknowledged that some participants were satisfied with the operation of the Scheme, but noted that others 'continue to take the view that they are better off opting-out of the Scheme.' The submission stated that:

Participants' choice needs to be respected and under the current provisions it is not. The [Law Society's Injury Compensation] Committee recognises that for some people, participation in the Scheme does work, and for those people the right choice is to remain with it.¹³⁹

¹³⁷ 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*, Report 37, October 2008, pp 40-41.

¹³⁸ Submission 7, Australian Lawyers Alliance, p 6.

¹³⁹ Submission 16, Law Society of NSW, p 11.

- 4.5** Ms Danielle De Paoli, a member of the Law Society’s Injury Compensation Committee, provided some examples of people who might want to opt-out:

The classic example is people who are quadriplegics. They are in the Scheme, they have their full capacity to understand the decisions that they are making. They have not sustained brain injuries and they are capable of looking after themselves.... It [the Scheme] does not afford them the independence they rightly deserve and that they rightly want.¹⁴⁰

- 4.6** Ms De Paoli added that opting-out of the Scheme should occur only where appropriate safeguards are in place. In their view, these would include ensuring that any person who wishes to opt-out has the mental capacity to make an informed decision and understands the ramifications of doing so. In addition, the Society stated that it should not be possible for a participant to opt-out merely because they are frustrated with the bureaucracy or operation of the Scheme.¹⁴¹
- 4.7** Other stakeholders echoed this view. The Physical Disability Council of NSW, for example, suggested that the LTCSA should provide ‘mechanisms that facilitate personalized budgets and self-directed funding’ and provide greater opportunities for self-management of care.¹⁴²
- 4.8** Similarly, SCIA stated that having to follow strict guidelines and explain every detail through an authority in order to receive necessary treatment and services ‘means people feel like they have no independence’.¹⁴³ In this regard SCIA recommended that monthly payments to individuals should be considered in lieu of individual approval of services.¹⁴⁴
- 4.9** The Committee’s previous reviews have highlighted that some Scheme participants are also very keen to see a method for opting-out of the Scheme or for self-managed care to be implemented. For example, Mr Mark Harris, a Scheme participant with a spinal cord injury, has argued strongly in support of giving mentally competent participants the opportunity to exit the Scheme and manage their own care.¹⁴⁵ Mr Harris, together with his wife Mrs Nicky Harris and his father, Mr David Harris, appeared before the Committee during the Third Review and have again voiced their concerns in submissions to the present review.¹⁴⁶
- 4.10** Mr Mark Harris told the Committee during its Third Review that the delays in having his requests processed and approved caused unnecessary frustration and upset, for himself and his family.¹⁴⁷ The joint submission of Mr and Mrs Harris to the Committee this year stated:

I am still left feeling like I have to fight to get anything out of LTCSA and this means that they have now and will always have control over my life. I am sick and tired of

¹⁴⁰ Ms Danielle De Paoli, Member, Law Society Injury Compensation Committee, New South Wales Law Society, Evidence, 10 October 2011, p 6.

¹⁴¹ Ms De Paoli, Evidence, 10 October 2011, p 6.

¹⁴² Submission 12, Physical Disability Council of NSW, p 4.

¹⁴³ Submission 11, Spinal Cord Injuries Australia, p 5.

¹⁴⁴ Submission 11, p 5.

¹⁴⁵ 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*, Report 45, November 2010, p 36.

¹⁴⁶ Submission 3, Mr David Harris; and Submission 4, Mr and Mrs Mark Harris, pp 1-2.

¹⁴⁷ Standing Committee on Law and Justice, Report 45, p 36.

arguing with the LTCSA and having to share every personal detail with them. All I want is to have control of my own life and not have the added stress of dealing with LTCSA, as life in a wheelchair is hard enough.¹⁴⁸

- 4.11** Mr Mark Harris' father, Mr David Harris, also made a submission to the present review to request that the Act be amended to enable a lump sum payments to be made to Scheme participants who choose to opt-out. Like the Law Society, Mr David Harris acknowledged that 'it may be that it will be considered necessary to place some restrictions on how a lump sum payment is used or invested'.¹⁴⁹
- 4.12** However, the view that there should be an 'opt-out' provision in the Act is not unanimously held. For example, submission to the present review from a number of medical specialists stated that while a participant's short term needs may be relatively predictable, long term needs are not clear in many cases. In relation to brain injured participants in particular, these medical specialists expressed the view that 'the current arrangements where people cannot "opt-out"... should continue.'¹⁵⁰
- 4.13** Greater self-management of care and supporting participant choice in general is an important element of *Stronger Together: A new direction for disability services in NSW (Stronger Together II)*, the NSW Government's disability services strategy, the second phase of which commences this year. In its submission, National Disability Services stated that the Committee's Review should be conducted with the focus and direction of *Stronger Together II* in mind.¹⁵¹
- 4.14** National Disability Services (NDS) note that, under *Stronger Together II*, 'all individualised, portable funding arrangements[s] will become available to all people with disability receiving disability services by the end of 2012/14'. NDS acknowledges that the LTCS Scheme is based on a similar model and encourages the Scheme to adapt to the 'broader paradigm shift' towards more 'person-centred' approaches.¹⁵²
- 4.15** The Law Society of NSW suggested that where a participant has a brain injury but wishes to opt-out of the Scheme, a judge should be required to determine whether that person can opt-out and ensure appropriate safeguards are in place:

In instances where there is a severe brain injury a Judge should be required to give approval for any opting-out of the Scheme. The Judge will likely want to be informed during this process of the views of any guardian or tutor. The Judge will want to make sure that the Scheme participant has sought appropriate advice on opting-out and that an appropriate financial management order is in place.¹⁵³

- 4.16** The Executive Director of the LTCSA, David Bowen, explained during the Committee's last review that a great deal of consideration was given to an opt-out clause when the Act

¹⁴⁸ Submission 4, p 2.

¹⁴⁹ Submission 3, p 1.

¹⁵⁰ Submission 19, medical specialists, p 2.

¹⁵¹ Submission 10, National Disability Services, p 4.

¹⁵² Submission 10, p 4.

¹⁵³ Answers to supplementary questions 15 November 2011, Ms Danielle De Paoli, Law Society of NSW, Question 3, p 2.

establishing the Scheme was first introduced to Parliament.¹⁵⁴ He noted that other compensation schemes have moved away from allocating lump sum payments and cited the example of a worker's compensation claim, where claimants receive a periodic payment for care and support rather than a lump sum amount.¹⁵⁵

4.17 Mr Bowen advised the Committee that principles of self-management and individual funding underlie section 6(3) of the Act, which permits the LTCSA to enter into arrangements with Scheme participants to manage their own care.¹⁵⁶ That is, the LTCSA can assess the value of care for a period of time and negotiate appropriate periodic payments.

4.18 The Chair of the Lifetime Care and Support Advisory Council, Mr Douglas Herd, noted that the experience of other jurisdictions had shown that, even where an option for self-management is available, less than 10 per cent of participants will adopt it. He explained that this is because of the demands of managing fulltime care.

...all the evidence we have from Australian and overseas jurisdictions about the direct funded option... is that less than 10 per cent of clients will ever take up that option. Not because they have any kind of ideological disagreement with it, it is just that it becomes all consuming...for most people who do it, they think this is how I want to live my life, but most of the people do not do it and it is the overwhelming number that recognize that it is very time consuming. You have to act as if you own a small business employing quite a large number of casual employees.¹⁵⁷

4.19 The LTCSA has not yet implemented section 6(3) and as such, self-management is not currently possible under the Scheme. In the First Review, The LTCSA advised that it was developing a process to implement section 6(3) of the Act which provides for the LTCSA to enter into an agreement with a participant to allow them to self-manage their care.¹⁵⁸ This process remains ongoing and has been expedited by a recent ruling of the Australian Taxation Office.

Australian Taxation Office Ruling on taxation of LTCS payments

4.20 In the 2010 review of the LTCSA, the Authority informed the Committee that it was in the process of developing guidelines to allow participants to receive periodic payments. It explained that this process had been delayed while it sought a class ruling from the Australian Taxation Office (ATO) to ensure that any payments made to participants to manage their own care are not regarded as income for taxation purposes.

4.21 In the present review, the Authority advised the Committee that its application for a taxation class ruling was filed in January 2011¹⁵⁹ and that an ATO ruling had been finalized in October

¹⁵⁴ Indeed, during the establishment of the LTCS Scheme, lump sum payments for life were considered but ultimately ruled out. It was found that for many people who were awarded such a payment, the funds were depleted well before their lifetime forcing them to seek financial support elsewhere: Standing Committee on Law and Justice, Report 45, p 40.

¹⁵⁵ Standing Committee on Law and Justice, Report 45, p 40.

¹⁵⁶ Standing Committee on Law and Justice, Report 45, p 40.

¹⁵⁷ Mr Douglas Herd, Chair, LTCSAC, Evidence, 17 October 2011, p 55.

¹⁵⁸ Standing Committee on Law and Justice, Report 37, p 41.

¹⁵⁹ Answers to pre-hearing questions on notice, LTCSA, 29 September 2011, Questions 19 and 20, pp 9-10.

2011. The ruling stipulated that, subject to certain conditions, payments from the LTCSA to individual participants who chose to manage their own care will not be subject to taxation.¹⁶⁰

- 4.22** The tax exemption is conditional. In order for a periodic payment from the Authority to a participant to attract an income tax exemption, the participant will need to enter into agreement with the LTCSA that specifies that the funds will be spent exclusively on their care and support needs. In addition, participants cannot employ a family member and any unspent funds must be returned to the Authority.¹⁶¹ Other obligations on the participant which form part of the agreement include that he or she must maintain the money provided by the LTCSA in a separate bank account and must keep receipts for every single item of expenditure.¹⁶²
- 4.23** Prior to the ATO ruling, and as a first step, the Authority obtained an exemption for payments for self-purchasing from the income test under social security law.¹⁶³ This means that a person's social security income would not be affected because that person also receives periodic payments to fund their care and support through the LTCSA.
- 4.24** The LTCSA further explained that the guidelines to govern how participant's can manage their own care through periodic payments to fund approved services are still being developed. Thus, periodic payments cannot presently be offered to participants although the Authority is working towards this. The Authority's final draft of the legal agreement that would exist between the LTCSA and a participant wanting to take up the self-purchase option, appears at Appendix 4.

Committee comment

- 4.25** The issue of providing some participants with a lump sum payment for life was given thorough consideration when the Scheme was first proposed but ultimately ruled out. Indeed, one of the primary rationales for establishing the Scheme was to address the serious risks involved with managing large sums of money over long periods of time. This includes the accompanying risk that, however carefully it is calculated, the lump sum payment may not last for a person's entire life. These concerns ultimately led to the establishment of the LTCS Scheme.
- 4.26** The Committee reiterates the conclusion reached in its Third Review that it is not clear whether providing participants with the ability to opt-out of the Scheme is in the best interests of their lifelong care and treatment and that it is, in fact, contrary to the Scheme's rationale.
- 4.27** In this regard, the Committee notes that the ATO ruling has opened the door for subsection 6(3) of the Act to be implemented. As outlined above, that section permits the LTCSA to enter into an agreement with a participant to allow them to self-manage their care through appropriate periodic payments.

¹⁶⁰ Mr David Bowen, Executive Director, LTCSA, Evidence, 17 October 2011, p 50.

¹⁶¹ Mr Bowen, Evidence, 17 October 2011, p 53.

¹⁶² Answers to questions on notice taken during evidence 17 October 2011, LTCSA, attachment 2, pp 6-7. The full text of the ATO's decision can be found on the ATO's website, accessed 28 November 2011, <<http://law.ato.gov.au/atolaw/view.htm?docid=CLR/CR201185/NAT/ATO/00001>>.

¹⁶³ Answers to pre-hearing questions on notice, LTCSA, 29 September 2011, Questions 19 and 20, p 9.

- 4.28** The Committee also notes the concerns of Mr Herd that for some participants, self-management of care would be akin to managing a small business with a number of casual employees, and that for most participants the option to self-manage care will not be taken up. However, the Committee is also mindful that the option to self-manage care is important in order to respect the autonomy of participants.
- 4.29** On the other hand, the capacity to self-manage care is an option that some participants are crying out for. The Committee's notes that improved participant choice has been a recurring theme in this review and underpins the second phase of the NSW Government's overarching disability strategy.
- 4.30** The Committee hopes that the self-management option (when it is made available) will prove an appropriate alternative to fully opting-out. The Committee commits to monitoring the implementation of the self-management option in its next review of the LTCS Scheme.

Medical eligibility criteria and assessment tools

- 4.31** As outlined in Chapter 2, eligibility for the Scheme is based upon the satisfaction of two criteria: the relevant injury must have been the result of a registered motor vehicle accident, and must be of a type and severity of injury covered by the Scheme. The latter criterion is determined by medical assessment.¹⁶⁴
- 4.32** This section examines stakeholder concerns regarding eligibility criteria for participation in the LTCS Scheme and focuses especially on medical assessment. Consideration is given to the tools for conducting, and the timing of, the medical assessment. This section also describes new eligibility criteria for people who have had amputations.

Previous reviews

- 4.33** The Functional Index Measure (FIM) for adults and WeeFIM for children, which measures whether a person is independent in an activity or requires assistance, is the main tool used to assess medical eligibility to enter the LTCS Scheme.¹⁶⁵
- 4.34** In the Third Review, the Committee noted that the medical assessment tools used to assess eligibility for the Scheme had neither changed nor been evaluated since the commencement of the Scheme in 2006. Accordingly, and notwithstanding the LTCS' assertion that these tools remain adequate, the Committee recommended that the LTCSA conduct an evaluation of the medical assessment tools and report on any alternative and/or additional tools that may be appropriately used, including the Paediatric Care and Needs Scale.¹⁶⁶
- 4.35** In the present review, the LTCSA reported that it has not conducted a formal evaluation of the assessment criteria and that the Authority continues to use the FIM to assess eligibility. It added that no other appropriate measures have been identified by the Authority.

¹⁶⁴ Standing Committee on Law and Justice, Report 37, p 7.

¹⁶⁵ Standing Committee on Law and Justice, Report 40, p 28.

¹⁶⁶ Standing Committee on Law and Justice, Report 45, p 48.

- 4.36** The Authority also utilises specific eligibility criteria set out for the different injuries covered by the Scheme. For example, in relation to traumatic brain injury, post traumatic amnesia scores are often not available at the time eligibility is being determined due to the person being in a coma or affected by medication. As such, the Authority has introduced the additional criterion of significant impact to the head or significant brain imaging abnormality where those PTA scores are unavailable.¹⁶⁷ A detailed explanation of Scheme eligibility can be found in the *First Review Report*.¹⁶⁸
- 4.37** The LTCSA has recently revised the eligibility criteria for people who have had amputations as a result of a motor vehicle accident. The Authority explained that these criteria had been revised to resolve ambiguity and to specify the types of amputations that will make a person eligible for the Scheme for the benefit of stakeholders. The revisions also propose the expansion of eligibility criteria to include specific types of unilateral amputations. The revisions were undertaken in consultation with a number of stakeholders including health and legal specialists.¹⁶⁹

Stakeholder views

- 4.38** During the First Review, the Brain Injury Rehabilitation Directorate (BIRD) raised issues relating to Scheme eligibility and the tools used to assess medical eligibility criteria. Specifically, BIRD suggested that the medical assessment tools used to assess eligibility need to be evaluated. At the time, the LTCSA suggested that any evaluation should take place after more participants had entered the Scheme and had gone on to be assessed for lifetime participation.¹⁷⁰
- 4.39** The Committee followed up on this issue as part of the Second Review, during which the LTCSA advised that, while an evaluation had not taken place, the medical tools used to assess potential participants were working well. Nevertheless, the LTCSA suggested that it was receptive to other objective and reliable assessment tools as an alternative to the Functional Independence Measure (FIM).¹⁷¹
- 4.40** As part of the Second Review, the Department of Rehabilitation at the Children's Hospital at Westmead raised concerns about the limitations of the WeeFIM assessment tool in determining lifetime participation for children with brain injuries and suggested that the Paediatric Care and Needs Scale (PCANS) for 5-18 year olds be used as an additional tool to aid in this assessment. The LTCSA advised that, at the time, an evaluation of the PCANS tool was one of their current research projects.¹⁷²

¹⁶⁷ Answers to pre-hearing questions on notice, LTCSA, 29 September 2011, Question 13, pp 6-7.

¹⁶⁸ Standing Committee on Law and Justice, Report 37, pp 7-8.

¹⁶⁹ Answers to pre-hearing questions on notice, LTCSA, 29 September 2011, Question 11, pp 5-6. A copy of the updated guidelines is available on the LTCSA website, accessed 14 October 2011: <http://www.lifetimecare.nsw.gov.au/Draft_eligibility_criteria_for_amputations/News.aspx>.

¹⁷⁰ Standing Committee on Law and Justice, Report 37, p 36.

¹⁷¹ Standing Committee on Law and Justice, Report 40, p 28.

¹⁷² Standing Committee on Law and Justice, Report 40, p 28.

- 4.41** In the present review, the Authority advised the Committee that while the PCANS has been ‘evaluated and validated with Australian normative data’, it is ‘not a suitable assessment to be used as a threshold test for eligibility to the Scheme’.¹⁷³
- 4.42** During the present review, BIRD noted that eligibility can be dictated by the time at which a person is assessed and expressed concern that this results in some injured people being unfairly prejudiced. BIRD explained that people who initially have a very severe injury but improve quite quickly can miss out on interim participation in the Scheme if they are not assessed soon after their initial injury. On the other hand, someone with similar injuries who is assessed quickly might qualify for interim participation. The effect of this is that the person who was assessed sooner receives two years of paid treatment and care and the other person does not.
- [The problem is that]... those who have a neurological impairment of a very severe injury and yet improve rapidly... get in the Scheme, if they are assessed early, and [for others] if their application is delayed by two or three months [they] will not get into the Scheme, even though they have similar injuries. This may not be a problem if they then exit the Scheme after the two year interim, but it certainly produces inequity when you have two people with fairly similar injuries, one who can have two years of treatment and care and one who does not.¹⁷⁴
- 4.43** The BIRD further explained that the acute treating team need to be aware of the implications of eligibility for lifetime care and support through the Scheme to prompt them to conduct the assessment. In this regard, it was suggested that there may be insufficient knowledge of the Scheme in the medical community, including in acute care.¹⁷⁵ The issue of knowledge of the LTCS Scheme among medical professionals is examined further in Chapter 5.

Amended eligibility criteria for people who have had amputations

- 4.44** The LTCSA outlined that it had revised the eligibility criteria for people who have had amputations. It explained that the criteria have been revised to resolve ambiguity and to specify the types of amputations that are eligible for the Scheme.¹⁷⁶
- 4.45** The Authority consulted with stakeholders on the revised criteria including representatives from academia, medical specialists and the legal community. The Authority reported that the feedback from stakeholders generally agreed that the FIM was not a useful measure for Scheme eligibility for people who have had amputations.¹⁷⁷
- 4.46** The revisions to the eligibility criteria propose their expansion for specific types of unilateral amputations. Among those expansions of the criteria is the inclusion for eligibility of people who have had unilateral hindquarter amputation and unilateral hip disarticulation. The

¹⁷³ Answers to pre-hearing questions on notice, LTCSA, 29 September 2011, Question 14, p 7.

¹⁷⁴ Dr Adeline Hodgkinson, Rehabilitation Physician, Brain Injury Rehabilitation Unit, Liverpool Hospital, Evidence, 17 October 2011, p 4.

¹⁷⁵ Dr Hodgkinson, Evidence, 17 October 2011, pp 4-5.

¹⁷⁶ Answers to pre-hearing questions on notice, LTCSA, 29 September 2011, Question 11, pp 5-6.

¹⁷⁷ Answers to pre-hearing questions on notice, LTCSA, 29 September 2011, Question 11, pp 5-6.

Authority advised the Committee, that the stakeholders with which it consulted agreed that these should be included.¹⁷⁸

- 4.47 The revised eligibility criteria remain at a draft stage.

Committee comment

- 4.48 In the Third Review, the Committee recommended that the LTCSA evaluate the current medical assessment tools used to assess eligibility criteria and investigate and report on any alternative and/or additional tools that may appropriately be used, including PCANS.
- 4.49 The Committee appreciates that the LTCSA has now evaluated the PCANS as a method for determining eligibility for children and determined it an inappropriate tool, but notes that the Authority has not conducted an evaluation of its other tools for assessing eligibility.
- 4.50 This is especially concerning in the context of potential situations of inequity in eligibility described by BIRD. These include the complications of pre-existing medical conditions including in relation to mental health and that eligibility can be adversely affected by the time at which the assessment is conducted.
- 4.51 The Committee recommends, therefore, that the LTCSA evaluate the current medical assessment tools used to assess eligibility criteria, and investigate and report on any alternative and/or additional tools or strategies that may be appropriately be used to avoid inequity in Scheme eligibility. The Authority should consult with stakeholders during this process.

Recommendation 3

That the Lifetime Care and Support Authority evaluate the current medical assessment tools used to assess eligibility criteria, and investigate and report on any alternative and/or additional tools or strategies that may be appropriately used to avoid inequity in Scheme eligibility. The Authority should consult with stakeholders during this process.

- 4.52 The Committee will monitor the implementation of the revised eligibility criteria for people who have had amputations.

Access to independent legal advice and advocacy

Previous reviews

- 4.53 In response to the Committee's *First Review Report*,¹⁷⁹ the LTCSA prepared a discussion paper, in consultation with the LTCSAC and various stakeholders, on the provision of advocacy

¹⁷⁸ Answers to pre-hearing questions on notice, LTCSA, 29 September 2011, Question 11, pp 5-6.

¹⁷⁹ Standing Committee on Law and Justice, Report 37, p 55.

services to Scheme participants.¹⁸⁰ During its Second Review, the Committee was advised that following the release of the discussion paper, the LTCSAC determined that a well-established disability advocacy network already existed, which Scheme participants could access. The LTCSA concurred and stated that a new advocacy body was not necessary due to the existing advocacy services available.

- 4.54** In response to specific concerns about brain injured participants accessing advocacy services, the LTCSA commented that it would include information in training sessions for service providers about how participants can access advocacy services. Nevertheless, in its *Second Review Report* the Committee expressed its continued concern about the ability of brain injured participants to initiate contact with advocacy groups and encouraged the LTCSA to further consider the issue.¹⁸¹
- 4.55** During the Third Review of the Scheme, the LTCSA advised the Committee that more information about advocacy, including a fact sheet, has been published on its website. The LTCSA had been in touch with a number of advocacy groups, including the NSW Disability Authority Advocacy Network, to explain the Scheme and to inform them that information about their services have been disseminated to the Scheme's participants. In addition, the Authority circulated a paper on the provision of advocacy services to participants in the Scheme.¹⁸²

Stakeholder views

- 4.56** In its submission to the present review, the Physical Disability Council of NSW commended the LTCSA for improvement in its provision of information on access to community based advocacy services to participants.¹⁸³ However, it is apparent from other stakeholder comments that the initiatives undertaken by the LTCSA were inadequate to allay all stakeholder concerns.
- 4.57** In its submission to the present review, the ALA acknowledged the information on advocacy services published by the Authority but noted again the lack of *legal* advocacy services nominated.¹⁸⁴ The ALA argued that legal advice and advocacy is especially important for participants in the Scheme in order that they properly understand their rights under the Scheme and the implications of LTCSA decisions.¹⁸⁵ The ALA provided the following example:

It is not realistic to expect, for example, the non-English speaking parents of a catastrophically injured child to be able to fully understand, let alone draw up submissions in relation to, any inadequacy in a care plan developed by an assessor.¹⁸⁶

¹⁸⁰ NSW Government, Government Response to the Standing Committee on Law and Justice, *Review of the Lifetime Care and Support Authority and the Lifetime Care and Support Advisory Council*, Report 37, October 2008, p 2.

¹⁸¹ Standing Committee on Law and Justice, Report 40, p 22.

¹⁸² Standing Committee on Law and Justice, Report 45, p 56.

¹⁸³ Submission 12, p 5.

¹⁸⁴ Submission 7, pp 2-3.

¹⁸⁵ Submission 7, p 2.

¹⁸⁶ Submission 7, p 2.

4.58 The primary concerns of both the ALA and the Law Society in this regard relate to the operations of sections 18 and 29 of the Act. In their view, these sections restrict access to legal services by providing that costs are not payable for legal services in connection with referral of a matter for a determination nor in respect of treatment and care needs assessment.¹⁸⁷ Both the ALA and the Law Society assert that participants should be allowed legal costs under the Act.

4.59 The Law Society of NSW stated that it finds it ‘extraordinary’ that legal costs are not payable by the LTCSA, particularly given that people who are catastrophically injured are especially vulnerable. It further noted that:

If ever there was a vulnerable group that required access to legal advice and representation, it is those who have suffered injuries that are so catastrophic that they qualify as participants in the Scheme.¹⁸⁸

4.60 Moreover, the Law Society stated, not only are the participants vulnerable, but the legal issues associated with disputes under the LTCS Scheme are indeed complex. The Society noted that the Act itself ‘contains some 68 sections, including three Schedules and is the subject of a range of Guidelines relevant to decisions made in accordance’ with the Act.¹⁸⁹ In this context, the Society argued, specialist legal advice is important to ensure that participants understand their rights:

Thorough knowledge of both Acts, associated Regulations and Guidelines is required in order to make informed choices and exercise rights under the Lifetime Care Act. Participants cannot possibly possess such knowledge.¹⁹⁰

4.61 The ALA commented positively on the introduction of the Accident Advice Support Grant in 2008. The grant provides a one-off payment of up to \$5000 to fund legal and accident investigation advice.¹⁹¹ However, the ALA also submitted that this amount is not enough and reiterated its concern that section 18 of the Act effectively restricts access to legal advice.¹⁹²

4.62 During the Third Review, and in response to stakeholder concerns, the LTCSA noted that the sections of the Act referred to by the ALA relate to medical decisions and that legal costs are in fact recoverable for disputes about whether an accident was a motor vehicle accident:

Sections 18 and 29 address decisions about medical or clinical issues, not legal issues, for example the level of function of the injured person, whether the injured person has a permanent neurological deficit or whether a participant requires speech therapy. Whether the accident was a “motor accident” is a legal question and legal costs are recoverable for disputes about these questions.¹⁹³

4.63 At the time, the LTCSA informed the Committee that, while participants are able instruct lawyers to assist with disputes, it generally did not consider it necessary for participants to seek

¹⁸⁷ Submission 7, p 2.

¹⁸⁸ Submission 16, p 9.

¹⁸⁹ Submission 16, p 9.

¹⁹⁰ Submission 16, p 9.

¹⁹¹ Submission 7, p 2.

¹⁹² Submission 7, p 2.

¹⁹³ Answers to pre-hearing questions on notice, LTCSA, 29 September 2011, Question 17, p 16.

legal assistance for disputes about treatment and care on account of the dispute's complexity. Moreover, in the view of the Authority, such disputes 'are not essentially legal disputes'.¹⁹⁴

- 4.64** In its submission to the present review and in response to the above comments of the LTCSA, the Law Society of NSW expressed the view that whether the LTCSA considers the disputes as 'legal' in nature is not relevant to whether a participant might want or require legal advice. Moreover, the Law Society submitted, the statement that disputes do not involve legal issues is mistaken:

The statement that the disputes do not involve legal issues is extraordinary given that the rights and obligations established by the Act, and the exercise and review of those rights, are by their very nature "legal issues" and complex ones at that.¹⁹⁵

- 4.65** The Law Society added that the limited access to legal advice provided for under the Scheme 'becomes of greater significance because the Scheme does not provide for external, independent, review of decisions.' It added that the LTCS Scheme 'eliminates' scrutiny of its decisions by permitting only internal mechanisms for review and that the non-payment of legal costs 'reinforces this position'.¹⁹⁶ Dispute resolution mechanisms are considered in the next section of this Chapter.

Committee comment

- 4.66** The Committee acknowledges the work undertaken by LTCSA to provide more information to participants about advocacy networks and services. The LTCSA has shown in this regard that it is responsive to the concerns of stakeholders and has taken steps to improve access to advice and advocacy services.
- 4.67** The Committee recognises the importance of ensuring that participant's and their carers understand their legal rights. As stated in the Third Review, the Committee recognises that the Accident Advice Support Grant has improved access to legal advice and accident investigation advice by Scheme participants. However, the Committee is mindful of the ALA's concern that the cap of \$5000 could render the grant inadequate.
- 4.68** The Committee is of the view that the LTCSA should review the adequacy of the Accident Advice Support Grant on an annual basis and at minimum annually increase the grant to meet increases in the Consumer Price Index.

Recommendation 4

That the Lifetime Care and Support Authority should review the adequacy of the Accident Advice Support Grant on an annual basis and at minimum annually increase the grant to meet increases in the Consumer Price Index.

¹⁹⁴ Standing Committee on Law and Justice, Report 45, p 52.

¹⁹⁵ Submission 16, pp 9-10.

¹⁹⁶ Submission 16, p 9.

- 4.69** The Committee also acknowledges the concerns that legal costs incurred for disputes about eligibility and treatment, rehabilitation and care are not recoverable under the Scheme. The LTCSA has previously advised that such disputes rarely require legal assistance. The Committee will monitor whether this remains the case as the Scheme continues to grow.
- 4.70** The Committee encourages the LTCSA to work with the ALA and the Law Society on these issues and to continue its efforts to ensure that participants are aware of their legal rights and obligations and also of the organisations from which they can receive legal advice.

Review of decisions and dispute resolution

- 4.71** Stakeholders again raised a number of concerns about the adequacy of the dispute resolution processes of the LTCS Scheme, in particular, whether the mechanisms are sufficient and independent.

Review mechanisms

- 4.72** As described in Chapter 2, the LTCSA is under a legislative obligation to provide mechanisms for the review of decisions relating to participation in the Scheme where an applicant or participant does not agree with the LTCSA's decision. The LTCSA provides these mechanisms in two distinct areas: eligibility (including what is deemed a 'motor accident injury') and treatment, rehabilitation and care needs.

Eligibility to enter the LTCS Scheme

- 4.73** Decisions about eligibility involve determining whether a participant satisfies the severe injury criteria to participate in the Scheme and/or whether their injury is appropriately classified as a 'motor accident injury'. Decisions about the former are based on a medical assessment.¹⁹⁷
- 4.74** As outlined in the *Third Review Report*, where an applicant disagrees with an LTCSA decision about their medical eligibility, that person may lodge a formal dispute with the Authority. Once received, the LTCSA refers the dispute to an Assessment Panel.¹⁹⁸ Each Assessment Panel is made up of three dispute assessors who are appointed by the LTCSA¹⁹⁹ and are trained medical and allied health professionals.
- 4.75** If an applicant seeks to appeal a decision made by an Assessment Panel, the dispute can be referred to a Review Panel of three different dispute assessors.²⁰⁰ A referral to a Review Panel can occur only where that claim meets one of the grounds for review under the Act. These are where:
- there has been a change in the condition of the injured person
 - additional relevant information about the injury has become available
 - the determination was not made in accordance with LTCS guidelines; or

¹⁹⁷ Standing Committee on Law and Justice, Report 45, p 49

¹⁹⁸ *Motor Accidents (Lifetime Care and Support) Act 2006* s 14.

¹⁹⁹ *Motor Accidents (Lifetime Care and Support) Act 2006* s 13.

²⁰⁰ Standing Committee on Law and Justice, Report 45, p 49.

- the determination is demonstrably incorrect in a material respect.²⁰¹
- 4.76 A decision of a Review Panel is final and legally binding²⁰² and there are no further avenues for appeal under the Scheme.
- 4.77 Determinations as to whether the injury suffered was a ‘motor accident injury’ are another type of decision about eligibility and relate specifically to whether an injury arises from a ‘motor accident’. This is a legal decision and a matter of determining whether the motor accident or motor vehicle meets definitions under the *Motor Accidents Compensation Act 1999*.
- 4.78 Disputes about whether a person’s injury is a ‘motor accident injury’ are referred to the Principal Claims Assessor of the Motor Accidents Authority (MAA), who will convene and appoint a panel of three claims assessors to determine the matter.²⁰³
- 4.79 Because disputes about ‘motor accident injury’ are about the interpretation of law, the panel of claims assessors is comprised of legal professionals with experience in personal injury claims. Once made, the panel’s decision is final and legally binding.²⁰⁴

Treatment, rehabilitation and care needs

- 4.80 A decision about the treatment, rehabilitation and care needs of an individual participant involves a determination of whether the services sought are ‘reasonable and necessary’ in the circumstances.²⁰⁵ ‘Treatment and care needs’ is a phrase defined in the Act. According to that definition, such needs include services such as medical treatment, and rehabilitation but also extend to include domestic assistance, education and vocational training, modifications to the home, vehicle, workplace and educational facility.²⁰⁶
- 4.81 Where a participant disagrees with a decision of the LTCSA over the treatment, rehabilitation and care needs for which it will pay, in the first instance, the participant may ask the LTCSA to arrange for another staff member to review the decision.²⁰⁷ This is considered an informal approach to resolving the matter as the LTCSA may contact other people involved with the participant to discuss the issues and agree on solutions together.²⁰⁸
- 4.82 If the issue is not resolved participants may lodge a dispute in writing within 28 days from the date the assessment is received. The dispute will be referred to a single dispute assessor.²⁰⁹ That assessor is not an employee of the LTCSA but is appointed to the role by the Authority in accordance with the Act. The Act also requires that each assessor is a health professional or other suitably qualified person.²¹⁰

²⁰¹ *Motor Accidents (Lifetime Care and Support) Act 2006* s 15.

²⁰² *Motor Accidents (Lifetime Care and Support) Act 2006* s 16.

²⁰³ Standing Committee on Law and Justice, Report 45, p 49.

²⁰⁴ Standing Committee on Law and Justice, Report 45, p 49.

²⁰⁵ *Motor Accidents (Lifetime Care and Support) Act 2006* s 23.

²⁰⁶ *Motor Accidents (Lifetime Care and Support) Act 2006* s 6(2).

²⁰⁷ Standing Committee on Law and Justice, Report 45, p 50.

²⁰⁸ Standing Committee on Law and Justice, Report 45, pp 49-50.

²⁰⁹ Standing Committee on Law and Justice, Report 45, pp 49-50.

²¹⁰ *Motor Accidents (Lifetime Care and Support) Act 2006* s 24(3)

Issues raised by stakeholders

- 4.83** In the *First Review Report*, the Committee recommended that the LTCSA and LTCSAC formally consider the range of options available to applicants and participants wishing to dispute a decision about their eligibility, or treatment, rehabilitation and care needs, with a view to recommending the preferred option for both.²¹¹ In response, the NSW Government stated that a ‘robust independent review system’ was built into the LTCS Scheme.²¹² Nevertheless, in the Second Review stakeholders again expressed concern about the dispute resolution mechanisms including how they operate for brain injured participants.²¹³ In the *Second Review Report*, the Committee acknowledged the specific difficulties for brain injured participants in engaging these processes and encouraged the LTCSA to further consider the issue.²¹⁴
- 4.84** During both the Third and the current reviews, stakeholders suggested that the dispute resolution processes available under the Scheme still required improvement. In particular, questions have been raised about the independence of these processes.
- 4.85** In the present review, the NSW Law Society echoed the concerns it expressed in the Third Review²¹⁵ that, because the LTCSA itself appoints the dispute assessors, the dispute resolution process is not truly independent. The Law Society states in its submission that the Authority has minimised accountability by denying participants a right to appeal LTCSA decisions to an external review body. It further stated that the reality for participants is that there is no ‘meaningful and transparent review process in place’ and recommends that a method for external review should be incorporated into the Act:
- The independent tribunal established by the Lifetime Care and Support Authority is not truly independent. It is supported and [remunerated] by the Authority... The Committee submits that a system of external review needs to be incorporated into the Lifetime Care Act.²¹⁶
- 4.86** Similarly, the Australian Lawyers Association reiterated its concerns that there is no right of appeal on the merits to an external body:
- The scheme does not provide for a right of appeal on the merits of a decision to any body external to the Authority. The ALA submits that this is major weakness of the scheme and inherently unjust.²¹⁷
- 4.87** In previous reviews, the LTCSA has defended its dispute resolution system, explaining to the Committee that its dispute assessors are independent professionals with a range of experience

²¹¹ Standing Committee on Law and Justice, Report 37, p 55.

²¹² NSW Government, Government Response to the Standing Committee on Law and Justice, *Review of the Lifetime Care and Support Authority and the Lifetime Care and Support Advisory Council*, Report 37, October 2008, p 1.

²¹³ 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*, Report 40, September 2009, pp 20-22.

²¹⁴ Standing Committee on Law and Justice, Report 40, p 22.

²¹⁵ Submission 11, p 4.

²¹⁶ Ms De Paoli, Evidence, 10 October 2011, p 8.

²¹⁷ Submission 7, p 4.

in medicine, health and rehabilitation.²¹⁸ The LTCSA has also expressed its view that it is ‘vital’ that disputes about treatment and care needs are resolved by professionals with backgrounds in health or medicine.²¹⁹

- 4.88** In its submission to the current review, the BIRD again made a recommendation as to how the dispute resolution processes could be improved. It noted that it is common for people with a traumatic brain injury to rely on the staff of the NSW Brain Injury Rehabilitation Program to advocate on their behalf when services are needed.²²⁰ In this context, the BIRD has suggested that where treatment decisions cannot be agreed, ‘an external process needs to be available’.
- 4.89** The BIRD explained that it envisions that referral of a disagreement about treatment decisions to an external professional would be a useful step prior to the escalation of a dispute to the formal dispute resolution processes.²²¹ A similar suggestion was put forward by the BIRD in the Third Review.²²²

Committee comment

- 4.90** The Committee notes the concerns expressed by the Australian Lawyers Alliance over the extent to which the LTCSA’s dispute resolution mechanisms are independent from the Authority. Indeed, the LTCSA does appoint its own dispute assessors, although it does so from a selection of external professionals.
- 4.91** The Committee appreciates the BIRD’s suggestion that the Scheme would benefit from the introduction of a referral process whereby disagreements between the LTCSA and the treating clinicians as to treatment and care needs should be referred at first instance to an external reviewer.
- 4.92** The Committee sees value in pursuing the BIRD’s idea that referral of a disagreement about treatment decisions to an external professional prior to the escalation of a dispute to the formal dispute resolution processes. This is especially so in the context of an ongoing concern about brain injured participants’ ability to exercise a right to review LTCSA decisions as outlined in the Second and Third Reviews.²²³ Accordingly, the Committee encourages the LTCSA to work with the BIRD to consider the merits of the BIRD’s idea for initial referral of disputes to an external professional.

²¹⁸ Standing Committee on Law and Justice, Report 45, p 51.

²¹⁹ Standing Committee on Law and Justice, Report 45, p 51.

²²⁰ Submission 14, NSW Agency for Clinical Innovation, p 9.

²²¹ Submission 14, p 9.

²²² Standing Committee on Law and Justice, Report 45, pp 52-53.

²²³ Standing Committee on Law and Justice, Report 45, p 54.

Recommendation 5

That the Lifetime Care and Support Authority work with the Brain Injury Rehabilitation Directorate and other stakeholders to examine the feasibility of a more robust and independent dispute resolution process for disputes concerning eligibility and treatment.

Chapter 5 Administration of the Scheme

In this Chapter the Committee outlines issues raised by stakeholders in relation to various aspects of the LTCS Scheme's administration. These include the administrative and resource burden on service providers, the approval process for treatment, rehabilitation and care services, privacy concerns and the Scheme's renewed focus on community based care. This Chapter also looks at issues raised in relation to LTCS Coordinators, who play a vital function in the Scheme's provision of treatment and care. Many of the issues examined in this Chapter are related and some continue from the Committee's previous Reviews.

The administrative burden

Issues raised in previous reviews

- 5.1** Stakeholder concerns regarding the administrative burden of the LTCS Scheme were considered by the Committee in its First Review of the LTCSA. In particular, the Committee received evidence regarding the volume of paperwork that participants and clinicians must complete. At the time, the Authority advised that it was undertaking several measures to streamline procedures.²²⁴ Notwithstanding some improvements in LTCS procedures for requesting treatment rehabilitation and care requests, stakeholders reiterated their concerns in the Second Review.²²⁵
- 5.2** During the Third Review, NSW Health completed its review of the impact of the LTCS Scheme on health resources and delivered its *Report on the NSW Health review of the impact of the Lifetime Care and Support Scheme*. The findings of the NSW Health review confirmed stakeholder concerns and found that there was a clear and significant impact on AHS service provision as a result of the LTCS Scheme, including an increase in administrative and clinical workload.
- 5.3** The NSW Health review stated that 'the greatest impacts to its system were related to administration associated with the Scheme. All respondents advised that the administrative burden had significantly reduced clinician time with patients.'²²⁶ The review also found that there was need for additional resources in the form of additional administrative and clinical staff to assist in meeting the needs of LTCS participants.²²⁷

²²⁴ 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*, Report 37, October 2008, pp 47-48.

²²⁵ NSW Legislative Council, Standing Committee on Law and Justice, *Second Review of the Lifetime Care and Support Authority and the Lifetime Care and Support Advisory Council*, Report 40, September 2009, pp 39-42.

²²⁶ 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*, Report 45, November 2010, p 65.

²²⁷ Standing Committee on Law and Justice, Report 45, p 64.

Stakeholder concerns raised in current Review

Paperwork

- 5.4 A number of stakeholders involved in the Committee's current Review acknowledged the work undertaken by the LTCSA to review and improve some of the Scheme's forms and processes. The streamlining of processes for the discharge of patients from hospital was mentioned particularly.²²⁸
- 5.5 The LTCSA advised that to further streamline its processes it has also developed a list of pre-approved equipment that can be prescribed directly by the relevant hospital without first having to seek approval from the Authority. Requests are required only for equipment that falls outside that list. The Authority also noted that, in addition, LTCS Coordinators are delegated to approve up to \$5,000 worth of services or equipment through a simplified process.²²⁹
- 5.6 Nevertheless, stakeholders reported a continuing administrative burden that was taking clinicians' time away from their patients. For example, the Brain Injury Rehabilitation Directorate (BIRD) estimates that LTCS paperwork amounted to a 25 per cent reduction in the amount of time clinicians can spend treating patients.²³⁰
- 5.7 The BIRD welcomed the improvements in discharge procedures undertaken by the LTCSA but noted that '[d]espite the expectation to do so, no other form has been reviewed collaboratively with us to reduce and simplify the administrative burden'.²³¹ In this regard, the BIRD called for further simplification and streamlining of forms.²³²
- 5.8 The Children's Hospital at Westmead also provided numerical estimates of the workload generated by the LTCS Scheme. In the Brain Injury Service at the Children's Hospital, the total number of patients currently receiving treatment is 533, of whom 32 are LTCS participants.²³³ The Hospital noted that LTCS Scheme participants are a small proportion of their patients and the administrative work in relation to their treatment takes up a disproportionate amount of clinicians' time.
- 5.9 In relation to future participants, the Children's Hospital at Westmead expects the number of LTCS participants it treats to increase by seven people per year. It noted that the relationship each patient has with the Hospital can last decades, for example, a participant who entered the Scheme as one year old in 2006 will continue to receive treatment from the Children's Hospital until they transfer to adult services in 2024.²³⁴ From the year 2024, the Children's

²²⁸ Dr Adeline Hodgkinson, Rehabilitation Physician, Brain Injury Rehabilitation Unit, Liverpool Hospital, Evidence, 17 October 2011, p 1; Associate Professor James Middleton, Director, Spinal Cord Injury Service, Evidence, 17 October 2011, p 7.

²²⁹ Mr David Bowen, Executive Director, Lifetime Care and Support Authority, Evidence, 17 October 2011, p 49.

²³⁰ Dr Hodgkinson, Evidence, 17 October 2011, p 1.

²³¹ Dr Hodgkinson, Evidence, 17 October 2011, p 1.

²³² Dr Hodgkinson, Evidence, 17 October 2011, p 8.

²³³ Answers to questions taken on notice during evidence 10 October 2011, The Children's Hospital at Westmead, Question 2, p 3.

²³⁴ Answers to questions taken on notice during evidence 10 October 2011, The Children's Hospital at Westmead, Question 2, p 3.

Hospital estimates that the number of LTCS participants it treats will stabilise at approximately 125 patients at any one time.²³⁵

- 5.10** Some stakeholders suggest that the administrative burden of the LTCS Scheme is compounded by a lack of transparency and consistency in LTCSA decision-making.²³⁶ The State Spinal Cord Injury Service pointed out that when decisions are not transparent it is not clear to clinicians how to better explain the need for the service or equipment. This can result in a great deal of to and fro between a clinician and the LTCSA with four or five requests for the same thing being rejected in turn ‘and it has not really clear why that has been’.²³⁷
- 5.11** The LTCSA explained that it is making efforts to streamline processes in order to minimise the additional work required, but will be unable to completely remove the administrative burden.²³⁸ In relation to the paper work required, Mr David Bowen, Executive Director of the Lifetime Care and Support Authority, stated that it is not ‘a big ask’ for the LTCSA to ask for written justification of programs which might cost as much as \$60,000 each.²³⁹ Moreover, he stated, it is a necessary question in order for the Authority to be able to approve the expenditure.²⁴⁰
- 5.12** With regards to ongoing efforts to minimise the administrative work involved with requests under the LTCS Scheme, Ms Lulham, Director of Service Delivery at the LTCSA, explained that the Authority will soon review the assessments for attendant care in the hope that this too would streamline processes.²⁴¹

Inability to access cumulative participant history

- 5.13** Some clinicians were frustrated over the inability of the LTCSA to access a participant’s cumulative history, as this means that information must be duplicated in each application for treatment and care needs. This concern related both to the administrative burden of the Scheme on clinicians, as well as being a cause of delay in approval processes (the latter is discussed in the next section).
- 5.14** This issue has been raised in previous reviews, where service providers have expressed frustration that the LTCSA does not have the capacity to draw on a participants’ cumulative medical history to consider requests for services or equipment.²⁴²
- 5.15** For service providers, the reproduction of a patient’s relevant medical history, and the collation of other detailed information required by the LTCSA, limits the amount of time clinicians can spend with other patients. This is especially so in situations where an initial request is rejected, there is a request for more information, the secondary request is rejected

²³⁵ Answers to questions taken on notice during evidence 10 October 2011, The Children’s Hospital at Westmead, Question 2, p 3.

²³⁶ Associate Professor Middleton, Evidence, 17 October 2011, p 7.

²³⁷ Associate Professor Middleton, Evidence, 17 October 2011, p 7.

²³⁸ Ms Suzanne Lulham, Director, Service Delivery, Lifetime Care and Support Authority, Evidence, 17 October 2011, p 52.

²³⁹ Mr Bowen, Evidence, 17 October 2011, p 52.

²⁴⁰ Mr Bowen, Evidence, 17 October 2011, p 52.

²⁴¹ Ms Lulham, Evidence, 17 October 2011, p 52.

²⁴² Standing Committee on Law and Justice, Report 45, p 75.

and there is a further request for more information and so on (also discussed below at paragraphs 5.26-5.34).²⁴³ This can mean that a service provider is spending a lengthy period of time on a single request.²⁴⁴

- 5.16** The LTCSA explained that while the Authority would continue to monitor the volume of information required for requests, it is nevertheless necessary that applications for treatment and care have sufficient detail in order to comply with legislative requirements and also to justify the relevant expenditure.²⁴⁵

Availability of work force

- 5.17** Both the Children's Hospital at Westmead and the Brain Injury Rehabilitation Program emphasised that staff are being stretched to their limits in order to treat participants.²⁴⁶ This is made worse by the administrative burden of the Scheme.

- 5.18** The Children's Hospital at Westmead explained that of the 32 LTCS participants currently receiving treatment from the Brain Injury Service at the Hospital, 40 per cent also have a staff member of the Hospital acting as their case manager.²⁴⁷ As the number of participants increase, the Children's Hospital predicts that its workload will become progressively more difficult to manage. It outlined the staffing difficulties as follows:

Considering the above numbers we would estimate that by 2024, our projected number of LTCSS participants seen in our Service would be 64 with 26 (40%) of those case managed within our department. With a ratio of 5 LTCS participants per FTE case managers, our required staffing for case managers in 2024 would be 5.2 FTE case managers (current staffing is 3.3 FTE case managers).²⁴⁸

Our budget for staffing is determined by the Sydney Children's Hospitals Network (Randwick and Westmead) within the NSW Ministry of Health. This budget is unlikely to increase over the coming years and thus our staffing numbers will remain static.²⁴⁹

- 5.19** The LTCSA itself expressed some concern about the capacity of the LTCS Scheme to cope as the number of participants reliably grows year to year. Indeed, Mr Bowen stated that the availability of work force is the single largest issue for the Scheme to monitor. He noted that '[i]t is an older work force. It is ageing. It is quite lowly paid and it is in a context where there

²⁴³ Dr Hodgkinson, Evidence, 17 October 2011, p 2.

²⁴⁴ Standing Committee on Law and Justice, Report 45, p 81.

²⁴⁵ Mr Bowen, Evidence, 17 October 2011, p 50; see also: Standing Committee on Law and Justice, Report 45, p 82; *Motor Accidents (Lifetime Care and Support) Act 2006*, s 6.

²⁴⁶ Dr Hodgkinson, Evidence, 17 October 2011, p 1; Ms Helene Chew, Coordinator, Brain Injury Service, Children's Hospital Westmead, Evidence, 10 October 2011, p 54.

²⁴⁷ Answers to questions taken on notice during evidence 10 October 2011, The Children's Hospital at Westmead, Question 2, p 3.

²⁴⁸ Answers to questions taken on notice during evidence 10 October 2011, The Children's Hospital at Westmead, Question 2, p 4.

²⁴⁹ Answers to questions taken on notice during evidence 10 October 2011, The Children's Hospital at Westmead, Question 2, p 5.

is likely to be a significant increase in demand.²⁵⁰ Mr Bowen added that workforce availability is especially concerning for participants who live in regional NSW.²⁵¹

- 5.20** In its report on the National Injury Insurance Scheme, the Productivity Commission has considered the capacity of the workforce to cope with care needs.²⁵² It suggested that both Commonwealth and State Governments need to consider more informal care arrangements. However, this solution would not address the apparent shortage of medical specialist service providers raised by some stakeholders.

Committee comment

- 5.21** The Committee recognises the importance of clinicians spending time with their patients rather than completing paperwork. The Committee notes with concern that the time that clinicians can spend with their patients is being eroded due to the administrative burden of completing LTCS forms. However, this concern needs to be balanced against the need to keep the LTCS Scheme operational by ensuring that it pays for only those treatment, rehabilitation and care services and equipment that are ‘reasonable and necessary’.
- 5.22** The Committee agrees with the LTCSA that paperwork cannot be eliminated altogether but we are also of the view that there is room for improved efficiency. In this regard we note the suggestion of the BIRD that more LTCS forms could be simplified and standardised.
- 5.23** The Committee therefore recommends that the LTCSA collaborate with the BIRD, SSCIS, Children’s Hospital at Westmead and other service providers to simplify forms with a view to minimising the duplication of information and limiting the administrative burden on service providers.
- 5.24** The Committee acknowledges that the future availability of workforce, particularly in attendant care, will be an ongoing and long-term issue for the LTCS Scheme. The Committee will remain apprised of the issue in future reviews and will monitor the approach taken by the federal Government if and when the National Injury Insurance Scheme is introduced.

Recommendation 6

That the Lifetime Care and Support Authority collaborate with the Brain Injury Rehabilitation Directorate, the State Spinal Cord Injury Service, the Children’s Hospital at Westmead and other service providers to simplify and standardise forms with a view to minimising the duplication of information and limiting the administrative burden on service providers.

²⁵⁰ Mr Bowen, Evidence, 17 October 2011, p 61.

²⁵¹ Mr Bowen, Evidence, 17 October 2011, p 51.

²⁵² Productivity Commission, *Disability Care and Support*, August 2011, Chapter 15.

Approval process for treatment, rehabilitation and care services

5.25 Scheme participants and some service providers raised concerns about delays in the LTCS Scheme. Concerns about two forms of delay were voiced especially. First, approval of treatment, rehabilitation and care services, and, second, delays in the approval of transitional accommodation so that people may leave hospital. The section below considers the first of these. The second issue is discussed in Chapter 6.

Delays in approval process

5.26 The *LTCS Guidelines* state that ‘the Authority will acknowledge all applications in writing within 10 working days of receipt of the complete Application Form’ and that ‘applicants will receive the Authority’s determination in writing, including reasons for the decision.’²⁵³

5.27 In the LTCSA’s first participant survey, minimising delay in the approval of and access to services was one of the key areas identified for improvement.²⁵⁴ Similarly, in the second and most recent participant survey, 28 per cent of participants surveyed stated that they had experienced a problem with LTCS services in the past three months.²⁵⁵ More than a third of those who experienced problems stated that these were related to a delay in the approval of access to services.²⁵⁶

5.28 Mrs Donna Axiak, the mother of a pediatric participant, explained the effect that a delayed or last-minute decision can have on the life of her family:

On one occasion in September last year, one current plan had concluded, the next plan although submitted had not yet been approved. I was terrified that Alana would have no care, could not go to school or therapies because we had not received approval for the next plan period. The deadline arrived – I arranged for time away from work, for grandparents to come and help out because if care wasn’t approved we would have to be there for Alana. Her not being able to go to school was the worst part...it was her only link to her old life.²⁵⁷

5.29 Other stakeholders share the view that approval processes are not always efficient. Spinal Cord Injuries Australia (SCIA) stated that the bureaucracy of the LTCS Scheme can be ‘very frustrating’ for participants and involve ‘lengthy’ processes.²⁵⁸

5.30 In the experience of Dr Adeline Hodgkinson, a rehabilitation physician at the Brain Injury Rehabilitation Unit at Liverpool Hospital, there have been many situations where the time frame for approval has, in practice, exceeded 10 days, notwithstanding each time the LTCSA provides a response at the conclusion of the 10 day period. Dr Hodgkinson explained that this delay disadvantages both the patient and the hospital:

²⁵³ LTCSA, *Lifetime Care and Support Guidelines*, 2010, Pt 1, p 7, accessed 7 November 2011 <www.lifetimecare.nsw.gov.au/Guidelines_and_Policies_for_Professionals.aspx>.

²⁵⁴ Standing Committee on Law and Justice, Report 45, p 75.

²⁵⁵ Answers to pre-hearing questions on notice, LTCSA, 29 September 2011, attachment 2, p 34.

²⁵⁶ Answers to pre-hearing questions on notice, LTCSA, 29 September 2011, attachment 2, p 35.

²⁵⁷ Submission 2, Mrs Donna Axiak, p 4.

²⁵⁸ Submission 11, Spinal Cord Injuries Australia, p 5.

If you can imagine, you put in a plan, you wait 10 days for the approval time and then there is further questions [sic], so you put in another review, another 10 days goes by and then another question and then finally you are able to see the way forward but what this has resulted in is a month to six weeks of delay before your proposed plan is approved and a patient kept in hospital that time is disadvantaged and it also disadvantages others who move through.²⁵⁹

- 5.31** Dr Hodgkinson also explained that sometimes, although the communication between the service provider and the LTCS Coordinator might be quite clear, difficulties can arise where that Coordinator provides the information back to a more senior approver at the LTCSA:

If our liaison is with the Lifetime Care Coordinator and we think we are explaining the situation and the context of it, all of that may not necessarily go into our paperwork which then is not seen, so what happens is there is a rejection despite what we have said and we have to come back and we have to put in words like “the difficulty with the patient’s gait and walking arises from his brain injury”... It is a matter of getting our words perfect and our submission perfect.²⁶⁰

- 5.32** The BIRD stated that there needs to be a reliable process for achieving a response faster than the 10 day turnaround time currently committed to by the Authority.²⁶¹ Dr Hodgkinson explained to the Committee that delay in approval of services can have very real implications for a person’s treatment because it delays their receipt of necessary services.²⁶² This includes situations where requests are repeatedly rejected before finally being approved.²⁶³
- 5.33** In this regard, NSW Health stated in its submission that it supports the recommendation contained in the Committee’s *Third Review Report* that the LTCSA should ensure that sufficient information as to the reasons why a particular form of treatment, rehabilitation or care is rejected.²⁶⁴ NSW Health also commended Enable NSW for the work it is doing to ‘ensure that consumers and prescribers have access to clear, consistent and transparent information about the eligibility criteria for the assistive technology devices it provides’ and for doing so through ‘extensive consultation with stakeholders’.²⁶⁵
- 5.34** In evidence, Ms Lulham noted that the Authority continues to work with Enable NSW to improve efficiencies for prescribed items such as wheelchairs.²⁶⁶ She also explained that the LTCSA meets the 10 day turnaround time that it commits to for the majority of requests.²⁶⁷

²⁵⁹ Dr Hodgkinson, Evidence, 17 October 2011, p 3.

²⁶⁰ Dr Hodgkinson, Evidence, 17 October 2011, p 8.

²⁶¹ Submission 14, NSW Agency for Clinical Innovation, p 9.

²⁶² Dr Hodgkinson, Evidence, 17 October 2011, p 8.

²⁶³ Dr Hodgkinson, Evidence, 17 October 2011, p 8.

²⁶⁴ Submission 5, NSW Health, p 1.

²⁶⁵ Submission 5, p 1.

²⁶⁶ Ms Lulham, Evidence, 17 October 2011, p 62.

²⁶⁷ Mr Bowen, Evidence, 17 October 2011, p 49.

Delays in delivery of equipment and services

- 5.35** In its *Third Review Report*, the Committee noted with concern that some participants experienced significant delays in receiving equipment. The Committee recommended that the LTCSA improve the process for interim equipment hire and consider the suggestion of accepting original equipment orders as justification for hire.
- 5.36** During the current review, the Authority confirmed that it ‘had always been willing to accept original equipment orders as justification for hire’ and that there has been only one instance where this did not occur.²⁶⁸
- 5.37** Although no stakeholders have again raised the issue of original equipment orders as justification for hire, several pointed to delays in the delivery of equipment and services. SCIA notes in its submission that people can be waiting up to twelve months for relatively simple equipment such as an adapted mouse for a computer. SCIA notes that for a person with quadriplegia, the delay in the provision of equipment can ultimately delay that individual’s independence.

If someone has acquired a serious spinal cord injury, then a timely turn-around in the approvals of aids and equipment is vitally important. People are waiting up to 12 months for things like adaptive computer aids such as a QuadJoy mouse. For someone with high level quadriplegia this can mean the difference in gaining some form of independence.²⁶⁹

- 5.38** Ms Lulham explained that delays are not always due to LTCSA processes. She stated that there might be a delay between when the script for equipment was issued and when that equipment was received, but that the LTCSA meets its commitment to provide a response within 10 days ‘the majority’ of the time.²⁷⁰ Ms Lulham also noted that the LTCSA is about to implement a process whereby items such as ‘continence products and scripts...will be routinely approved’.²⁷¹

Web based client management

- 5.39** In the context of alleviating delay and improving Scheme efficiency, the LTCSA was asked during the hearings whether it had considered the use of the web for client management. The Authority stated that it is already using voice over internet protocol to communicate with participants, particularly rural participants.²⁷² Ms Lulham explained that better use of web client management is something that the Authority is working towards but that she expects it will a few years before that will be fully in place. She also said ‘we do envisage a time where a participant will log on and just view all of their own information’.²⁷³

²⁶⁸ Answers to pre-hearing questions on notice, LTCSA, 29 September 2011, Question 30, p 14.

²⁶⁹ Submission 11, p 4.

²⁷⁰ Ms Lulham, Evidence, 17 October 2011, p 62.

²⁷¹ Ms Lulham, Evidence, 17 October 2011, p 62.

²⁷² Ms Lulham, Evidence, 17 October 2011, p 58.

²⁷³ Ms Lulham, Evidence, 17 October 2011, p 59.

- 5.40** In the meantime, and in order to improve the efficiency of the current system, Mr Bowen advised the Committee that the Authority is working towards streamlining processes including the availability of on-line applications for some services. The Authority aims to have that system in place sometime in 2012.²⁷⁴ The LTCSA is also planning to undertake a general review of its business processes next year in order to identify further efficiencies and ‘will plan further upgrades accordingly.’²⁷⁵

Committee comment

- 5.41** The Committee recognises that it is vital that Scheme participants receive necessary equipment and services in a timely manner. In this regard the Committee is disappointed that it continues to hear evidence of delays in the approval of requests from the LTCSA.
- 5.42** In the context of ongoing complaints of delay and overly-bureaucratic procedures, the Committee encourages the LTCSA to actively pursue the establishment of greater web management of client information where appropriate. The Committee further encourages the LTCSA to consider additional methods for expediting its processes, and supports the LTCSA’s work towards the better use of web-based client management platforms to this end. The Committee received limited evidence on this issue in the present review but commits to further consideration of it in future reviews.
- 5.43** The Committee acknowledges the need to reduce the amount of time clinicians and other stakeholders spend completing approval applications. The Committee hopes that the adoption of Recommendation 4 of this report with regard to the collaborative streamlining of forms will go some way towards limiting such delays.

Privacy and confidentiality

- 5.44** During the Third Review, concerns were raised by some stakeholders with regard to respect for the privacy and confidentiality of Scheme participants. For example, one stakeholder expressed dissatisfaction that the Scheme’s processes require participants to repeatedly and unnecessarily share personal information in order to have their requests processed.²⁷⁶
- 5.45** In the present review, Mrs Donna Axiak described in her submission that each assessment required by the LTCSA is intrusive, impinges on her daughter’s sense of well being, and leaves the family feeling vulnerable. In this regard, Mrs Axiak expressed her family’s desire to have a more efficient and less intrusive mechanism for assessment. She described that her family:

...sit in anticipation of the LTCS decision, of judgement. Alana’s life, our life is not only controlled by Alana’s brain injury and its subsequent effects but by Lifetime Care and the multiple assessments they require her to endure. We just seem to settle into a pattern, a routine that Alana is comfortable with and it’s time for a new Care Plan, therefore, bang! More assessments. Each time Alana participates in an assessment of some sort it reinforces her disabilities to her. Assessments are proof to Alana [of] what she is incapable of. I realise the best decisions for Alana can only be made by

²⁷⁴ Mr Bowen, Evidence, 17 October 2011, p 65.

²⁷⁵ Answers to questions taken on notice during evidence 17 October 2011, LTCSA, Question 3, p 2.

²⁷⁶ Standing Committee on Law and Justice, Report 45, p 83.

having the correct reading of her needs and ability however there has to be a more efficient and less intrusive way to achieve this outcome.²⁷⁷

5.46 The Children’s Hospital at Westmead noted the importance of confidentiality as the ‘foundation for a trusting therapeutic relationship’.²⁷⁸ The Hospital explained that clinicians necessarily gain a broad understanding of each family’s specific social and medical circumstances and that this assists clinical teams to make the most appropriate decisions for the child. Furthermore, this knowledge also guides the support for the family and community to which that child will ultimately return.²⁷⁹

5.47 The information imparted to clinicians in these circumstances is wide-ranging and can include very personal family situations such as the breakdown of relationships and mental health issues. The Children’s Hospital at Westmead explained that:

Information gleaned by health clinicians ranges from very specific personal responses to the child’s injury but extends quite significantly to the impact of the injury in relation to other social issues such as breakdown of relationships in the family, other family crises, mental health factors, child protection issues and financial strain.²⁸⁰

5.48 The Brain Injury Service at the Children’s Hospital at Westmead noted that it had experienced incidents in which the LTCSA had inappropriately sought ‘explicit detail of family social issues’ irrelevant to the service request. Similarly, the Hospital also stated that there are recent instances where case managers had also sought inappropriate information from the Service:²⁸¹

It has been the experience of The Brain Injury Service that the LTCSS has requested explicit detail of family social issues which the health clinician has determined not to be relevant to the service request.

There are recent incidences where LTCSS funded case managers have sought to influence the content of psychological interventions or requested inappropriately the minutiae of confidential therapeutic sessions.²⁸²

5.49 The Brain Injury Service at the Children’s Hospital at Westmead further stated that it was not its practice to divulge personal information of clients unless that information is relevant to a service request.²⁸³ Moreover, it noted, health professionals are bound by ethical requirements and privacy regulations as stipulated by the Ministry of Health and relevant professional

²⁷⁷ Submission 2, pp 3-4.

²⁷⁸ Answers to questions taken on notice during evidence 10 October 2011, The Children’s Hospital at Westmead, Question 1, p 1.

²⁷⁹ Answers to questions taken on notice during evidence 10 October 2011, The Children’s Hospital at Westmead, Question 1, p 1.

²⁸⁰ Answers to questions taken on notice during evidence 10 October 2011, The Children’s Hospital at Westmead, Question 1, p 1.

²⁸¹ Answers to questions taken on notice during evidence 10 October 2011, The Children’s Hospital at Westmead, Question 1, p 1.

²⁸² Answers to questions taken on notice during evidence 10 October 2011, The Children’s Hospital at Westmead, Question 1, p 1 [original emphasis].

²⁸³ Answers to questions taken on notice during evidence 10 October 2011, The Children’s Hospital at Westmead, Question 1, p 2.

associations.²⁸⁴ These obligations can be breached only where it is in the best interest of the child or family member or where it is necessary to ensure individual safety.²⁸⁵

5.50 The Brain Injury Service also alluded to situations where LTCS Coordinators or case managers have tried to influence the content of therapeutic counselling sessions in order to encourage a participant's acceptance of an LTCS decision.²⁸⁶ The Service expressed the strong view that it is not appropriate for this to occur:

...it is inappropriate for either Lifetime Care Coordinators or their funded Case Managers to specifically request that particular issues be addressed in therapeutic counselling sessions which aim to justify or encourage a participant's acceptance of a decision made by LTCSS to reduce or remove services. The content of therapeutic intervention is managed and agreed upon by the clinician and client.²⁸⁷

5.51 In this regard, the Brain Injury Service at the Children's Hospital at Westmead suggested that there may be some benefit in clarifying the role of the LTCS Scheme vis-à-vis the role of clinicians in the lives of participants.²⁸⁸

5.52 The Service also noted the inherent tension of the LTCS being both a manager of financial resources and at the same time the determinant of what is 'reasonable and necessary' in a participant's life. In the opinion of the Brain Injury Service, unlike the LTCSA, a patient's clinician must maintain a patient's trust in order to ensure the success of the provision of direct clinical services. It stated that 'there needs to be continued work between LTCSS and rehabilitation providers, public and private, regarding professional boundaries'.²⁸⁹

Committee comment

5.53 The Committee acknowledges that health clinicians at all acute treatment facilities develop a close relationship with the families of the people they treat. Indeed, these clinicians invariably have an intimate knowledge of family circumstances well beyond that directly related to the medical condition of the individual. Accordingly, privacy is a fundamental aspect of a person's treatment and care and is crucial to the success of any government assistance scheme.

5.54 The Committee notes with concern the comments of the Brain Injury Service at the Children's Hospital at Westmead that the LTCSA has requested explicit detail of family social issues and also the 'minutiae' of confidential therapeutic sessions. Although it is important that

²⁸⁴ Answers to questions taken on notice during evidence 10 October 2011, The Children's Hospital at Westmead, Question 1, p 2.

²⁸⁵ Answers to questions taken on notice during evidence 10 October 2011, The Children's Hospital at Westmead, Question 1, p 2.

²⁸⁶ Answers to questions taken on notice during evidence 10 October 2011, The Children's Hospital at Westmead, Question 1, p 2.

²⁸⁷ Answers to questions taken on notice during evidence 10 October 2011, The Children's Hospital at Westmead, Question 1, p 2.

²⁸⁸ Answers to questions taken on notice during evidence 10 October 2011, The Children's Hospital at Westmead, Question 1, p 2. Note that further discussion of possible second-guessing of clinical decisions by LTCS Coordinators is contained in Chapter 6.

²⁸⁹ Answers to questions taken on notice during evidence 10 October 2011, The Children's Hospital at Westmead, Question 2, p 4.

the LTCSA receives all the information it requires to make a decision, the collection of information needs to be appropriately limited. It is of the utmost importance that the LTCSA limit its requests for information to only that which is relevant to the request for treatment, care or rehabilitation needs which it may be considering. The Committee notes that the concerns of the Brain Injury Service at the Children's Hospital at Westmead elaborate on similar concerns raised during last year's review.

- 5.55** The Committee is mindful, however, that in the time available it was unable to seek a response and explanation from the LTCSA in relation to these concerns. The Committee encourages the LTCSA to ensure that it provides comprehensive training to its staff on appropriate and inappropriate requests for information and ensures that staff are aware of the privacy requirements of both the Ministry of Health and relevant professional associations. The Committee commits to reviewing this issue again in future reviews.

LTCS Coordinators

- 5.56** Issues relating to the role of LTCS Coordinators have been raised in all of the Committee's Reviews to date, including the present. An explanation of the role of LTCS Coordinators is provided in Chapter 2.
- 5.57** During the Committee's First Review the LTCSA advised the Committee of steps it had taken to clarify the role of Coordinators and provide them with additional training. In the *First Review Report* the Committee noted the important role of the LTCS Coordinators and that the Authority was responding to the concerns.²⁹⁰
- 5.58** During the Second Review, stakeholders advised the Committee of confusion about the role of the LTCS Coordinator, and expressed concern about the time at which Coordinators are introduced to potential participants and their families, particularly child participants. Concerns were also raised about inconsistencies in the application of the *LTCS Guidelines* by different Coordinators.²⁹¹
- 5.59** In its *Second Review Report*, the Committee noted that despite LTCSA efforts, some confusion about the role of the LTCS Coordinator remained. The Committee noted that this could be due to the relative infancy of the Scheme and the continuing growth of the number of participants and Coordinators. The Committee encouraged the LTCSA to continue to work with service providers to resolve this confusion. The Committee also recommended that the LTCSA consult with the treating rehabilitation team regarding the appropriate timing for the introduction of the LTCS Coordinator.²⁹²
- 5.60** In the Third Review, stakeholders stated that the knowledge of different Coordinators in relation to the Scheme was not consistent particularly in terms of their understanding of some specific disabilities such as brain injuries.²⁹³ Several stakeholders suggested that this could be remedied as a matter of further training.²⁹⁴ In response, the LTCSA expressed a willingness to

²⁹⁰ Standing Committee on Law and Justice, Report 37, pp 49-51.

²⁹¹ Standing Committee on Law and Justice, Report 40, pp 44-49.

²⁹² Standing Committee on Law and Justice, Report 40, pp 48-49.

²⁹³ Standing Committee on Law and Justice, Report 45, p 88.

²⁹⁴ Standing Committee on Law and Justice, Report 45, pp 88-89.

discuss the provision of further education and training for Coordinators and case managers.²⁹⁵ In addition, some stakeholders experienced difficulties in communicating with Coordinators.²⁹⁶

- 5.61** In the current Review, stakeholders again pointed to inconsistency in LTCS Coordinator decision-making and in the application of the guidelines by different Coordinators. Stakeholders also stated that the broad knowledge of Coordinators about the injuries participants have suffered was lacking and that further training might be required. In this regard, there was some recognition among stakeholders that recent training in spinal cord injuries undertaken by LTCS Coordinators was a positive step.²⁹⁷
- 5.62** Some stakeholders also observed an apparent ongoing tension between the clinical decisions of the treating team and the opinions of Coordinators. This is discussed further in Chapter 6.

Expertise and training of LTCS Coordinators

- 5.63** During the Third Review, the LTCSA advised the Committee that it was open to further discussion of the provision of education and training by SSCIS for Coordinators and case managers.²⁹⁸ An outcome of the resultant collaboration between the LTCSA and SSCIS was the July 2011 delivery by SSCIS of a training session for LTCS Coordinators and case managers on spinal cord injuries.²⁹⁹
- 5.64** Associate Professor James Middleton, Director of the SSCIS, stated that this was a very positive first step towards ensuring LTCS Coordinators and contractors are fully aware of some of the complex ongoing health needs of someone with a spinal cord injury.³⁰⁰ He also expressed his hope that this program would be the beginning of an ongoing program of training.
- 5.65** Professor Middleton noted in this regard that a spinal cord injury is unique in that it alters a person's entire physiology: '[it] is not just a physical impairment but the whole system changes that occur with a spinal cord injury and the ongoing impact of that in terms of risk of developing complications and trying to prevent those.'³⁰¹ Accordingly, he stated, there needs to be ongoing education in conjunction with a risk management approach to treatment incorporated into planning within the LTCS Scheme.³⁰² This view was supported by Spinal Cord Injuries Australia (SCIA).³⁰³

²⁹⁵ Standing Committee on Law and Justice, Report 45, pp 90.

²⁹⁶ Standing Committee on Law and Justice, Report 45, pp 86-91.

²⁹⁷ Associate Professor Middleton, Evidence, 17 October 2011, p 6; Mr Sean Lomas, Policy and Advocacy Manager, Spinal Cord Injuries Australia, Evidence, 17 October 2011, p 11.

²⁹⁸ Standing Committee on Law and Justice, Report 45, p 92.

²⁹⁹ Associate Professor Middleton, Evidence, 17 October 2011, p 6.

³⁰⁰ Associate Professor Middleton, Evidence, 17 October 2011, p 6.

³⁰¹ Associate Professor Middleton, Evidence, 17 October 2011, p 6.

³⁰² Associate Professor Middleton, Evidence, 17 October 2011, p 6.

³⁰³ Submission 11, p 5.

- 5.66** Mr Sean Lomas, Policy and Advocacy Manager at SCIA supported the idea of further training in spinal cord injuries for LTCS Coordinators. Although, he also stated that he was yet to see the benefits of the additional spinal cord injury training so far:

Dr Middleton certainly spoke about there being this new sort of training that is happening with regards to Lifetime Care Scheme case managers et cetera, to get them to understand the needs of people with spinal cord injuries. We have not seen the benefit of that yet. I am sure there are benefits which are happening which have been analysed enough to see that.³⁰⁴

- 5.67** In relation to the need for further training for LTCS Coordinators, the Authority pointed out that Coordinators already receive induction training³⁰⁵ and that it has also facilitated recent training on spinal cord injuries (mentioned above) provided by SSCIS. Mr Bowen, the Executive Director of the Authority, pointed out that many of the LTCSA staff come out of specialist units in hospitals and that nearly all Coordinators have allied health qualifications 'often to a higher level than the person who is putting the request in to them'.³⁰⁶ He explained staff come from a range of different backgrounds and include, among others, occupational therapists, physiotherapists, social workers and counselors.³⁰⁷

Communication

- 5.68** In the Third Review, stakeholders acknowledged the overall collaborative approach taken by the LTCSA in communicating with participants and clinicians, however, some also noted that it was at times difficult for participants to communicate with the Authority and more specifically with the Coordinators.³⁰⁸
- 5.69** In the present review the issue of communication has again risen to prominence in submissions and hearings. Stakeholders noted that communication between the LTCSA and participants, as well as between the LTCSA and clinicians, could be improved.³⁰⁹
- 5.70** For example, Mr Tony Jones, a Policy and Advocacy Officer from SCIA, was of the view that improved communication between LTCS Coordinators and case managers with the participants with whom they work would be valuable:

Improving communication between case managers and coordinators and the individuals they are assisting would help. These things always help. Often there is not enough communication in all services aimed at people with disability and this idea of person centred that we seem to be heading into now is a way of dealing with that in the future.³¹⁰

³⁰⁴ Mr Sean Lomas, Evidence, 17 October 2011, p 11.

³⁰⁵ Answers to pre-hearing questions on notice, LTCSA, 29 September 2011, Question 33, p 15.

³⁰⁶ Mr Bowen, Evidence, 17 October 2011, p 48.

³⁰⁷ Mr Bowen, Evidence, 17 October 2011, p 48.

³⁰⁸ Standing Committee on Law and Justice, Report 45, pp 89-91.

³⁰⁹ Standing Committee on Law and Justice, Report 45, pp 89-91.

³¹⁰ Mr Tony Jones, Policy and Advocacy Officer, Spinal Cord Injuries Australia, Evidence, 17 October 2011, p 11.

- 5.71** Some stakeholders provided personal examples to illustrate poor communication between the LTCSA and participants. For instance, Mrs Donna Axiak, the mother of a child participant in the Scheme, felt that communication between the LTCSA and her family was lacking. She noted in her submission that despite LTCSA documentation saying that she and her family would be visited by the LTCSA, no one from the Authority, including her daughter's appointed Coordinator, has ever met her daughter.³¹¹
- 5.72** Mr Mark Harris, a participant in the Scheme, also described difficulty communicating with his Coordinator. Mr Harris explained that he had found different Coordinators to be 'unresponsive' in getting back to him and other members of his family.³¹² He described situations where Coordinators had failed to attend meetings and also failed to keep him updated as to other important changes.³¹³
- 5.73** Some participant dissatisfaction in relation to communication with the LTCSA was also illustrated in the results of the most recent participant satisfaction survey. The results showed that more participants felt that the Authority could improve communication with participants than any other aspect of the Scheme.³¹⁴
- 5.74** In evidence to the Committee, and in response to the survey results, Ms Lulham, the Director of Service Delivery at the Authority, stated that the LTCSA is currently reviewing its internal processes for communicating with participants. The Authority is considering a system to ensure that each participant is contacted by the LTCSA within a minimum contact time, that is, monthly, six monthly or annually.³¹⁵
- 5.75** Service providers and non-government organisations also expressed frustration in communication from the LTCSA. For example, when asked by the Committee whether SCIA had put its idea about leisure and recreation activities to the Authority, the representatives of SCIA replied that it had, and that the Authority had not provided any meaningful response.³¹⁶ Mr Lomas stated that the kind of response that the SCIA receives is: "This is very interesting. We will take it into consideration. Thank you very much." That is if you get a response, and "goodbye".³¹⁷
- 5.76** Dr Hodgkinson from the BIRD commented that service providers hold regular meetings with LTCSA Coordinators but that these have not been as useful as the BIRD had hoped.³¹⁸ Similar views were expressed by Dr Joe Gurka, also a rehabilitation physician with the BIRD, who explained that when they raise issues with the LTCSA, they are listened to but then not a great deal happens in response to their concerns:

We get the perception that there [is] some lack of appreciation or lack of a full awareness of the issues that we face, because when they are raised they seemed to be

³¹¹ Submission 2, p 5.

³¹² Submission 4, Mr Mark Harris, p 1.

³¹³ Submission 4, p 1.

³¹⁴ Answers to pre-hearing questions on notice, LTCSA, 29 September 2011, attachment 2, p 42.

³¹⁵ Ms Lulham, Evidence, 17 October 2011, p 62.

³¹⁶ Mr Lomas, Evidence, 17 October 2011, p 10.

³¹⁷ Mr Lomas, Evidence, 17 October 2011, p 10.

³¹⁸ Dr Hodgkinson, Evidence, 17 October 2011, p 2.

listened to but then there is very little that happens in response to that, so we feel as though we need to have our message be heard.³¹⁹

- 5.77** Dr Gurka suggested ways to improve outcomes might include a workshop or brainstorming exercise but also suggested that might be something that clinicians could work out with the Authority directly.³²⁰ When questioned further about this idea, Dr Gurka explained that he wrote to the LTCSA to arrange a meeting some six weeks before the hearing and only very recently received a response. He hoped that this meeting would shortly be arranged to allow some of the specific concerns from Westmead Hospital to be addressed.³²¹
- 5.78** Dr Hodgkinson noted the LTCSA's commitment to reviewing its processes and expressed appreciation that the Authority routinely consults with clinicians on proposals to amend parts of the Scheme or guidelines. However, they also stated that such consultation often occurs in the final stages of policy development rather than in policy formulation and that this hinders true collaboration between clinicians and the LTCSA.³²²

Committee comment

- 5.79** The Committee notes that the relevant expertise of LTCS Coordinators was an issue given detailed consideration by the Committee in its Third Review. The Committee recommended in that report that the LTCSA review the suggestions made by stakeholders to improve the effectiveness of Coordinators.³²³ The Committee notes that the LTCSA has, on its own initiative, taken up a number of those suggestions and we applaud this proactive approach.
- 5.80** The Committee also commends the LTCSA in its responsiveness to the participant survey results and in working towards the instigation of a new system to ensure that the Authority retains adequate contact with participants. However, we encourage the Authority to give further consideration to the ongoing and specific participant concerns regarding effective communication with Coordinators.
- 5.81** Although the Committee has not received a great deal of information on the issue of communication with participants in the present review, it has been the subject of more detailed consideration in previous reviews. These factors combined with the results of the most recent participant survey indicate that there may be a more systemic issue which the LTCSA should investigate and the Committee urges the LTCSA to do so.
- 5.82** The Committee is encouraged by the willingness of the LTCSA to collaborate with clinicians on improvements to the Scheme. However, we are also concerned by some reports that the Authority may be merely paying lip service to some of the issues that clinicians have sought to address with it directly.

³¹⁹ Dr Joe Gurka, Rehabilitation Physician, ACI Brain Injury Program, Brain Injury Unit, Westmead Hospital, Evidence, 17 October 2011, p 3.

³²⁰ Dr Gurka, Evidence, 17 October 2011, p 3.

³²¹ Dr Gurka, Evidence, 17 October 2011, p 3.

³²² Dr Hodgkinson, Evidence, 17 October 2011, p 2.

³²³ Standing Committee on Law and Justice, Report 45, p 94.

- 5.83** The Committee recommends that the LTCSA take up the suggestion of Dr Joe Gurka and work with SSCIS and the BIRD directly to develop methods for improved communication between clinicians and the Authority and to put in place a system whereby clinicians receive meaningful responses to the concerns they raise.

Recommendation 7

That the Lifetime Care and Support Authority work with the State Spinal Cord Injury Service and the Brain Injury Rehabilitation Directorate directly to develop methods for improved communication between clinicians and the Authority and to act on the concerns of service providers and to put in place a system whereby clinicians receive meaningful responses to the concerns they raise.

Scheme priorities into the future: community based care

- 5.84** With each year of its operation, the number of people in the LTCS Scheme grows. Mr Bowen advised the Committee that, at any one time, there are approximately 50 participants receiving acute treatment in hospital and the remaining participants are living in the community. With more than 500 people currently in the Scheme and growing, the needs of participants living in the community are now the primary focus of the Authority.³²⁴
- 5.85** Mr Bowen advised the Committee that about 80 per cent of the cost of the Scheme is now dedicated to people in the community rather than acute services. However, he noted that service providers are also very ‘Sydney-centric’, in that most are located in or close to the city of Sydney. There is a more limited choice of service providers in other parts of NSW (as acknowledged in paragraph 5.19).³²⁵
- 5.86** The LTCSA stated that it had recently established a ‘co-regulatory arrangement’ with the Attendant Care Industry Association which requires all attendant care providers to be part of a new industry based quality accreditation program.³²⁶
- 5.87** However, National Disability Services argued in its submission that the requirements placed on organisations to become an approved care provider for the LTCSA are unnecessarily onerous and in fact deter service providers from involvement in the Scheme.³²⁷ In addition, the NDS reported that there does not seem to be adequate assessments of participants as their care needs change from acute to community-based care.³²⁸
- 5.88** In the context of community based care, Ms Fiona Davies, Chief Executive Officer of the Australian Medical Association (AMA) NSW, expressed concern that, in general, doctors specialising in general practice have a limited understanding of the LTCS Scheme.

³²⁴ Mr Bowen, Evidence, 17 October 2011, p 50.

³²⁵ Mr Bowen, Evidence, 17 October 2011, p 50.

³²⁶ Mr Bowen, Evidence, 17 October 2011, p 51.

³²⁷ Answers to supplementary questions 7 November 2011, National Disability Services, Question 5, p 6.

³²⁸ Submission 10, National Disability Services, p 5.

...there still seems to be a lack of understanding, and that is to be expected; it is not a Scheme that they would be required to interact with regularly...there would seem to be some benefit in providing better advice, particularly to general practitioners, who are often the patient's advocate- they are the first port of call when terrible accidents and impacts happen to families.³²⁹

- 5.89** Ms Davies further stated that in the context of the possible implementation of a federal National Injury Insurance Scheme (as discussed in Chapter 2) it would be both timely and useful to provide more information to GPs about the LTCS Scheme, which has informed the proposed federal model. Dr Adeline Hodgkinson a rehabilitation physician in the Brain Injury Rehabilitation Directorate agreed that there is insufficient knowledge in the medical community about eligibility and access criteria for the LTCS Scheme.³³⁰
- 5.90** In response, Ms Suzanne Lulham, Director of Service Delivery at the LTCSA acknowledged that the Authority does not have any targeted mechanisms to inform GPs about the Scheme. Ms Lulham explained that it is usually the role of the discharging medical team at the hospital to provide relevant information to the GP.³³¹ She added that there might be as many as 8,000 GPs in NSW and about only 500 participants living in the community.³³²
- 5.91** On the other hand, Mr Bowen noted that engagement with GPs will become increasingly important as more participants get stabilised in the community. With the Scheme still in its infancy, most participants are still going to their rehabilitation physician for treatment but over time this will change.³³³
- 5.92** In its evidence to the Committee, the AMA NSW suggested that it would be useful if it could work with the LTCSA on how best to get information to its members.³³⁴ The LTCSA expressed its willingness to work with the AMA to better inform GPs about the operation of the LTCS Scheme.³³⁵
- 5.93** As mentioned above, Dr Adeline Hodgkinson shared the view that there is insufficient knowledge of the LTCS Scheme in the wider medical community, but stated that this is also true of medical professionals working in acute care. Dr Hodgkinson outlined that it is especially important that the acute treating team are aware of the implications of eligibility for lifetime care and support through the Scheme (as also discussed in Chapter 4). This knowledge will prompt a treating team to conduct an assessment to determine if a person is eligible for the LTCS Scheme. The BIRD explained that the timing of an initial assessment for eligibility can affect that person's success in meeting the eligibility criteria. In this way, a treating team's knowledge of the Scheme can be critically important to an individual's ongoing care.³³⁶

³²⁹ Ms Fiona Davies, Chief Executive Officer, Australian Medication Association (NSW), Evidence, 10 October 2011, p 60.

³³⁰ Dr Hodgkinson, Evidence, 17 October 2011, p 5.

³³¹ Ms Lulham, Evidence, 17 October 2011, p 59.

³³² Ms Lulham, Evidence, 17 October 2011, p 60.

³³³ Mr Bowen, Evidence, 17 October 2011, p 60.

³³⁴ Ms Davies, Evidence 10 October 2011, p 60.

³³⁵ Ms Lulham, Evidence, 17 October 2011, p 60.

³³⁶ Dr Hodgkinson, Evidence, 17 October 2011, p 4.

Committee comment

- 5.94** Over the course of the next few years the LTCS Scheme is likely to be subject to additional pressures as the number of participants grows. In this context, the Committee will monitor carefully the concerns expressed by the Authority and by clinicians about the capacity of specialist staff to treat and care for participants as the number of Scheme participants increases and the number of staff does not.
- 5.95** The Committee notes the LTCSA's particular focus on community based care as the vast and increasing majority of participants move out of acute treatment and back into the community. The Committee also accepts the statements of the AMA and the BIRD that knowledge of the LTCS Scheme among GPs and acute treating teams is apparently limited. We are especially mindful that the knowledge of the Scheme among acute treating teams can, in some circumstances, have a determinative effect on whether a person receives support from the LTCS Scheme. The Committee therefore recommends that the LTCSA develop and then employ effective measures to better inform both GPs and acute treating teams of the LTCS Scheme and report to the Committee on these mechanisms in its next review.

Recommendation 8

That the Lifetime Care and Support Authority develop and then employ effective mechanisms to better inform both general practitioners and acute treating teams of the Lifetime Care and Support Scheme and report to the Committee on these mechanisms in its next review.

Chapter 6 Treatment, rehabilitation and care services

This Chapter considers the issues raised by stakeholders relating to the treatment, rehabilitation and care services provided to LTCSA Scheme participants. First, the requirement that services be ‘reasonable and necessary’ is examined followed by consideration of treatment decisions and participant choice. Issues identified in relation to accommodation are then explored, as is consideration of the *Carers Recognition Act 2010* and support for family carers. The Chapter concludes with a discussion of recreation and leisure activities and educational support for children.

‘Reasonable and necessary’ treatment and services

- 6.1 As described in Chapter 2, the LTCSA coordinates and pays for treatment, rehabilitation and care services that are ‘reasonable and necessary’ to meet the needs of participants as a result of their injury from a motor accident.
- 6.2 The LTCSA makes its decisions on a case by case basis and participants are advised that ‘you will get what you need – not things that are simply nice to have’.³³⁷ In determining whether a service is reasonable or necessary, a number of factors are considered, including:
- benefit to the participant
 - appropriateness of the service or request
 - appropriateness of the provider
 - relationship of the service or request to the participant’s injury, and
 - cost effectiveness considerations.³³⁸
- 6.3 In the Committee’s Third Review, a number of stakeholders called upon the LTCSA to clarify the meaning of ‘reasonable and necessary’ medical treatment, care and support. Concerns about the clarity of this phrase have again been raised again in the present Review.
- 6.4 Some Scheme participants expressed confusion and frustration about the decisions of the LTCSA as to what it will and will not pay for. Mr Greg Moore, a participant in the Scheme, describes his frustration at requesting services to promote his rehabilitation and independence and having those requests denied.³³⁹ He described having recently had his request to participate in a program that would include, among other things, ground to chair work, stretching and strengthening, balance, trunk control, coordination, motivation and rehabilitation more generally denied by the Scheme.³⁴⁰

³³⁷ LTCSA, What we pay for, accessed 2 November 2011
 <http://www.lifetimecare.nsw.gov.au/What_we_pay_for.aspx>.

³³⁸ LTCSA, Lifetime Care and Support Guidelines 2010 (hereafter referred to as ‘LTCS Guidelines’), Pt 6: Reasonable and Necessary Decision Making in the LTCS Scheme, accessed 30 October 2010,
 <www.lifetimecare.nsw.gov.au/Guidelines_and_Policies_for_Professionals.aspx>.

³³⁹ Submission 9, Mr Greg Moore, p 1.

³⁴⁰ Submission 9, p 1.

- 6.5 Mr Moore explained that he is especially frustrated by this denial because he is ‘extremely keen to promote [his] rehabilitation and become as independent as possible and regain an occupation as soon as possible’.³⁴¹
- 6.6 Similarly, Mrs Donna Axiak, the mother of a child participant in the Scheme, stated in her submission that she does not understand how the measurement ‘reasonable and necessary’ is applied and believes individual interpretation of the term could lead to its inconsistent application. She explains:
- I know what a metre is as I can see it, I know what a kilogram is because I can feel the weight but I am not able to tell what reasonable and necessary is. It is my concern that it is an abstract term that will have a different meaning depending on who is using it.³⁴²
- ...it seems that ‘deemed reasonable and necessary’ is a judgment call, an onerous decision open to one LTCS Coordinator’s individual interpretation and experiences, being applied to another person, often a child’s life which then in turn affects the wellbeing, physical, emotional and mental [wellbeing], of a whole family unit.³⁴³
- 6.7 Dr Adeline Hodgkinson, a rehabilitation physician at the Brain Injury Rehabilitation Unit at Liverpool Hospital, informed the Committee that some clinicians are still experiencing inconsistent decision making in response to requests made on behalf of patients.³⁴⁴ This issue was outlined in greater depth as part of the Third Review where, according to Kids Rehab, ‘[t]he decision making process does not allow understanding of what medical or rehabilitation basis a well documented and evidenced submission for a service is accepted or rejected’.³⁴⁵

Committee comment

- 6.8 The Committee acknowledges that some stakeholders remain frustrated with the apparent ambiguity of what is considered ‘reasonable and necessary’ treatment, rehabilitation and care services. The Committee notes that it has received considerably less information on this issue in the present review as compared to the Third Review.
- 6.9 As outlined in the Third Review Report, the Committee is reluctant to recommend that the LTCSA define specific services as being ‘reasonable and necessary’, because this could have the effect of limiting the operation of the Act. Accordingly, and notwithstanding the frustration of some stakeholders, the Committee remains of the view that the LTCSA’s current approach of making its decisions with consideration of the individual circumstances involved, is appropriate.³⁴⁶

³⁴¹ Submission 9, p 1.

³⁴² Submission 2, Mrs Donna Axiak, p 5 [original emphasis omitted].

³⁴³ Submission 2, p 5.

³⁴⁴ Dr Adeline Hodgkinson, Rehabilitation Physician, Brain Injury Rehabilitation Unit, Liverpool Hospital, Evidence, 17 October 2011, 2.

³⁴⁵ 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*, Report 45, November 2010, p 95.

³⁴⁶ Standing Committee on Law and Justice, Report 45, p 96.

- 6.10** However, the Committee encourages the LTCSA to do its utmost to provide consistency in its decision-making for ‘reasonable and necessary’ treatment, rehabilitation and care in order to ensure fairness to participants. In doing this, the Authority should ensure that the reasons it provides for rejecting an application for such services is sufficiently detailed to enable an applicant to understand the basis for the decision and where appropriate amend their application.

Treatment decisions

Participant choice

- 6.11** Focus on participant choice and ‘person-centred’ approaches to disability services are key elements of the second phase of the NSW Government’s disability services strategy, *Stronger Together*, which plans for services from 2011-2016 and have also been one of the themes of evidence to the Committee’s review.
- 6.12** National Disability Services (NDS) noted the concerns of its member organisations in this regard that the move to more ‘person-centred’ approaches in the disability sector generally has not been reflected in the LTCS Scheme:

Anecdotal evidence from disability service providers suggested to us that there is a fundamental conflict between the disability sector’s move toward person-centredness, and the current process-driven approaches to service provision experienced by disability service providers when implementing the LTCS Scheme.³⁴⁷

- 6.13** One participant in the Scheme, Mr Greg Moore, expressed his frustration with being subject to the opinions of ‘experts’ on what is best for him. He stated that:

I would like to see a more team like approach to my rehabilitation and an understanding that it is ‘my’ rehabilitation, I am grateful for the help and support [but] I am the ‘expert’ in my life.³⁴⁸

- 6.14** NDS’ member organisations have suggested that one method for improvement would be for the LTCSA to avoid ‘defining an individual’s needs by their injury’ alone.³⁴⁹ NDS pointed out that the disability sector is experiencing a broad ‘paradigm shift towards person-centred approaches, individualised funding and an emphasis on a lifespan approach.’³⁵⁰
- 6.15** Similarly, the Children’s Hospital at Westmead emphasised the importance of respecting the choices and goals of the participant and their family. A representative from the Hospital explained to the Committee that these goals and choices need to be afforded the ‘flexibility that family life demands’³⁵¹ and that without such flexibility, clinical decisions can be undermined.

³⁴⁷ Answers to supplementary questions 7 November 2011, National Disability Services, Question 1, p 3.

³⁴⁸ Submission 9, p 1.

³⁴⁹ Answers to supplementary questions 7 November 2011, National Disability Services, Question 1, p 3.

³⁵⁰ Answers to supplementary questions 7 November 2011, National Disability Services, Question 1, p 5.

³⁵¹ Ms Helene Chew, Coordinator, Brain Injury Service, The Children’s Hospital at Westmead, Evidence, 10 October 2011, p 55.

- 6.16** The LTCSA acknowledged that, in relation to attendant care services, participant choice is constrained in part by the limited availability of service providers and explained that the Authority is taking steps to improve that service capacity:

We put out a new tender last year and that was filled earlier this year, as a result of which the number of approved attendant care providers increased from 14 to 22... That means that [in] virtually every area of the State we can offer our participants a choice of approved attendant care provider, which is quite important.³⁵²

- 6.17** However, NDS advised the Committee that its member organisations have reported that the requirements for becoming an approved care provider for the LTCSA are unnecessarily onerous and in fact deter service providers from involvement in the Scheme.³⁵³ The NDS submission explained that ‘the upfront payment and time commitment’ that must be undertaken for a new organisation to become involved in the LTCS Scheme are a ‘significant disincentive’.³⁵⁴
- 6.18** NDS noted a substantial difference between the LTCSA approach and that taken by Ageing, Disability and Home Care (ADHC) within the NSW Department of Family and Community Services.³⁵⁵ It pointed out that attendant care through ADHC permits people to ‘self direct their services’.³⁵⁶

Committee comment

- 6.19** The Committee supports the spirit of the second phase of *Stronger Together* and, in particular, its emphasis on ensuring person-centred approaches to disability services. The Committee acknowledges that the LTCSA is working towards incorporating greater participant choice in the operation of the Scheme, including through the establishment of a system of periodic payments to those participants who would prefer to manage their own care (as discussed further in Chapter 4).³⁵⁷
- 6.20** The Committee also appreciates the concerns of NDS member organisations that the LTCS Scheme has not transitioned to an emphasis on participant choice as quickly or as completely as other disability services. On the other hand, the Committee also believes that the intensity of care for many lifetime care participants necessarily limits the scope and speed with which a complete paradigm shift in LTCS operation is possible.

³⁵² Mr David Bowen, Executive Director, Lifetime Care and Support Authority, Evidence, 17 October 2011, p 51.

³⁵³ Answers to supplementary questions 7 November 2011, National Disability Services, Question 5, p 6.

³⁵⁴ Answers to supplementary questions 7 November 2011, National Disability Services, Question 5, p 6.

³⁵⁵ Answers to supplementary questions 7 November 2011, National Disability Services, Question 5, p 6.

³⁵⁶ Answers to supplementary questions 7 November 2011, National Disability Services, Question 5, p 6.

³⁵⁷ Pursuant to subsection 6(3) of the Act and outlined in further detail in Chapter 4.

Second-guessing clinician decisions

- 6.21** In the Third Review, the State Spinal Cord Injury Service noted that the potential overlap between the role of clinicians and Coordinators can create real tension between the two.³⁵⁸ Similarly, the Royal Rehabilitation Centre Sydney noted the improvements in communication between Coordinators and case managers since the Scheme was first introduced, but observed that there were still areas of tension.³⁵⁹
- 6.22** In the present review, there was some stakeholder concern that this tension continues.³⁶⁰ Ms Martine Simons, a Senior Social Worker at the Children’s Hospital at Westmead, expressed concern that there are occasions when, however inadvertently, the LTCS Scheme has actually limited participant choice by second-guessing the treatment decisions made by the specialist treating team.³⁶¹ An example provided by Ms Simons was where an LTCS Coordinator has approached the family of a child participant and suggested, for example, that it might be time for that child to move out of hospital and into the community. Suggestions such as this, she suggests, have been made directly to the family without consultation with the clinicians about the participant’s care needs.³⁶²
- 6.23** Ms Helene Chew, Coordinator of the Brain Injury Service at the Children’s Hospital Westmead, explained that this practice limits a family’s choices because vulnerable families are easily directed onto particular paths by either the LTCS Coordinator or clinicians.³⁶³ Ms Simons elaborated that second-guessing of decisions of a treatment team can be ‘very destabilising’ for families and that:

[The families] are still recovering from the psychologically catastrophic nature of their child’s injury and the fact it will have long-term effects for that child’s life. They are coping with all of that. They are attending for treatment, they are receiving perhaps multiple treatments from our team-occupational therapy, physiotherapy, speech therapy, a combination of those things- and the funding body says “Oh, we think maybe that should change”.³⁶⁴

- 6.24** Ms Simons described how this could lead a family to become concerned that the treatment their child is receiving is not the most appropriate or that, if they do not act on the Coordinator’s suggestion, this could impact on the future care of their child.³⁶⁵
- 6.25** The Brain Injury Service recommended that, where there is disagreement on service delivery, including the most appropriate service provider for the participant’s treatment and care needs:

...the best outcome for participants comes when all parties can meet collaboratively to discuss the specifics of the issue:

³⁵⁸ Standing Committee on Law and Justice, Report 45, p 87.

³⁵⁹ Standing Committee on Law and Justice, Report 45, p 87.

³⁶⁰ Other areas of stakeholder concern regarding the role of LTCS Coordinators are discussed in Chapter 5.

³⁶¹ Ms Martine Simons, Senior Social Worker, Brain Injury Service, The Children’s Hospital Westmead, Evidence, 10 October 2011, p 52.

³⁶² Ms Simons, Evidence, 10 October 2011, p 52.

³⁶³ Ms Chew, Evidence, 10 October 2011, p 52.

³⁶⁴ Ms Simons, Evidence, 10 October 2011, p 52.

³⁶⁵ Ms Simons, Evidence, 10 October 2011, p 52.

- To determine if more information is required by the LTCSS to assist their decision making for requests for further or future services
- To ensure that the best rehabilitation planning can take place without compromising the dignity and privacy of the participant and family
- To ensure that the therapeutic relationship [of] clinical staff with the participant is not compromised
- To understand the rationale of LTCSS for wanting to change service provider when a therapeutic relationship already exists between participant and clinician.³⁶⁶

6.26 Mr Lomas from SCIA also noted that he had heard of LTCS Coordinators second-guessing clinician decision in the past, although not recently. He stated that ‘last year there were instances where we were hearing of Lifetime Care Scheme Coordinators going up against clinicians, which is deplorable.’ Mr Lomas explained that, in his view, the clinician has a better understanding of the physical situation of their patient.³⁶⁷

6.27 Mr Lomas added that he had also heard of instances where LTCS Coordinators have questioned a participant’s medication and that it is inappropriate for a Coordinator to have any input as to appropriate medication:

... this is not a debate which a Lifetime Care Scheme Coordinator should be involved in whatsoever, seeing the clinicians and the specialists are the people who are trained to do this to support the individual. It is not up to a Lifetime Coordinator to start talking about medication.³⁶⁸

6.28 The BIRD observed the effect that such second-guessing of clinician decisions can have on the clinicians themselves. Dr Hodgkinson noted that clinicians have been left feeling that their expertise and knowledge is not respected despite most having a ‘higher level’ of skill and experience than Coordinators:

The above frustrations and experiences have led to a general perception amongst staff working in the brain injury programs that their skills, expertise and knowledge of what is best for the clients is not well respected. Most clinicians working within our program have many years of brain injury experience leading to high levels of skill and knowledge, a level far outweighing that of the lifetime care and support coordinators. It is our view that some lifetime care and support decisions are in fact clinical decisions rather than administrative, which falls outside [the Coordinators’] role.³⁶⁹

6.29 In evidence to the Committee, Mr Bowen addressed the assertion that ‘the Authority somehow curtails clinical judgment.’³⁷⁰ He explained that LTCSA staff have a statutory responsibility to determine that the services requested are ‘reasonable and necessary’ before approving payment for them. Mr Bowen stated that the staff of the Authority ‘are very well qualified’ and that most have allied health qualifications ‘often at a higher level than the person

³⁶⁶ Answers to supplementary questions 3 November 2011, The Children’s Hospital at Westmead, Question 1, p 3.

³⁶⁷ Mr Sean Lomas, Policy and Advocacy Manager, Spinal Cord Injuries Australia, Evidence, 17 October 2011, p 14.

³⁶⁸ Mr Sean Lomas, Evidence, 17 October 2011, p 14.

³⁶⁹ Dr Hodgkinson, Evidence, 17 October 2011, p 2.

³⁷⁰ Mr Bowen, Evidence, 17 October 2011, p 48.

who is putting the request to them'.³⁷¹ Mr Bowen also pointed out that there is a discrepancy between what is prescribed for public patients and what is prescribed for LTCS Scheme participants:

It should be noted that in the context of medical and rehabilitation requests there is a significant discrepancy between what is prescribed by a clinician for public patients and what is often prescribed by clinicians for lifetime care and authority participants. When this occurs it is reasonable for the Authority to require a clinical justification for the higher level of service...³⁷²

- 6.30** During the hearing, the Committee queried whether it would be helpful for the LTCSA and the Children's Hospital at Westmead to establish a protocol to clarify that LTCS staff should first speak to clinicians before floating ideas with participants and their families. In relation to the Children's Hospital at Westmead, Ms Chew replied that although she had discussed her concerns in relation to individual cases with the LTCSA, the Hospital had not pursued the establishment of a protocol. She acknowledged that this is an idea worth exploring.³⁷³
- 6.31** In direct response to the concerns of the Children's Hospital at Westmead, Ms Lulham, Director of Service Delivery for the LTCSA, stated that the Authority already had quarterly meetings with the Children's Hospital but thinks that the establishment of a protocol between the Hospital and the LTCSA 'would be an excellent idea'.³⁷⁴

Committee comment

- 6.32** The Committee appreciates that the LTCSA is supported by a professional staff of LTCS Coordinators. The Committee also acknowledges that the relationship between treating clinicians, the participants and their families is important to ensure the most effective and appropriate care plans are developed. This is especially so in relation to the treatment of children.
- 6.33** Thus the Committee is concerned by the evidence from the Children's Hospital at Westmead that some LTCS Coordinators may be second-guessing the treatment recommendations of clinicians. This is problematic not only because it could damage the relationship between families and clinicians but also because it may be indicative of a broader communication breakdown between clinicians and the LTCSA in some circumstances.³⁷⁵
- 6.34** The Committee acknowledges that the LTCSA hires Coordinators with relevant skills and experience, but, notwithstanding the value of this prior experience to their role, this knowledge cannot replace the judgment of the medical professionals who are working directly with the participant. As such, the Committee recommends that the LTCSA ensure that it provides, as part of its induction training for LTCS Coordinators, information on respect for

³⁷¹ Mr Bowen, Evidence, 17 October 2011, p 48.

³⁷² Mr Bowen, Evidence, 17 October 2011, p 48.

³⁷³ Ms Chew, Evidence, 10 October 2011, p 53.

³⁷⁴ Ms Suzanne Lulham, Director, Service Delivery, Lifetime Care and Support Authority, Evidence, 17 October 2011, p 64.

³⁷⁵ Other stakeholder concerns regarding communication between LTCS Coordinators and clinicians are outlined in Chapter 5.

expert clinician decisions and treatment recommendations notwithstanding Coordinators' previous skills and experience.

- 6.35** The Committee notes also the particular concerns of the Children's Hospital at Westmead regarding some instances where Coordinators have made recommendations to the family of a participant without first consulting the treating team. The Committee is encouraged by the enthusiasm of both the Children's Hospital and the LTCSA to agree on a protocol for such matters. Accordingly, the Committee recommends that the Lifetime Care and Support Authority consult with the Children's Hospital at Westmead to develop an agreed protocol to enable discussion of a participant's appropriate treatment options with clinicians prior to any discussion with a participant's family.
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Recommendation 9

That the Lifetime Care and Support Authority ensure that it provides, as part of its induction training for Lifetime Care and Support Coordinators, information on respect for expert clinician decisions and treatment recommendations notwithstanding Coordinators' previous skills and experience.

Recommendation 10

That the Lifetime Care and Support Authority consult with the Children's Hospital at Westmead to develop an agreed protocol to enable discussion of a participant's appropriate treatment options with clinicians prior to any discussion with a participant's family.

Accessible housing: transitional accommodation

- 6.36** The issue of locating appropriate accommodation for participants was considered in depth as part of the Third Review and the Committee committed to considering the issue again as part of the Fourth Review.³⁷⁶ In the present review, stakeholders have focused on the availability on transitional accommodation, that is, accommodation to which a participant may be transferred from hospital while waiting for appropriate permanent accommodation to become available or for their home to be modified.
- 6.37** In particular, the Committee received information from some stakeholders about the availability, and LTCSA approval of, transitional accommodation. The submission from the SSCIS highlighted the importance of transitional accommodation:

Support for discharge to transitional accommodation allows the client to return to community living and in so doing, commence the slow process of adapting to their new disability in the community environment.³⁷⁷

³⁷⁶ Standing Committee on Law and Justice, Report 45, p 106.

³⁷⁷ Submission 14, NSW Agency for Clinical Innovation, p 5.

- 6.38** SCIA stated that the foremost problem in relation to accommodation is the length of time it takes to get people discharged from hospital and into suitable accommodation and that sometimes participants are ‘stuck in hospitals for months after they are ready for discharge’.³⁷⁸
- 6.39** Dr Hodgkinson acknowledged the work that has already been done to improve supported accommodation options but noted that there is more work to be done. Indeed, Dr Hodgkinson confirmed that she knew of one in-patient facility where four patients have been attempting to access supported accommodation over a six month period, and none have yet been able to move out of hospital.³⁷⁹ Furthermore, Dr Hodgkinson stated, that the ‘processes and bureaucracies’ that need to be negotiated in order to access appropriate accommodation are ‘time consuming, confusing and frustrating for client and family’.³⁸⁰
- 6.40** Dr Hodgkinson also explained that the detriment to patients who are ready to leave the hospital but have to stay for lack of suitable and available accommodation is ‘a worsening of challenging behavior and institutionalization.’³⁸¹ Several stakeholders noted that delay in moving a participant out of hospital when they are ready to be discharged is not only disadvantageous for the participant, but also results in ‘bed block’.³⁸² This refers to a situation where a person is taking up a hospital bed unnecessarily and it therefore reduces the hospital’s capacity to treat other patients.
- 6.41** Some stakeholders made specific suggestions for improvement. For example, Mr Tony Jones, the Policy and Advocacy Manager at SCIA noted the suggestion that SCIA had put to the Committee in its previous review regarding the establishment of a registry of accessible housing in NSW.³⁸³ Mr Jones suggested that such a register could be the start of better planning for accessible housing needs in NSW.³⁸⁴ In response to this recommendation in last year’s review, the LTCSA stated that ‘the Authority does not consider that its role is to maintain a registry of wheelchair accessible housing.’³⁸⁵
- 6.42** In the present review, Mr Bowen from the LTCSA acknowledged that ‘accommodation remains the single biggest reason why people are unnecessarily delayed in rehabilitation units’.³⁸⁶ However, he also pointed out that, in his view, lifetime care participants move out of rehabilitation units faster than other patients because of the resources the LTCSA provides.³⁸⁷
- 6.43** The Authority explained that it is not funded to provide housing or accommodation for participants but recognises that suitable accommodation continues to be difficult to access at

³⁷⁸ Submission 11, Spinal Cord Injuries Australia, p 3.

³⁷⁹ Dr Hodgkinson, Evidence, 17 October 2011, p 2.

³⁸⁰ Dr Hodgkinson, Evidence, 17 October 2011, p 2.

³⁸¹ Dr Hodgkinson, Evidence, 17 October 2011, p 2.

³⁸² See for example: Mr Tony Jones, Policy and Advocacy Officer, Spinal Cord Injuries Australia, Evidence, 17 October 2011, p 12; Associate Professor James Middleton, Director, Spinal Cord Injury Service, Evidence, 17 October 2011, p 6; Dr Hodgkinson, Evidence, 17 October 2011, pp 5-6.

³⁸³ Mr Jones, Evidence, 17 October 2011, p 12.

³⁸⁴ Mr Jones, Evidence, 17 October 2011, p 12.

³⁸⁵ Standing Committee on Law and Justice, Report 45, p 106.

³⁸⁶ Mr Bowen, Evidence, 17 October 2011, p 49.

³⁸⁷ Mr Bowen, Evidence, 17 October 2011, p 49.

times.³⁸⁸ For this reason, the Authority operates two homes in Sydney for participants with high support needs in Revesby and Blacktown and will soon open another in Liverpool. In addition, it has purchased land in Ermington in Sydney and at Coffs Harbour for the same purpose.³⁸⁹

6.44 The Authority clarified the financial arrangements for participants living in its purpose-built accommodation. As tenants in the property, the participants pay rent through a community housing provider and contribute to household running costs.³⁹⁰ The LTCSA pays for the participants' care in the property and other rehabilitation costs, in the same way as it would for other participants.³⁹¹

6.45 Mr Bowen outlined that the LTCSA will fund accommodation itself in some limited circumstances:

We do fund accommodation for very high needs patients, where they have no prospect at all of going elsewhere and where it is in the context of some savings to the authority through congruent care arrangements.³⁹²

6.46 The State Spinal Cord Injury Service expressed specific concern that 'the LTCSA will not support the process of finding and assessing the appropriateness of transitional accommodation until the approval for the long term discharge destination has been completed'.³⁹³

6.47 Associate Professor James Middleton, Director of the State Spinal Cord Injury Service, suggested in this regard that approval for transitional accommodation should be separate to approval for long-term accommodation. Instead, where possible, efforts to find long-term accommodation should occur as a process distinct from the location and approval of suitable transitional accommodation.³⁹⁴

6.48 On behalf of the LTCSA, Mr Bowen expressed the view that the Authority is concerned not to finalise requests for equipment until a discharge destination is known because equipment needs to be customised to fit a person's home.³⁹⁵

6.49 Professor Middleton stated that the process would benefit from 'intensive...dialogue and support and better resourcing' to allow the two processes of acquiring interim and then long-term accommodation to take place in parallel and that a patient's discharge to interim accommodation should not be connected to the successful location of long-term accommodation. However, Professor Middleton also noted that this could be complicated in relation to the need for customised equipment essential to discharge.³⁹⁶

³⁸⁸ Answers to pre-hearing questions on notice, LTCSA, 29 September 2011, Questions 25 and 26, p 12.

³⁸⁹ Answers to pre-hearing questions on notice, LTCSA, 29 September 2011, Questions 25 and 26, p 12.

³⁹⁰ Answers to pre-hearing questions on notice, LTCSA, 29 September 2011, Questions 25 and 26, p 12.

³⁹¹ Answers to pre-hearing questions on notice, LTCSA, 29 September 2011, Questions 25 and 26, p 12.

³⁹² Mr Bowen, Evidence, 17 October 2011, p 49.

³⁹³ Submission 14, p 6.

³⁹⁴ Associate Professor Middleton, Evidence, 17 October 2011, p 6.

³⁹⁵ Mr Bowen, Evidence, 17 October 2011, p 49.

³⁹⁶ Associate Professor Middleton, Evidence, 17 October 2011, p 6.

Committee comment

- 6.50** The Committee recognises the difficulties participants face in finding appropriate accommodation in order to be able to leave hospital. The Committee also acknowledges the related concerns over the impact that delay in discharge can have for the participant themselves and, more broadly, for the effective administration of hospitals.
- 6.51** In this regard, the Committee commends the LTCSA in its efforts to develop suitable accommodation options for participants, including the establishment of three houses and the purchase of land for the development of two more. The Committee encourages the LTCSA to continue to develop suitable accommodation for Scheme participants.
- 6.52** The Committee accepts that both the lack of appropriate housing and the absence of a register of accessible properties compounds an already difficult situation. However, the Committee also accepts the advice of the LTCSA that it is not its role to establish a register or database for accessible properties in NSW. We note, as in the Third Review, that a clearer understanding of the availability and location of accessible housing in NSW would be of great benefit to the LTCS Scheme participants.
- 6.53** Given the apparent crisis in suitable accommodation for Scheme participants, the Committee supports a cautious approach to the suggestion of the SSCIS that discharge to interim accommodation should not be connected to suitable long-term accommodation. The risk is that the participant could be left without accommodation should the arrangements for interim accommodation expire prior to long-term accommodation having been found.
- 6.54** However, the suggestion may work well for some participants where interim accommodation is arranged in such a way so as to permit ongoing accommodation until a long-term solution is found or where customised equipment is not essential to discharge. On this basis, the Committee recommends that the LTCSA investigate options for permitting participants to be discharged from hospital to interim accommodation prior to long-term accommodation having been secured.

Recommendation 11

That the Lifetime Care and Support Authority investigate options for permitting participants to be discharged from hospital to interim accommodation, prior to long-term accommodation having been secured.

Support for carers

- 6.55** The adequacy of support and recognition provided to unpaid carers has been an issue considered the Committee's previous reviews of the LTCSA. This section of the Committee's report canvasses the implications of the introduction of the *Carers Recognition Act 2010* to the operation of the LTCSA and also outlines some issues raised by stakeholders surrounding financial payments to family carers.

Carers Recognition Act 2010

- 6.56** The *Carers (Recognition) Act 2010* (NSW) (the Carers Act) passed into law last year.³⁹⁷ The Carers Act provides legal recognition for the work of unpaid carers. Thus, a family member or friend who provides unpaid care and support to a participant in the LTCS Scheme would be a carer for the purposes of the Act.³⁹⁸ The Act establishes the NSW Carers Charter which specifically recognises the ‘the role and contribution of carers to our community and to the people they care for’.³⁹⁹
- 6.57** Pursuant to the Carers Act, the principles of the NSW Carers Charter must be understood by the staff of all NSW public sector agencies, including the LTCSA.⁴⁰⁰ The Charter provides, among other things, that carers should be recognised and supported and that support should be timely, responsive, appropriate and accessible. In addition, carers’ choices in that role should be recognised in the assessment, planning, delivery and review of services that impact upon carers.⁴⁰¹
- 6.58** In its answers to questions on notice, the LTCSA advised the Committee that the Authority has obligations under section 7 of the Carers Act and confirmed that it would ‘ensure that all staff are advised of the NSW Carers Charter’.⁴⁰² The Authority also expressed its support for the spirit of the legislation. It further noted that it has regularly invited Carers NSW to provide feedback on guidelines and participate on advisory groups when relevant and that it will continue to do so.⁴⁰³
- 6.59** Some submissions emphasised the importance of the passage of the Carers Act in the context of the LTCSA.⁴⁰⁴ Carers NSW commended the LTCSA for ensuring its staff are informed of the Charter, but noted that this was only a first step. Carers NSW suggested a number of other steps the LTCSA could take to ensure compliance with the spirit and form of the Charter:

Options for consideration by the LTCSA include:

- Incorporation of the NSW Charter into induction processes
- Inclusion of the NSW Carers Charter into induction processes on an equal footing with other key documents and standards
- Provision of information about the role and needs of carers to assist staff to contextualise and understand the importance of the NSW Carers Charter
- Prominent display of the NSW Carers Charter in all LTCSA workplaces
- Facilitation of discussion about the NSW Carers Charter, through periodically recurring agenda items in staff meetings (where appropriate), or through articles in LTCSA newsletters or other publications.⁴⁰⁵

³⁹⁷ Submission 1, Carers NSW, p 2.

³⁹⁸ *Carers (Recognition) Act 2010* s 5. Note that a person will not be a ‘carer’ for the purposes of the Act solely by virtue of being a person’s de facto spouse, relative, or guardian of the person.

³⁹⁹ *Carers (Recognition) Act 2010* s 3.

⁴⁰⁰ *Carers (Recognition) Act 2010* s 7.

⁴⁰¹ *Carers (Recognition) Act 2010* sch 1.

⁴⁰² Answers to pre-hearing questions on notice, LTCSA, 29 September 2011, Question 10, pp 4-5.

⁴⁰³ Answers to pre-hearing questions on notice, LTCSA, 29 September 2011, Question 10, pp 4-5.

⁴⁰⁴ Submission 1, p 2; Submission 10, National Disability Services, p 3.

⁴⁰⁵ Answers to supplementary questions 25 October 2011, Carers NSW, Question 1, p 2.

Financial support for family carers

- 6.60** Currently the LTCS Scheme pays for some support for families of participants including counseling, child care, cleaning services and travel and accommodation when accompanying participants.⁴⁰⁶ The LTCSA will also provide other support services to families from time to time. For example, the Executive Director of the LTCSA, Mr David Bowen, reported to the Committee that it had recently run a pilot program aimed at ‘building resilience amongst families of people with spinal cord injury’ and stated that it was ‘phenomenally successful’.⁴⁰⁷ Mr Bowen noted that, given the success of the program, the Authority is currently considering developing a family support program across the entire Scheme.⁴⁰⁸
- 6.61** Nevertheless, there are limitations on the volume and methods of support the LTCSA can provide to family carers. The *LTCSA Guidelines* state that the employment of and, therefore direct financial payment to, family members or friends for providing attendant care is not encouraged and will only occur when all other alternative options have been considered. The intent behind this policy is to maintain a functional family unit (see *Second Review Report* for further detail).⁴⁰⁹
- 6.62** In the Committee’s Second Review, the issue of financial support for family members who care for LTCS participants was raised. In the *Second Review Report*, the Committee heeded the comments that were made by the LTCSA, LTCSAC and social workers on the potentially negative impact of the Scheme funding family members to be carers. The Committee noted that the Commonwealth Carers Allowance is available to family carers of participants who meet the criteria for that allowance and encouraged the LTCSA to advise family carers of the Commonwealth carers allowance when appropriate.⁴¹⁰
- 6.63** The issue of unpaid family assistance was brought to the Committee’s attention again in the Third Review by the Australian Lawyers Alliance (ALA) and by some participants in the Scheme. For some participants, there was no need for family members to become full time carers.⁴¹¹ For others, however, this was not the case.
- 6.64** Mr Lyndon Wait, a lifetime participant, advised the Committee that his wife was required to become a full time carer and the amount of leave that his wife had to take eventually led to her losing her job. Mr Wait told the Committee that there was no compensation received from the Scheme for this.⁴¹²
- 6.65** In its submission to the present review, the ALA suggested that the LTCSA should consider providing payment to suitably trained family members for the provision of voluntary care. The

⁴⁰⁶ LTCSA, LTCS Guidelines, pp 11 and 39, accessed 30 October 2010, <www.lifetimecare.nsw.gov.au/Guidelines_and_Policies_for_Professionals.aspx>.

⁴⁰⁷ Mr Bowen, Evidence, 17 October 2011, p 51.

⁴⁰⁸ Mr Bowen, Evidence, 17 October 2011, p 51.

⁴⁰⁹ LTCSA, LTCS Guidelines, pp 46-48, accessed 30 October 2010, <www.lifetimecare.nsw.gov.au/Guidelines_and_Policies_for_Professionals.aspx>; and NSW Legislative Council, Standing Committee on Law and Justice, *Second Review of the Lifetime Care and Support Authority and the Lifetime Care and Support Advisory Council*, Report 40, September 2009, p 36.

⁴¹⁰ Standing Committee on Law and Justice, Report 40, p 39.

⁴¹¹ Standing Committee on Law and Justice, Report 45, pp 112-113.

⁴¹² Standing Committee on Law and Justice, Report 45, p 113.

ALA gave examples of when a family might choose to provide care themselves and explained that in doing so, the family was effectively subsidising the Scheme:

The reality is that many families will choose to continue to provide some care on an unpaid basis. For example:

- (a) The family may choose not to have a carer in the home for 24 hours to look after a young child but may prefer to cover over night care needs in exchange for some privacy.
- (b) A parent may choose to give up or restrict their work hours in order to accompany their brain-injured child to school rather than use a paid carer.

By volunteering to provide such services the family member, in effect, becomes an unpaid subsidiser of the LTCS Scheme.⁴¹³

6.66 In the current review the LTCSA elaborated on its policy on the provision of financial assistance to family carers and explained that such payment will occur only in very rare circumstances. Mr Bowen explained that there is only one circumstance where because of the remote location in which the participant resides, the Scheme agreed to pay a family member as a carer. In that case, Mr Bowen explained, the carer was an employee of a care service provider in order to ensure that requirements were met to ensure the person could do the work both well and safely.⁴¹⁴

6.67 In addition, Mr Douglas Herd, Chairperson of the Lifetime Care and Support Advisory Council explained that to create a financial nexus between family members could be problematic for family relationships insofar as one family member is reliant on the ongoing disability of another for an income:

It makes both the service user and the family member depend upon one another in a way that is mediated through cash and it creates problems in the longer term that may be insurmountable when some crisis emerges.

In as much as it is humanly possible for us, we should avoid any temptation to go down that route, except in those circumstances where it absolutely is the last resort to prevent any other individual going into some kind of institutional inappropriate medical care.⁴¹⁵

6.68 The Committee inquired as to whether payment to family members might be possible when subsection 6(3) of the Act, which permits the LTCSA to enter into an agreement with a participant to allow them to self-manage their care, is implemented (see Chapter 4 for further discussion). This question was asked in the context of the implementation of the second phase of *Stronger Together*, the NSW Government's disability services strategy, which plans for services from 2011-2016. As outlined in Chapter 4, the strategy is particularly focused on ensuring respect for participant choice.

⁴¹³ Submission 7, Australian Lawyers Alliance, pp 4-5.

⁴¹⁴ Mr Bowen, Evidence, 17 October 2011, pp 53-54.

⁴¹⁵ Mr Douglas Herd, Chair, Lifetime Care and Support Advisory Council, Evidence, 17 October 2011, p 54.

6.69 Mr Herd explained that although, in his view, the choice to pay a family member as a carer is not a wise one, it is one that should be respected if that is what the participant ultimately decides:

An even smaller proportion will be people who will choose the direct funded option and choose, for whatever reasons, to make payments to direct family members...if, in the final analysis, that is what they choose, then we ought to be able to support people to make that choice... but still my advice is not to do it because it has the potential to ruin your relationship with your mother, father, brother or sister and the day that happens you will rue you decision to pay them anything at all, not because you do not love them but because you do.⁴¹⁶

Committee comment

- 6.70** The Committee acknowledges the important work that carers undertake in providing support and care for members of the community who have disabilities. In particular we express our appreciation for the informal care arrangements that so often underpin rehabilitation.
- 6.71** In this regard the Committee lauds the entry into force of the *Carers Recognition Act 2010* and encourages the LTCSA's full compliance with the provisions and the spirit of the legislation. The Committee welcomes the LTCSA's commitment to ongoing consultation with Carers NSW in this regard.
- 6.72** The Committee acknowledges the suggestion made by the Australian Lawyers Alliance to provide payment to family members who are caring for participants, which was also made in the Second and Third Reviews.
- 6.73** The Committee accepts that it is only in exceptional circumstances that the LTCSA will pay a family member to act as a carer for a Scheme participant. In this regard, we heed the advice of Mr Herd that creating a situation where one family member's income is directly linked to another family member's ongoing disability could be extremely problematic for family relationships.
- 6.74** The Committee's position has not changed from the last Review when it accepted the LTCSA's advice that it does not pay family members to become carers due to the potential negative impact on functional family relationships. The Committee also notes that the Commonwealth Carers Allowance is available in appropriate circumstances.
- 6.75** The Committee acknowledges that when subsection 6(3) of the Act becomes operational, there may be circumstances in which a participant will seek to pay a family member for care services. The Committee commits to giving this further consideration after the subsection has come into operation and will remain apprised of the issue.

⁴¹⁶ Mr Herd, Evidence, 17 October 2011, p 55.

Recreation and leisure activities

Previous Reviews

- 6.76** During the Committee's Second Review, stakeholders highlighted the importance of recognising recreation and leisure activities as a significant part of the rehabilitation and socialisation of participants. A number raised concerns that the LTCSA would not providing funding for recreation and leisure activities for participants.⁴¹⁷
- 6.77** The Committee acknowledged these concerns and recommended in its *Second Review Report* that the LTCSA consider funding the cost of recreation and leisure activities, especially for those participants who cannot return to work. The *Second Review Report* also recommended that the LTCSA interpret 'recreation and leisure' activities broadly so that unusual activities of particular interest and therapeutic value to participants might also be funded.⁴¹⁸
- 6.78** The Government responded to the Committee's recommendations by stating that the LTCSA would pay for recreation and leisure and access to it when there is a therapeutic benefit from the activity and it is part of a rehabilitation program. Furthermore, the Government advised that the LTCSA was continuing to work on the recreation and leisure guidelines, and would consider the role and funding for recreation and leisure in this context.⁴¹⁹
- 6.79** The LTCSA subsequently released a consultation paper entitled *Leisure and recreation in the Lifetime Care and Support Scheme* in March 2009, which resulted in a set of draft guidelines for access to and funding of leisure and recreation activities. However, the feedback received from stakeholders on the draft guidelines was so varied that the Authority ultimately withdrew them. The Authority proposed that it would instead consider each request individually and in doing so, assessing the needs of a participant as a whole and assessing these in relation to all of their activities, the participant's capacity, and local and community resources.⁴²⁰
- 6.80** In the Third Review some stakeholders emphasised that transportation to recreation and leisure activities should also be funded under the Scheme. They asserted that to do so would be beneficial not only to facilitate the possible physical benefits but also to foster a sense of independence for the participant.⁴²¹ In response, the LTCSA noted that it will pay for transport costs and the attendance of carer when they are required to assist a person to attend recreational activities.⁴²²
- 6.81** The LTCSA advised that a more expansive approach to payment for recreation and leisure activities would have 'significant cost implications' for the Scheme.⁴²³ Mr Bowen, acknowledged that the issue was challenging and ultimately was 'a very big question and I cannot see that it has been resolved anywhere' (referring to similar Schemes in other

⁴¹⁷ Standing Committee on Law and Justice, Report 40, pp 57-61.

⁴¹⁸ Standing Committee on Law and Justice, Report 40, p 61.

⁴¹⁹ Government Response to the Standing Committee on Law and Justice, Report 40, p 3.

⁴²⁰ Standing Committee on Law and Justice, Report 45, p 120.

⁴²¹ Standing Committee on Law and Justice, Report 45, p 118.

⁴²² Standing Committee on Law and Justice, Report 45, p 119.

⁴²³ Standing Committee on Law and Justice, Report 45, p 119.

jurisdictions).⁴²⁴ However, he also noted at the time that the LTCSA Board will eventually need to consider this issue, and suggested it might only be resolved through a practical solution such as a capped dollar amount being made annually available to each participant to support recreation and leisure activities.⁴²⁵

Stakeholder views

- 6.82** In the current review, a number of stakeholders again emphasised the importance of recreation and leisure in a participant's habilitation and urged the LTCSA to pay for participant involvement in these activities.
- 6.83** In its submission, SCIA stated that recreation and leisure 'does not receive enough acknowledgement in the provision of care delivery for people with high needs'.⁴²⁶ It stated that people with severe disabilities often feel isolated at home as friends and family drift away or live far away and that recreation and leisure activities are especially valuable in this context.⁴²⁷ Similarly, the BIRD noted that 'involvement in community activities is a core component of integrating rehabilitation into everyday situations for people with severe TBI [traumatic brain injury]'.⁴²⁸
- 6.84** Representatives from SCIA suggested that the LTCSA could do more to support participants to partake in recreational activities which in turn would allow them to be more involved in their community.⁴²⁹ When asked by the Committee whether SCIA had put this view to the Authority, the representatives replied that they had, and that the Authority had not provided any meaningful response.⁴³⁰ Issues of communication are addressed more fully in Chapter 5.
- 6.85** NDS outlined in its submission that the promotion of social inclusion and community participation is consistent with the new agenda for disability services in NSW as underpinned by the second phase of its disability strategy: *Stronger Together*. It noted also that the *United Nations Convention on the Rights of People with Disabilities*, to which Australia is a signatory, recognises the rights of people with disabilities to 'participate in communities to the fullest extent possible'.⁴³¹ NDS thus 'strongly recommends that the importance of community involvement and participation be recognised and enabled for by the Scheme'.⁴³²
- 6.86** In its answers to questions on notice, the LTCSA stated that:

[The Authority] is not funded to pay for participant's leisure and recreation costs...[but]... will fund leisure and recreational activities for participants when the

⁴²⁴ Standing Committee on Law and Justice, Report 45, p 119.

⁴²⁵ Standing Committee on Law and Justice, Report 45, p 119.

⁴²⁶ Submission 11, p 4.

⁴²⁷ Submission 11, p 4.

⁴²⁸ Submission 14, p 9.

⁴²⁹ Mr Lomas, Evidence, 17 October 2011, p 10.

⁴³⁰ Mr Lomas, Evidence, 17 October 2011, p 10.

⁴³¹ Submission 10, p 5.

⁴³² Submission 10, p 5.

activity is part of a rehabilitation program and will assist the participant to develop independent living skills.⁴³³

- 6.87** NDS expressed the view that this approach did not strike the right balance. It stated that in the view of NDS members, ‘people don’t choose to participate in leisure activities to simply improve their independent skills, then why should people with disability be treated any differently.’⁴³⁴
- 6.88** In oral evidence, Ms Lulham, the Director of LTCSA Service Delivery, acknowledged that the issue of payment for recreation and leisure was a difficult one. She stated that the Authority recognizes the value in participant involvement in community activities but at the same time cannot meet the cost of leisure and recreation activities for participants.⁴³⁵
- 6.89** Ms Lulham explained to the Committee how the Authority differentiates between the activities it will and activities it will not pay for. She outlined that the Authority would pay for ‘activities that would lead to the acquisition of the skills that a person needs to develop recreation and leisure activities’ but would not pay for the actual cost of the recreation and leisure itself.⁴³⁶
- 6.90** Ms Lulham also advised that the Authority has developed a new draft guideline outlining its approach to funding recreation and leisure activities and Ms Lulham stated that she hoped that it would be gazetted soon.⁴³⁷ The Committee was informed that the guideline clarified that the LTCSA would not pay for the cost of recreation and leisure activities but that it would pay the cost of an attendant care worker to assist in leisure and recreation activities where necessary:

...if they need an attendant care worker to assist them partake in their recreation and leisure, we will fund that.... for instance... if they decide they want to go swimming, they pay their own way into the swimming pool but they might need an attendant care worker to assist them with the actual swimming, so we will pay for that attendant care worker.⁴³⁸

- 6.91** The Authority advised, for example, that it funds the ‘Burn Rubber Burn’ program. This is a not-for-profit exercise program for people with a spinal cord injury and other like conditions. The LTCSA stated that ‘[w]hile Burn Rubber Burn may provide a recreation opportunity for some people, it is primarily an exercise program not a leisure and recreation program.’⁴³⁹

Travel costs

- 6.92** A separate but related issue raised by some stakeholders was payment for the cost of travel, both to and from recreation and leisure activities, and also holiday travel.

⁴³³ Answers to pre-hearing questions on notice, LTCSA, 29 September 2011, Question 35, p 16.

⁴³⁴ Answers to supplementary questions 7 November 2011, National Disability Services, Question 3, p 5.

⁴³⁵ Ms Lulham, Evidence, 17 October 2011, p 56.

⁴³⁶ Ms Lulham, Evidence, 17 October 2011, p 55.

⁴³⁷ Ms Lulham, Evidence, 17 October 2011, p 55.

⁴³⁸ Ms Lulham, Evidence, 17 October 2011, p 56.

⁴³⁹ Answers to questions taken on notice 17 October 2011, LTCSA, Question 13, p 6.

6.93 The Australian Lawyers Alliance (ALA) stated in relation to holiday travel that the current LTCSA policy to pay for the cost of one economy airfare within Australia for a single carer per participant per year is inadequate:

Injured people who are unable to travel in economy class, or who need to stay in a more expensive hotel with better facilities, will either have to pay for the additional expense themselves or they won't be able to travel at all.⁴⁴⁰

6.94 The ALA told the Committee that there is no provision for funding overseas travel at all and this can be difficult for participants with family overseas. Accordingly, it recommended that the matter of participant travel and holidays should be reviewed and addressed within the LTCS Guidelines.⁴⁴¹

6.95 National Disability Services also expressed its support for the Authority to provide greater support for participant's community involvement including local travel costs. It noted that currently 'the hours gained from the Scheme are limited to housework support with very limited community inclusion and support activities'.⁴⁴²

6.96 The NDS also stated that while the LTCS will pay for an individual to travel to a given activity, if that person wants to then change activities, the LTCSA contribution to the cost of travel was limited:

The LTCS Scheme allocated a certain amount of funding to cover the cost of an individual to travel to a specific activity. When the client wanted to change activities, the choice for an alternative was limited to activities that were physically located within a similar scope or distance. The nature of this approach prevents individuals from exploring new options more in keeping with their changing needs.⁴⁴³

6.97 Similarly, the BIRD repeated concerns it expressed in last year's review that participant access to recreation and leisure activities was often impeded by a lack of appropriate transport to the activity. It noted that improving access to transport will provide access to 'opportunities for social inclusion that can improve challenging behaviour, reduce depression and lower the risk of suicide'.⁴⁴⁴

6.98 Mr Bowen, representing the LTCSA, stated that it is commonplace that families become financially stretched after an accident serious enough to place a family member in the Lifetime Care and Support Scheme. However, in relation to both recreation and leisure activities and travel costs he noted that 'the scheme is funded for a specific set of services only and we cannot step outside those statutory boundaries'.⁴⁴⁵

⁴⁴⁰ Submission 7, p 5.

⁴⁴¹ Submission 7, p 5.

⁴⁴² Submission 10, p 5.

⁴⁴³ Answers to supplementary questions 7 November 2011, National Disability Services, Question 1, p 3.

⁴⁴⁴ Submission 14, p 9.

⁴⁴⁵ Mr Bowen, Evidence, 17 October 2011, p 48.

Committee comment

- 6.99** The Committee notes with approval the ongoing work of the LTCSA to improve access to community participation within the scope of the Scheme. In this regard, one outcome of the Second Review was the implementation of a policy to pay for recreation and leisure activities of therapeutic and rehabilitative benefit.
- 6.100** The Committee notes that since the Third Review, the LTCSA has redrafted its guidelines on recreation and leisure in order to pursue a more holistic approach to assessing and meeting the needs of participants. The Committee is concerned that these guidelines have now been in a developmental stage for the past two reviews and encourages the LTCSA to expedite their gazettal in order to provide the guidance that some participants are clearly seeking. The Committee is keen to review these guidelines and the stakeholder response to them in the next review.
- 6.101** The Committee remains concerned that participants are unable to access recreation and leisure activities due to an inability to access or fund appropriate transport. The Committee is also mindful that there needs to be reasonable limitations placed on what the Authority will fund in order that it remain viable for future participants. In the absence of a response to the recommendations contained in the Committee's Third Review, the Committee is interested to hear the Government's view on this issue. Thus, reflecting on the recommendation on this matter from the previous review, the Committee recommends that the LTCS Scheme further consider funding for transport to and from leisure and recreation activities.
- 6.102** The Committee also notes the particular concerns raised by the Australian Lawyers Alliance over funding for care and services while a participant is on holiday. The Committee is mindful that the Authority is subject to a statutory limitation to pay for only those treatment, rehabilitation and care needs that are 'reasonable and necessary'.
- 6.103** That said, the Australian Lawyers Alliance has raised some important issues surrounding when the LTCSA should pay for treatment and care while a participant is on holiday or indeed overseas. Accordingly, the Committee recommends that the LTCSA clarify its guidelines and consider the extent to which the Authority will pay for treatment and care services while a participant is on holiday or overseas in order to balance the needs of participants with the scope and capacity of the Scheme.

Recommendation 12

That the Lifetime Care and Support Authority clarify its guidelines and consider the extent to which the Authority will pay for treatment and care services while a participant is on holiday or overseas in order to balance the needs of participants with the scope and capacity of the Scheme.

Recommendation 13

That the Lifetime Care and Support Authority publish its guidelines on recreation and leisure activities and clarify its policy on funding for the transport of participants and carers to and from recreation and leisure activities.

Educational support for children

- 6.104** Concerns over educational support for child participants in the LTCS Scheme first arose in the Third Review. The Brain Injury Services, Kids Rehab, The Children’s Hospital Westmead, were especially concerned that the LTCS Scheme should provide more educational support to child participants.⁴⁴⁶ Kids Rehab also suggested that ‘further dialogue between the LTCSA and the Department of Education and training may be beneficial to further negotiate how support for students should be funded and monitored long term within educational facilities.’⁴⁴⁷
- 6.105** The Committee acknowledged that educational support plays an important part in the long term habilitation of children with brain injuries. It also encouraged the LTCSA to work with KidsRehab to ensure that the responsibilities of the LTCSA are well understood and that any opportunities that exist, within the scope of the LTCSA’s role, to improve educational support can be further explored.⁴⁴⁸
- 6.106** During the Third Review, the LTCSA informed the Committee that it is not the primary resource for educational support services, but rather will ‘top up’ the educational support services a participant receives where necessary.⁴⁴⁹ The LTCSA elaborated that requests for educational support services are completed by the school, rather than the clinician and the Authority provides funds only in situations where other sources have been exhausted.⁴⁵⁰
- 6.107** In the present review, Ms Helene Chew, Coordinator of the Brain Injury Service at the Children’s Hospital Westmead, expressed appreciation for the work of the LTCSA in terms of improving their involvement with schools including in terms of consulting with the Department of Education and Communities. She noted that this work is ‘opening doors to try to set up better protocols in how we deal with the Department of Education and schools’.⁴⁵¹
- 6.108** Ms Chew stressed that operating within the nexus between health and education is central to the role of the Brain Injury Service at the Hospital:

The interface between health and education is at the core of the business that the rehabilitation service provides to clients with a brain injury. It is integral to our role that we consider how the impact of injury might influence the child’s future education and support needs that they may have.⁴⁵²

⁴⁴⁶ Standing Committee on Law and Justice, Report 45, p 121.

⁴⁴⁷ Standing Committee on Law and Justice, Report 45, p 121.

⁴⁴⁸ Standing Committee on Law and Justice, Report 45, p 122.

⁴⁴⁹ Standing Committee on Law and Justice, Report 45, p 121.

⁴⁵⁰ Standing Committee on Law and Justice, Report 45, p 121.

⁴⁵¹ Ms Chew, Evidence, 10 October 2011, p 55.

⁴⁵² Ms Chew, Evidence, 10 October 2011, p 55.

6.109 The Children’s Hospital at Westmead stressed that the relationship between the school and the case manager is important as the latter often acts as ‘the interface between medical and rehabilitation providers and funding bodies’ such as the LTCSA.⁴⁵³

6.110 Ms Martine Simons, a Senior Social Worker within the Brain Injury Service at the Children’s Hospital Westmead, explained how the Service works together with schools to facilitate the transition back to school for a participant. The first step is a meeting between clinicians, the principal of the school and key teachers to discuss the child’s brain injury and establish a plan for him or her in the forthcoming term and also discuss funding options.⁴⁵⁴

6.111 Ms Simons expressed appreciation for the effort the LTCSA has made with regards to collaboration with schools.⁴⁵⁵ However, the Children’s Hospital Westmead also stated in its submission that ‘there remain issues around policies and procedures specific to the interface of the scheme with schools and rehabilitation providers such as the Brain Injury Service’.⁴⁵⁶ The Children’s Hospital elaborated that feedback it had received from schools communication and administration are the key issues:

...the processes for informing schools about the requirements of the Lifetime Care and Support Scheme and assistance to complete the paperwork required to apply for learning support services continues to be variable from school to school. The new administrative load now on schools reflects the excessive documentation which has been reported in previous reviews by the Brain Injury Service.⁴⁵⁷

6.112 In this regard, the Children’s Hospital Westmead stated that it would welcome continued efforts on the part of the LTCSA to clarify its relationship with schools and to determine how schools, the LTCSA and the rehabilitation specialists interact.⁴⁵⁸ The Hospital further stated that it would be ‘extremely helpful’ if the LTCSA would clarify its position on specific policies including:

- The provision of teacher aide support in class and additional learning support strategies such as home tutors
- How schools will be informed, trained and resourced to provide the documentation required under the LTCS Scheme
- The collaboration of the LTCS Scheme, school and rehabilitation specialist in making recommendations for school based services
- Identifying within the LTCS Scheme who undertakes the tasks of:
 - Educating schools about the Scheme
 - Assisting education staff when they have issues with providing documentation or are needing clarification about how funding for services can be sought

⁴⁵³ Submission 18, The Children’s Hospital Westmead, p 5.

⁴⁵⁴ Ms Simons, Evidence, 10 October 2011, p 55.

⁴⁵⁵ Ms Simons, Evidence, 10 October 2011, p 55.

⁴⁵⁶ Submission 18, p 5.

⁴⁵⁷ Submission 18, p 5.

⁴⁵⁸ Submission 18, p 5.

- Whether all paediatric participants of the LTCS Scheme are required to apply to the Department of Education and Community for funding before they can apply for funding through the LTCSA.⁴⁵⁹

- 6.113** The Children’s Hospital further stated that any formal agreements, including any between the Department of Education and Community and the LTCSA, should be made explicit to paediatric service providers so that they may facilitate better support of the student.⁴⁶⁰
- 6.114** The timeframe for this inquiry did not permit the Committee to put to the LTCSA the concerns of the Children’s Hospital at Westmead regarding educational support for child participants.

Committee comment

- 6.115** The Committee recognises the important role that education support plays in the long term habilitation of children with brain injuries. In this regard, the Committee commends the work of the LTCSA, in conjunction with the Department of Education and Communities, to move towards improved processes for education supports for child participants in the LTCS Scheme.
- 6.116** The Committee acknowledges that as the number of child participants inevitably rises, the interaction of the LTCS Scheme with schools will become increasingly important. With the LTCSA’s shifting focus towards community based care, renewed consideration of its approach to its interaction with schools is both timely and appropriate. The Committee notes also the concerns of the Brain Injury Service at the Children’s Hospital Westmead and believes that a more streamlined and transparent process is possible.
- 6.117** As outlined above, the timeframe for inquiry did not permit the Committee to put the issue of educational support for child participants to the LTCSA directly and as such we did not receive evidence from the LTCSA on this matter. Although, we note that educational assistance was considered in greater detail in the Third Review Report.
- 6.118** Nevertheless, the Committee sees value in the LTCSA undertaking a review of the issues raised by the Children’s Hospital Westmead. The Committee therefore recommends that the LTCSA review the recommendations of the Children’s Hospital at Westmead as set out in paragraph 6.112 of this Chapter to improve and clarify the process of obtaining educational support for child participants in the Scheme, with a view to accepting and implementing those recommendations as appropriate. The Committee commits to considering this issue further in future reviews.

⁴⁵⁹ Submission 18, p 6.

⁴⁶⁰ Submission 18, p 6.

Recommendation 14

That the Lifetime Care and Support Authority liaise with the Department of Education and Training and review the issues raised by the Children's Hospital Westmead as set out in paragraph 6.112 of this Report to improve and clarify the process of obtaining educational support for child participants in the Scheme, with a view to accepting and implementing those recommendations as appropriate.

Appendix 1 Submissions

| No | Author |
|----|--|
| 1 | Carers NSW |
| 2 | Mrs Donna Axiak |
| 3 | Mr Edwin Harris |
| 4 | Mr and Mrs Mark Harris |
| 5 | NSW Health |
| 6 | Suncorp |
| 7 | Australian Lawyers Alliance |
| 8 | Youthsafe |
| 9 | Mr Greg Moore |
| 10 | National Disability Services |
| 11 | Spinal Cord Injuries Australia |
| 12 | Physical Disability Council of NSW |
| 13 | Motorcycle Council of New South Wales Incorporated |
| 14 | NSW Agency for Clinical Innovation |
| 15 | Australian Medical Association (NSW) Limited |
| 16 | Law Society of New South Wales |
| 17 | Dare to Do Australia |
| 18 | The Children's Hospital Westmead |
| 19 | Medical specialists |

Appendix 2 Witnesses

| Date | Name | Position and Organisation |
|--|--|--|
| Monday 10 October 2011 Macquarie Room Parliament House | Ms Danielle De Paoli | Member, Law Society Injury Compensation Committee, Law society of NSW |
| | Ms Jnana Gumbert | NSW Branch President, Australian Lawyers Alliance |
| | Dr Andrew Morrison SC | Member, Common Law Committee and Member MAC, Australian Lawyers Alliance |
| | Ms Helene Chew | Coordinator, Brain Injury Service, The Children's Hospital Westmead |
| | Ms Martine Simons | Senior Social Worker, Brain Injury Service, The Children's Hospital Westmead |
| | Ms Fiona Davies | Chief Executive Officer, Australian Medical Association (NSW) Ltd |
| | Ms Sarah Dahlenburg | Director, Australian Medical Association (NSW) Ltd |
| Monday 10 October 2011 Macquarie Room Parliament House | Dr Adeline Hodgkinson | Director, Brain Injury Rehabilitation Directorate |
| | Dr Joe Gurka | Director, Brain Injury Rehabilitation Service |
| | Associate Professor James Middleton | Director, State Spinal Cord Injury Service |
| | Mr Sean Lomas | Policy and Advocacy Manager, Spinal Cord Injuries Australia |
| | Mr Tony Jones | Policy and Advocacy Officer, Spinal Cord Injuries Australia |
| | Mr David Bowen | Executive Director, LTCSA & LTCSAC |
| | Ms Suzanne Lulham | Director, Service Delivery, LTCSA & LTCSAC |
| | Mr Douglas Herd | Chair, LTCSAC |

Appendix 3 Answers to questions on notice

The Committee received answers to questions on notice from:

Law Society of NSW

Australian Lawyers Alliance

The Children's Hospital Westmead

Australian Medical Association (NSW)

National Disability Services

Carers NSW

Lifetime Care and Support Authority and the Lifetime Care and Support Advisory Council.

Appendix 4 LTCSA Legal agreement for self-purchase of attendant care services



Lifetime Care and Support Authority of New South Wales

- and -

[Name of Scheme Participant]

**PARTICIPANT FUNDING AGREEMENT:
Direct self-purchasing of
attendant care services**

I V Knight
Crown Solicitor
Level 5, 60-70 Elizabeth Street
Sydney NSW 2000

DX 19 Sydney
Tel: (02) (02) 8224-5390
Fax: (02) 9224 5222
Ref: 200902366
T1 Sarah-jane Morris

200902366 D2010/312787

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LTCS Guidelines means the guidelines issued by the Authority under section 58 of the Act as amended from time to time;

Notice of Assessment and Certificate means the written certification of the Participant's treatment and care needs, a copy of which is annexed at Schedule 2;

Participant means the participant under s. 3 of the Act in respect of whom this Agreement is in force, and includes a Participant's Authorised Representative;

Participant's Authorised Representative means:

- (a) an attorney for the Participant under an enduring power of attorney;
- (b) a guardian of the Participant within the meaning of the *Guardianship Act 1987*, or a person responsible within the meaning of Part 5 of that Act;
- (c) a person having parental responsibility for the Participant, if that Participant is a child, or
- (d) a person who is otherwise empowered under law to exercise any functions as an agent of or in the best interests of the Participant.

Scheme Funding means the total money to be paid by the Authority to the Participant under this Agreement for the approved attendant care services;

Social Security Act means the *Social Security Act 1991* (Cth);

unexpended monies means excess monies, if any, referred to in clause 5.1; and

treatment and care needs has the same meaning as its definition in s. 6(2) of the Act.

Interpretation

1.2 In this Agreement, unless the contrary intention appears:

- (a) headings are inserted for guidance only and do not in any way limit or govern the meaning or construction of the terms of this Agreement;
- (b) any provision of this Agreement that is to be performed by two or more persons binds those persons jointly and severally;
- (c) references to any statute, regulation, by-law or ordinance includes amendments, re-enactments or consolidations of any of them;

Method of payment

- 4.4 The Authority will pay the instalments of Scheme Funding by electronic funds transfer into a bank account in the Participant's name, as notified in writing by the Participant from time to time.
- 4.5 The Authority cannot be required to pay the Scheme Funding (or instalments thereof) to any person other than the Participant or into any bank account not in the Participant's name.

Changes to regularity and method of payment

- 4.6 Notwithstanding anything in this Agreement, the Authority may at any time in its own discretion and without the Participant's consent change the regularity with which and/or the method of payment by which the Scheme Funding are to be paid by the Authority to the Participant.

5. UNEXPENDED PAYMENTS

- 5.1 In agreeing the amount of the Scheme Funding the parties intend there to be no excess monies from the Scheme Funding, that is, no monies that are not spent by the Participant on approved attendant care services.
- 5.2 When this Agreement expires or is otherwise terminated, the Participant must notify the Authority in writing of the amount of unexpended monies.
- 5.3 If there are unexpended monies at the expiry, termination or cessation of this Agreement and the parties enter into a new funding agreement, the Authority may, in its absolute discretion:
- (a) require the repayment of those monies by the Participant to the Authority, or
 - (b) agree to set off its right to repayment of those monies against its obligation to make payments to the Participant under the new funding agreement.
- 5.4 If there are unexpended monies at the expiry, termination or cessation of this Agreement and the parties do not enter into a new funding agreement, the Authority may, in its absolute discretion:
- (a) require the repayment of these monies by the Participant to the Authority, or
 - (b) allow the participant to keep these monies on the condition that the Participant agrees to spend the money only for other treatment and care needs under a new funding agreement.
- 5.5 This clause 5 survives the expiry or termination of this Agreement.

6. PARTICIPANT'S OBLIGATIONS

Payment for approved attendant care services

- 6.1 Subject to clause 5 above, the Participant must only spend the monies received from the Authority under this Agreement to pay for approved attendant care services that are provided only to the Participant and not to any other person.

Maintenance of Monies

- 6.2 Any monies received by a Participant from the Authority under this Agreement must be paid into an account which is separate to any other account maintained by the Participant.
- 6.3 Any interest earned on monies deposited in an account maintained in accordance with clause 6.2 above must be applied by the Participant as if those amounts of interest were monies received from the Authority under this Agreement.

No payment to friends or family

- 6.4 The Participant must not spend any of the monies received from the Authority under this Agreement to pay any of the Participant's friends, acquaintances, family members, guardians, or other persons with whom the Participant has a personal relationship, regardless of whether such a person provides assistance or services to the Participant in an unpaid or voluntary capacity.
- 6.5 To avoid doubt, clause 6.2 applies to services provided to a Participant who is a minor as well as to any other Participant.

Good faith and honesty

- 6.6 In spending any money received under this Agreement or dealing with the Authority, the Participant:
- (a) must act at all times in good faith and with honesty; and
 - (b) must acknowledge that the Scheme Funding is provided from public revenue and must be spent in accordance with the LTCS Guidelines and the Act.

Necessary and appropriate skills

- 6.7 The Participant must use reasonable endeavours to ensure that any person or service-provider who provides attendant care services to the Participant, which are to be paid for by monies received under this Agreement, is suitably qualified and has the necessary skills and experience to provide the services required.

7. REPORTING AND AUDIT

Reporting

- 7.1 The Participant must inform the Authority, within seven days, of any change of his or her circumstances affecting the nature or degree of attendant care services required by the Participant.

Receipts

- 7.2 During the term of this Agreement and for three (3) months following its expiry or termination, the Participant must keep receipts for every item of expenditure of monies received under this Agreement.

Reporting by the Participant

- 7.3 On a fortnightly basis, the Participant must provide the Authority with written certification that monies received under this Agreement have been spent on approved attendant care services by completing an Expenditure Declaration Form, which is to include the following details for the preceding fortnight:
- (a) the types of approved attendant care services provided to the Participant (with reference to the codes in the Authority's List of Payment Codes, as applicable from time to time);
 - (b) the name of the person or service-provider to whom payment was made; and
 - (c) the amount paid for those services.
- 7.4 The Participant must provide to the Authority the first completed Expenditure Declaration Form under clause 7.3 on or before the date that is two weeks after the Participant receives the first instalment of the Scheme Funding.

Audit by the Authority

- 7.5 At any time during the term of this agreement or within three (3) months after its expiry or termination, the Authority may conduct an audit of the Participant's receipts that are required to be kept under this Agreement by:
- (a) giving the Participant one week's notice in writing that an audit will be conducted; and
 - (b) requiring the Participant to provide the Authority, within 21 days of the date of the notice, with copies of all receipts for the provision of approved attendant care services within a specified period.
- 7.6 The Participant must comply with a notice issued under clause 7.5 and may request a reasonable extension of time to do so, which the Authority may grant in its discretion.

8. PARTICIPANT'S WARRANTIES

8.1 The Participant represents and provides the following warranties, which are each a condition of the Authority's entry into this Agreement.

- (a) that all information or documents provided by the Participant prior to entering into this Agreement is true and correct;
- (b) that, prior to entering into this Agreement, the Participant received legal and financial advice or had the opportunity to do so; and
- (c) that the Participant is not aware of any circumstances that would adversely affect the Participant's ability to fulfil all obligations under this Agreement;

9. INDEMNITY AND RELEASE

9.1 For the purposes of this clause 9, the following words have the respective meanings:

Claim means any claim, liability, loss, actions, proceedings, demands, damages or expenses of any kind; and

Protected Persons means:

- (a) the Authority and all its officers, staff members, agents, servants, contractors and any person claiming through or under it; and
- (b) any person exercising a function under the Act.

Participant's indemnity

9.2 At all times, the Participant indemnifies the Protected Persons from and against any Claim, which may arise by reason of or in connection with this Agreement, whether directly or indirectly, including but not limited to a Claim arising from or in connection with:

- (a) a failure by the Participant to comply with above clause 6;
- (b) any decision that unexpended monies are "assessable income" for the purposes of the *Income Tax Assessment Act 1997* (Cth);
- (c) any decision that unexpended monies are "income" for the purposes of the *Social Security Act*; or
- (d) any act or omission in good faith by the Protected Persons that results in:
 - i. personal injury or harm to, or the death of, any person; or
 - ii. loss of, or damage to, property.

Participant's release

- 9.3 At all times, the Participant releases and discharges the Protected Persons indemnified under clause 9.2 from any Claims whatsoever which, but for this clause, could be brought against or made upon any of the Protected Persons.
- 9.4 At all times, the Participant further releases the Protected Persons from any Claim whatsoever which, but for this clause, could be brought against or made upon them arising from or by reason of or in connection with any unlawful, wrongful or negligent act or omission:
- (a) by a person or service-provider (whether an approved attendant care service provider or not);
 - (b) whose assistance or services are paid for by Participant with monies received under this Agreement; and
 - (c) that results in:
 - i. personal injury or harm to, or the death of, any person;
 - ii. loss of, or damage to, property;
 - iii. an adverse effect on the Participant's standard of care; or
 - iv. a lower standard of quality and timeliness in the provision of assistance or services.

Exclusion from indemnity and release

- 9.5 Nothing in this clause 9 is to be taken as preventing the Participant from exercising, or making a Claim arising in relation to, the following rights:
- (a) the referral of a dispute under Part 3 of the Act; or
 - (b) a challenge to a decision made, or exercise of a function, under the Act by way of judicial review.

Participant's obligations ongoing

- 9.6 The Participant agrees that the obligations under this clause 9 continue after this Agreement expires or otherwise terminates, in respect of any Claim arising from an act, deed, matter or thing occurring before such expiration or termination.

10. DISPUTE RESOLUTION

10.1 The parties agree to use best endeavours to settle any dispute arising under or in relation to this Agreement by following the procedure set out in this clause, before resorting to court proceedings or any other dispute resolution process:

- (a) By notice in writing, a party may claim that a dispute has arisen.
- (b) Both parties must seek to resolve the dispute within 10 days of the notice being received by the other party. During this time, the LTCS Coordinator is the person responsible for discharging the Authority's obligations under this clause.
- (c) If the dispute is not resolved within that time, or such further period as agreed between the parties, the LTCS Coordinator may request the intervention of the Manager Service Coordination, Manager Assessment Review, Director Service Delivery or Executive Director, who must seek to resolve the dispute within 14 days of being requested to intervene.
- (d) If the dispute is not resolved with the 10 day period or such further period as the parties agree in writing, the dispute will be referred to the Australian Commercial Disputes Centre (ACDC) for mediation in accordance with the ACDC's 'Mediation Guidelines for Commercial Mediation' which are operating at the time the matter is referred to the ACDC. The ACDC's mediation guidelines set out the procedures to be adopted, the process of selection of the mediator and the costs involved. The terms of the ACDC's mediation guidelines are hereby deemed incorporated into this Agreement.
- (e) Where a dispute is referred to the ACDC for mediation, the parties will do all things reasonably required to facilitate mediation by the ACDC.
- (f) In the event that the dispute has not been settled within 20 days (or such other period as agreed to in writing between the parties) after the appointment of a mediator, or if no mediator is appointed within 20 days of the referral of the dispute to mediation, the parties are free to pursue any other procedures available at law for the resolution of the dispute.

10.2 Notwithstanding clause 10.1, where any dispute arises that is covered by the dispute resolution process in Part 3 of the Act, the relevant provisions of that Part will apply and not clause 10.1.

11. VARIATION AND TERMINATION

Variation

11.1 This Agreement may be varied at any time, in writing and with the prior consent of both parties.

Termination by the Participant

- 11.2 At any time, the Participant may terminate this Agreement by 2 weeks' notice in writing.

Termination by the Authority

- 11.3 At any time, the Authority may terminate this Agreement with 4 weeks' notice in writing that describes the reasons for the termination.
- 11.4 Prior to the Authority terminating this Agreement under clause 11.3, it must notify the Participant in writing that:
- (a) the Authority is considering terminating the Agreement;
 - (b) the reasons why the Authority is so considering;
 - (c) allow the Participant to respond within 2 weeks from the date the notice is received, or such further time as is reasonably granted by the Authority; and
 - (d) take into consideration the Participant's response (if any).

12. BREACH AND DEFAULT**Notice to remedy breach**

- 12.1 If the Participant breaches any provision of this Agreement and the breach is, in the Authority's reasonable opinion, capable of being remedied, the Authority may:
- (a) give the Participant notice in writing of the breach and remedy; and
 - (b) require the Participant to remedy the breach within 3 weeks of the date of the notice, or such further time as is agreed by the Authority.

Termination upon default

- 12.2 The Authority may immediately terminate this Agreement by notice in writing, if the Participant commits one or more of the following events of default:
- (a) a material breach of this Agreement, which includes but is not limited to one or more failures by the Participant to comply with the obligations in clause 6 above, which in all cases is deemed to be a material breach;
 - (b) the Participant fails to remedy a breach after a notice is issued under clause 12.1;
 - (c) the Participant fails to exercise good faith, as required under clause 6.6 above;

- (d) the Authority has reasonable grounds to believe that the Participant has acted in a manner that is dishonest, fraudulent or negligent; or
- (e) the Authority has reasonable grounds to believe that there is a significant risk of harm or injury to the Participant.

12.3 If the Authority exercises its right to terminate under clause 12.2, the Authority may exercise the additional right of requiring the Participant to repay to the Authority in whole or in part the monies already paid under this Agreement, irrespectively of whether it has been expended by the Participant:

- (a) the Authority notifies the Participant in writing of the amount required to be repaid; and
- (b) allows the Participant a reasonable time to repay the specified amount, such time to be specified in the notice and to be extended if reasonably required by the Participant.

13. COSTS

13.1 Each party must bear its own legal and other costs in entering into this Agreement.

13.2 For the avoidance of doubt, the Authority is not liable to pay any monies or costs to the Participant, except as provided under this Agreement.

14. NOTICES

14.1 Any notice required to be given under this Agreement must be:

- (a) in writing; and
- (b) delivered by one of the means specified for the respective party in Items 4 and 5 of Schedule 1, or such other means as notified in writing by the parties from time to time.

14.2 A notice under this Agreement will be deemed to be received:

- (a) in the case of delivery in person - when delivered to the recipient's address for service and a signature received as evidence of delivery;
- (b) in the case of delivery by post - within three business days of posting;
- (c) in the case of delivery by facsimile – at the time of dispatch if the sender receives a transmission report which confirms that the facsimile was sent in its entirety to the facsimile number of the recipient; and
- (d) in the case of delivery by email - on receipt of confirmation by the sender that the recipient has received the email.

15. MISCELLANEOUS**Cessation**

- 15.1 No right, obligation, duty or liability under this Agreement will survive the death of the Participant.

Further Assurances

- 15.2 Each party shall use best endeavours do all things and execute all further documents as are necessary to give full effect to this Agreement.

Entire agreement

- 15.3 This Agreement constitutes the entire agreement and understanding between the parties as to the subject matter of this Agreement. Any prior arrangements, representations or undertakings as to the subject matter of this Agreement are superseded.

Severability

- 15.4 Should any part of this Agreement become prohibited, void, voidable, unenforceable or otherwise legally ineffective under general law or by force of legislation then that part shall be severed from this Agreement, the remainder of which will otherwise continue to be valid and operative.

Governing Law

- 15.5 This Agreement is governed by the laws of New South Wales and the parties submit to the jurisdiction of that State.

EXECUTED AS A DEED:

Signed, sealed and delivered by the Authority:

in the presence of

.....
Executive Director
Lifetime Care & Support Authority

.....
Witness signature

Date:

.....
Witness name (please print)

Signed by the Participant:

in the presence of

.....
Participant's signature

.....
Witness' signature

.....
Participant's name

.....
Witness' name (please print)

Date:

FINAL DRAFT

Schedule 1

Item 1 **Commencement date**

[TBC]

Item 2 **Expiry date**

[TBC]

Item 3 **Frequency of instalments**

[TBC – eg fortnightly, monthly, yearly]

Item 4 **Notices: Authority**

Address: Level 24, 580 George Street, Sydney NSW 2000

Facsimile: 1300 738 583

Email: [Confirm instructions: contact email address.]

Item 5 **Notices: Participant**

Address: [TBC]

Schedule 2
Notice of assessment and certificate

FINAL DRAFT

Schedule 3
Expenditure Declaration Form

FINAL DRAFT

200902366 D2010/312787

Appendix 5 Minutes

Minutes No. 1

Wednesday 22 June 2011

Room 1153, Parliament House, Sydney at 10.05am

1. Members Present

Mr Clarke (*Chair*)

Mr Primrose (*Deputy Chair*)

Mr MacDonald

Mrs Mitchell

Mr Moselmane

Mr Shoebridge

2. Meeting declared open

The Chair declared the meeting open.

3. Establishment of the Committee

The Chair tabled the resolution of the House of 9th May 2011 establishing the Committee.

4. Committee membership

The Chair tabled the Minutes of the House of 24th May 2011 reporting the nominations for membership of the Committee.

5. Procedural resolutions of the Committee.

Resolved, on the motion of Mr Shoebridge:

Filming, broadcasting and still photography of public proceedings

That the Committee authorises the filming, broadcasting and still photography of the public proceedings of the Committee, in accordance with the resolution of the Legislative Council of 18 October 2007.

Publishing transcripts of evidence

That, unless the Committee decides otherwise, the Committee authorises the publication of transcripts of evidence taken at public hearings.

Publishing answers to questions on notice

That, unless the Committee decides otherwise, the Committee authorises the publication of answers to questions on notice.

Publishing submissions

That, at the start of each inquiry, the Committee may decide to authorise the publication of all submissions to the inquiry, subject to the Committee Clerk checking for confidentiality, adverse mention and other issues.

Media statements

That, unless the Committee decides otherwise, media statements on behalf of the Committee may be made only by the Chair.

Inviting witnesses

That, unless the Committee decides otherwise, arrangements for inviting witness are to be left in the hands of the Chair and the Committee Clerk, after consultation with the Committee.

6. Correspondence

7. Outstanding Government responses to previous inquiries

Resolved, on the motion of Mr Shoebridge: That the Committee write to the Leader of the Government in the House seeking the Government response to the following reports:

- ***

- ***
- Third Review of the Lifetime Care and Support Authority and the Lifetime care and Support Advisory Council: due 11 May 2011.

8. ***

9. **Review of the LTCSA and the LTCSAC**

Resolved, on the motion of Mr Primrose:

That the Committee commence its Fourth Review of the exercise and functions of the LTCSA and LTCSAC.

That the Committee seek a briefing from officers of the Lifetime Care and Support Authority and Lifetime Care and Support Advisory Council, on a date to be confirmed by the Secretariat after consultation with the Committee and the LTCSA.

That the commencement of the review be publicised on the Committee's web site and through a press release on 23 June 2011.

That the review and the call for submissions be advertised in The Sydney Morning Herald, The Daily Telegraph, The Land and Media Monitors as soon as practicable.

That the Secretariat distribute to the Committee for consideration and input a list of stakeholders to be invited to participate in the review, and that the stakeholders be invited to make a submission.

That the Committee hold at least one full day of hearings on a date to be confirmed by the Secretariat in consultation with the Chair and subject to the availability of members and witnesses.

That representatives of the LTSCA and the LTCSAC be invited to appear as witnesses along with any other witnesses determined by the Secretariat in consultation with the Chair and the Committee.

That a questions on notice process be conducted prior to the hearings as has occurred in previous reviews of the LTSCA.

That during the course of the Fourth Review the Committee consider the frequency of reviews of the LTSCA and the LTCSAC, with a view to future reviews corresponding to the same timetable as that of the MAA and MAC reviews.

That the Committee authorises the publication of all submissions to the Inquiry, subject to the Committee Clerk checking for confidentiality, adverse mention and other issues.

10. **Adjournment**

The Committee adjourned at 10.35am *sine die*.

Rachel Callinan

Clerk to the Committee

Minutes No. 2

Monday 18 July 2011

Level 25, 580 George Street, Sydney at 4:30 pm

1. **Members Present**

Mr Clarke (*Chair*)

Mr Primrose (*Deputy Chair*)

Mr MacDonald

Mrs Mitchell

Mr Moselmane

Mr Shoebridge

2. **Briefing from officers of the Motor Accidents Authority and the Lifetime Care and Support Authority**

The Committee attended the MAA Board Room, Level 25, 580 George Street, Sydney and was met by the following officers:

- Andrew Nicholls, Acting General Manager of the Motor Accidents Authority

- Carmel Donnelly, former General Manager of the Motor Accidents Authority
- David Bowen, Executive Director of the Lifetime Care and Support Authority

Mr Nicholls welcomed the Committee.

Mr Nicholls and Ms Donnelly provided a briefing on the Motor Accidents Scheme.

Mr Bowen provided a briefing on the Lifetime Care and Support Scheme.

3. Adjournment

The Committee adjourned at 5.15pm *sine die*.

Rachel Callinan

Clerk to the Committee

Minutes No. 3

Monday 10 October 2011

Macquarie Room, Parliament House at 9.50 am

1. Members Present

Mr Clarke (*Chair*)

Mr Primrose (*Deputy Chair*)

Mr MacDonald

Mrs Mitchell

Mr Moselmaine (from 10.43 am)

Mr Shoebridge (from 11.45 am)

2. Minutes

Resolved, on the motion of Mrs Mitchell: That Draft Minutes Nos. 1 and 2 be confirmed.

3. Correspondence Sent

- 22 June 2011 from the Chair to the Hon Michael Gallacher MLC, Leader of the Government in the Legislative Council, seeking the Government's response to three Law and Justice Committee Reports;
- 22 June 2011 from the Chair to the Hon Greg Pearce MLC, Minister for Finance and Services, advising that the Standing Committee on Law and Justice has commenced its inquiries into the MAA and LTCSA;
- 7 July 2011 from the Chair to the Hon Greg Pearce MLC, Minister for Finance and Services, seeking a briefing with officers from the MAA and the LTCSA;
- 21 July 2011 from the Chair to the Hon Greg Smith MP, Attorney-General and Minister for Justice, seeking information on a recommendation in the Second Review of the LTCSA re issue of awarded damages for the future use of injured people being used as part of divorce settlements;
- 25 August 2011 from the Chair to the Hon Greg Pearce MLC, Minister for Finance and Services, with a list of pre-hearing questions on notice to the MAA and the LTCSA.

Received

- ***
- ***
- 29 September 2011 letter from the Hon Greg Pearce MLC, Minister for Finance and Services, to the Chair re answers to pre hearing questions on notice from the MAA and LTCSA.

4. 11th Review of the Motor Accidents Authority and 4th Review of the Lifetime Care and Support Authority

4.1 Submissions

Resolved, on the motion of Mr MacDonald: That the Committee note that MAA Submission Nos. 1 to 7 and 9 to 12, and LTCSA submission Nos 1 to 18 were published by the Committee Clerk under the authorisation of an earlier resolution.

Resolved, on the motion of Mr MacDonald: That the Committee authorise the publication of MAA Submission No. 8 with the exception of the name and other identifying details of the author which are to remain confidential.

4.2 Answers to pre-hearing questions on notice

Resolved, on the motion of Mr MacDonald: That the Committee note that answers to pre-hearing questions on notice to the MAA and LTCSA were published by the Committee Clerk under the authorisation of an earlier resolution.

4.3 Timeframe for return of answers to questions

Resolved, on the motion of Mrs Mitchell: That witnesses be requested to return answers to questions on notice and / or supplementary questions from members within 21 days of the date on which questions are forwarded to the witnesses by the committee clerk.

4.4 Public hearing

The witnesses, the public and media were admitted.

The Chair made an opening statement regarding the broadcasting of proceedings and other matters.

The following witness was sworn and examined:

- Ms Danielle De Paoli, member, Injury Compensation Committee, Law Society of NSW

The evidence concluded and the witness withdrew.

The following witnesses from the NSW Bar Association were sworn and examined:

- Mr Alastair McConnachie, Deputy Executive Director
- Mr Andrew Stone, Member, Common Law Committee

The evidence concluded and the witnesses withdrew.

The following witnesses from the Australian Lawyers Alliance were sworn and examined:

- Ms Jnana Gumbert, NSW Branch President
- Dr Andrew Morrison SC, Representative

The evidence concluded and the witnesses withdrew.

The following witnesses from the Insurance Council of Australia were sworn and examined:

- Ms Mary Maini, Chair, CTP Claims Managers Committee
- Mr Tony Mobbs, Member, Motor Accident Insurance Policy Committee

The evidence concluded and the witnesses withdrew.

The following witnesses from the Motorcycle Council of NSW were sworn and examined:

- Mr Christopher Burns, Membership and Liaison Officer
- Mr Guy Stanford, Advisor

The evidence concluded and the witnesses withdrew.

The following witnesses from the Australian Physiotherapy Association were sworn and examined:

- Mr Gary Rolls, President, NSW Branch,
- Mr Tamer Sabet, Vice President, NSW Branch
- Mr Peter Magner, NSW Branch Councillor
- Mr Chris Winston, NSW Branch Manager
- Ms Paula Johnson, Senior Policy Officer

The evidence concluded and the witnesses withdrew.

The following witnesses from The Children's Hospital Westmead were sworn and examined:

- Ms Helene Chew, Coordinator, Brain Injury Service,

- Ms Martine Simons, Senior Social Worker, Brain Injury Service

The evidence concluded and the witnesses withdrew.

The following witnesses from the Australian Medical Association were sworn and examined:

- Ms Fiona Davies, Chief Executive Officer,
- Ms Sarah Dahlenburg, Director

The evidence concluded and the witnesses withdrew.

The public hearing concluded at 4.15 pm. The public and the media withdrew.

4.5 Tendered documents

Resolved, on the motion by Mr Shoebridge: That the Committee accept and publish the following documents tendered during the public hearing:

- Prepared answers to hearing questions by Mr Andrew Stone, Bar Association of NSW
- Prepared answers to hearing questions by Mr Christopher Burns, Motorcycle Council of NSW

Resolved, on the motion by Mr Shoebridge: That the Committee accept the following document tendered during the public hearing:

- 'Differences between CTP Insurance Statistics and Crash Statistics paper by Ross McColl', by Mr Christopher Burns, Motorcycle Council of NSW.

5. Adjournment

The Committee adjourned at 4.25 pm until 9.50 am Monday 17 October 2011.

Rachel Callinan

Clerk to the Committee

Minutes No. 4

Monday 17 October 2011

Macquarie Room, Parliament House at 9.50 am

1. Members present

Mr Clarke (*Chair*)

Mr Primrose (*Deputy Chair*)

Mr MacDonalld

Mrs Mitchell

Mr Shoebridge

2. Apologies

Mr Moselmane

3. Minutes

Resolved, on the motion of Mr Shoebridge: That Draft Minutes No. 3 be confirmed.

4. 11th Review of the MAA and 4th Review of the LTCSA

4.1 Correspondence received

- 13 October 2011 letter from the Hon Greg Pearce MLC, Minister for Finance and Services, to advise the Committee of persons who will appear as witnesses for the Motor Accidents Authority and the Motor Accidents Council as well as the Lifetime Care and Support Authority and the Lifetime Care and Support Advisory Council at the public hearing to be held on 17 October 2011.

4.2 Submissions

4.3 Timeframe for return of answers to questions

Resolved, on the motion of Mrs Mitchell: That witnesses be requested to return answers to questions on notice and / or supplementary questions from members within 21 days of the date on which questions are forwarded to witnesses from the Committee Clerk.

4.4 Public hearing

The 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 Adeline Hodgkinson, Director, Brain Injury Rehabilitation Directorate
- Dr Joe Gurka, Director, Brain Injury Rehabilitation Service
- Associate Professor James Middleton, Director, State Spinal Cord Injury Service.

The evidence concluded and the witness withdrew.

The following witnesses from Spinal Cord Injuries Australia were sworn and examined:

- Mr Sean Lomas, Policy and Advocacy Manager
- Mr Tony Jones, Member, Policy and Advocacy Officer.

The evidence concluded and the witnesses withdrew.

The following witness from Injury Management IQ was sworn and examined:

- Ms Frances O'Connor, Director.

The evidence concluded and the witness withdrew.

The following witnesses from the Motor Accidents Authority were sworn and examined:

- Mr Andrew Nicholls, General Manager
- Ms Sue Freeman, Acting Deputy General Manager.

The evidence concluded and the witnesses withdrew.

The following witnesses were sworn and examined:

- Mr David Bowen, Executive Director, Lifetime Care and Support Authority
- Ms Suzanne Lulham, Director, Service Delivery, Lifetime Care and Support Authority
- Mr Dougie Herd, Chair, Lifetime Care and Support Advisory Council.

The evidence concluded and the witnesses withdrew.

The public hearing concluded at 4.50 pm. The public and the media withdrew.

4.5 Tendered documents

4.6 Independent actuarial advice

4.7 Additional questions on notice

Resolved, on the motion of Mr Primrose: That the Committee provide any additional questions on notice to the Secretariat by 12.00 pm on Wednesday 19 October 2011.

5. Other business

5.1 ***

6. Adjournment

The Committee adjourned at 5.18 pm until a time to be decided on Wednesday 19 October 2011.

Rachel Callinan

Clerk to the Committee

Minutes No. 5

Thursday 20 October 2011

Room 1153, Parliament House at 1.05 pm

1. Members present

Mr Clarke (*Chair*)

Mr Primrose (*Deputy Chair*)

Mr MacDonald

Mrs Mitchell

Mr Shoebridge

2. Apologies

Mr Moselmane

3. Minutes

4. Resolved, on the motion of Mr MacDonald: That Draft Minutes No. 4 be confirmed.

5. 11th Review of the MAA and 4th Review of the LTCSA

5.1 Submissions

6. ***

7. 11th Review of the MAA and the MAC - Independent actuarial advice

8. Adjournment

The Committee adjourned at 1.25 pm *sine die*.

Rachel Callinan

Clerk to the Committee

Minutes No. 6

Thursday 10 November 2011

Members Lounge, Parliament House at 1.05 pm

1. Members present

Mr Clarke (*Chair*)

Mr Primrose (*Deputy Chair*)

Mr MacDonald

Mrs Mitchell

Mr Moselmane (at 1.09 pm)

Mr Shoebridge

2. Minutes

Resolved, on the motion of Mr Shoebridge: That Draft Minutes No. 5 be confirmed.

3. ***

Mr Moselmane arrived.

4. **11th Review of the MAA and 4th Review of the LTCSA**

4.1 **Late submissions**

4.2 **Engaging an actuary**

4.3 **Chair's Report deliberative date**

Resolved, on the motion of Mr Primrose: That the Committee meet on Tuesday 13 December 2011 from 9.00am to 1.00pm to deliberate on the MAA and LTCSA reports.

5. **Adjournment**

The Committee adjourned at 1.35 pm until Friday 18 November 2011, at 8.30 am.

Teresa McMichael

Clerk to the Committee

Minutes No. 7

Thursday 24 November 2011

Members Lounge, Parliament House at 1.05 pm

1. **Members present**

Mr Clarke (*Chair*)

Mr Primrose (*Deputy Chair*)

Mr MacDonald

Mrs Mitchell

Mr Moselmane

Mr Shoebridge

2. **Minutes**

Resolved, on the motion of Mrs Mitchell: That Draft Minutes No. 6 be confirmed.

3. **Correspondence**

4. **11th Review of the MAA and 4th Review of the LTCSA**

4.1 **Engaging an actuary**

5. **Adjournment**

The Committee adjourned at 1.25 pm until Tuesday 13 December 2011 at 9.00 am.

Teresa McMichael

Clerk to the Committee

Draft Minutes No. 8

Tuesday 13 December 2011

Standing Committee on Law and Justice

Rm 1153, Parliament House, Sydney at 10.30am

1. **Members present**

Mr Clarke (Chair)

Mr Primrose (*Deputy Chair*)

Mr MacDonald

Mrs Mitchell

Mr Moselmane

Mr Shoebridge

2. Previous minutes

Resolved, on the motion of Mr MacDonald: That draft Minutes No. 7 be confirmed.

3. Correspondence

The Committee noted the following items of correspondence:

Received**3.1 11th Review of the MAA and 4th Review of the LTCSA*****Received***

- 17 October 2011 – From the AMA (NSW) Ltd, providing answers to QON
- 26 October 2011 – From Carers NSW, providing answers to supplementary questions
- 3 November 2011 – From the Brain Injury Service at the Children’s Hospital at Westmead, providing answers to supplementary questions
- 4 November 2011 – From the Australian Lawyers Alliance, providing answers to QON
- 7 November 2011 – From National Disability Services, providing answers to supp. questions
- ***
- ***
- ***
- 15 November 2011 – From the Law Society of NSW, providing answers to QON
- ***
- 25 November 2011 – From the LTCSA, providing answers to supplementary questions.

3.2 ***

3.3 ***

4. *****5. 4th Review of the Lifetime Care and Support Authority**

The Chair submitted his draft report entitled Fourth Review of the Lifetime Care and Support Authority and the Lifetime Care and Support Advisory Council which, having been previously circulated, was taken as being read.

Chapter 1 read.

Resolved, on the motion of Mr Shoebridge: That the following paragraph be inserted as a separate paragraph before Recommendation 1: ‘This would not prevent the Committee from reviewing the LTCSA and the LTCSAC on an annual basis if particular concerns were raised, such as the imminent implementation of a national disability insurance scheme’.

Resolved, on the motion of Mr MacDonald: That Recommendation 1 be adopted.

Resolved, on the motion of Mr Shoebridge: That Chapter 1, as amended, be adopted.

Chapter 2 read.

Resolved, on the motion of Mr Moselmane: That Chapter 2 be adopted.

Chapter 3 read.

Resolved, on the motion of Mr Shoebridge: That paragraph 3.59 be amended by inserting the words ‘which could include a family member or carer of a brain injured participant’ after the word ‘Council’.

Resolved, on the motion of Mr Primrose: That Recommendation 2 be adopted.

Resolved, on the motion of Mrs Mitchell: That Chapter 3, as amended, be adopted.

Chapter 4 read.

Resolved, on the motion of Mr Moselmane: That Recommendation 3 be adopted.

Resolved, on the motion of Mr Shoebridge: That paragraph 4.67 be amended by omitting the words ‘and will monitor this issue in future reviews’.

Resolved, on the motion of Mr Shoebridge: That a new paragraph be inserted after paragraph 4.67 as follows: ‘The Committee is of the view that the LTCSA should review the adequacy of the Accident Advice Support Grant on an annual basis and at minimum annually increase the grant to meet increases in the Consumer Price Index.’

Resolved, on the motion of Mr Shoebridge: That a new recommendation be inserted after paragraph 4.67 as follows: ‘That the Lifetime Care and Support Authority review the adequacy of the Accident Advice Support Grant on an annual basis and at minimum annually increase the grant to meet increases in the Consumer Price Index.’

Resolved, on the motion of Mr Shoebridge: That a new recommendation be inserted after paragraph 4.91 as follows: ‘That the Lifetime Care and Support Authority work with the Brain Injury Rehabilitation Directorate and other stakeholders to examine the feasibility of a more robust and independent dispute resolution process for disputes concerning eligibility and treatment’.

Resolved, on the motion of Mrs Mitchell: That Chapter 4, as amended, be adopted.

Chapter 5 read.

Resolved on the motion of Mr Moselmane: That paragraph 5.22 be amended by deleting the words ‘made simpler’ at the end of the second sentence and inserting instead ‘simplified and standardised’.

Resolved, on the motion of Mr Moselmane: That Recommendation 4 be amended to insert the words ‘and standardise’ after the word ‘simplify’.

Resolved, on the motion of Mr Moselmane: That Recommendation 4, as amended, be adopted.

Resolved, on the motion of Mr Shoebridge: That Recommendation 5 be adopted.

Resolved, on the motion of Mr MacDonald: That Recommendation 6 be adopted.

Resolved on the motion of Mrs Mitchell: That Chapter 5, as amended, be adopted.

Chapter 6 read.

Resolved, on the motion of Mr Primrose: That Recommendations 7 and 8 be adopted.

Resolved, on the motion of Mr Moselmane: That Recommendation 9 be adopted.

Resolved, on the motion of Primrose: That Recommendation 10 be adopted.

Resolved, on the motion of Mr Shoebridge: That Recommendation 11: ‘That the Lifetime Care and Support Scheme further consider funding for transport to and from leisure and recreation activities’ be deleted and replaced with: ‘That the Lifetime Care and Support Authority publish its guidelines on recreation and leisure activities and clarify its funding for the transport of participants and carers to and from recreation and leisure activities’.

Resolved, on the motion of Mr Shoebridge: That Recommendation 11, as amended, be adopted.

Resolved, on the motion of Mr Shoebridge: That paragraph 6.118 be amended by deleting the words ‘recommendations made’ and replacing them with the words ‘issues raised’.

Resolved, on the motion of Mr Shoebridge: That Recommendation 12 be amended by deleting the words ‘recommendations made’ in the first sentence and replacing them with the words ‘issues raised by’.

Resolved, on the motion of Mr MacDonald: That Recommendation 12 be further amended by inserting the words ‘liaise with the Department of Education and Training and’ after the words ‘That the Lifetime Care and Support Authority’.

Resolved, on the motion of Mr Primrose: That Recommendation 12, as amended, be adopted.

Resolved, on the motion of Mrs Mitchell: That Chapter 6, as amended, be adopted.

Resolved, on the motion of Mr Moselmane: That the Secretariat include in the report an Executive Summary that faithfully reflects the contents of the report.

Resolved, on the motion of Mr Shoebridge: That the draft report, as amended, be the report of the Committee and that the Committee present the report to the House, together with transcripts of evidence, submissions, tabled documents, answers to questions on notice and to supplementary questions, minutes of proceedings and correspondence relating to the inquiry, except for any documents kept confidential by resolution of the Committee.

6. ***

7. **Adjournment**

The Committee adjourned at 12.55 pm until 9 am on Thursday 15 December 2011.

Rachel Callinan

Clerk to the Committee