

Standing Committee on Law and Justice

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

Ordered to be printed 1 September 2009

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

New South Wales. Parliament. 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 / Standing Committee on Law and Justice. [Sydney, N.S.W.] : the Committee, 2009. – [20?] p.; 30 cm. (Report ; no. 40)

Chair: Hon. Christine Robertson, MLC.
“September 2009”.

ISBN 9781921286414

1. Lifetime Care and Support Authority of NSW.
2. Lifetime Care and Support Advisory Council (N.S.W.)
3. Traffic accident victims—Services for—New South Wales.
- I. Title
- II. Robertson, Christine.
- III. Series: New South Wales. Parliament. Legislative Council. Standing Committee on Law and Justice. Report ; no. 40

363.125 (DDC22)

How to contact the Committee

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

The Director

Standing Committee on Law and Justice

Legislative Council

Parliament House, Macquarie Street

Sydney New South Wales 2000

Internet www.parliament.nsw.gov.au

Email lawandjustice@parliament.nsw.gov.au

Telephone 02 9230 2976

Facsimile 02 9230 3371

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*.¹

¹ LC *Minutes* No 5, 30 May 2007, Item 3, p 81

Committee membership

The Hon Christine Robertson MLC	Australian Labor Party	<i>Chair</i>
The Hon David Clarke MLC	Liberal Party	<i>Deputy Chair</i>
The Hon John Ajaka MLC	Liberal Party	
The Hon Greg Donnelly MLC	Australian Labor Party	
The Hon Amanda Fazio MLC	Australian Labor Party	
Ms Sylvia Hale MLC	The Greens	

Secretariat

Ms Rachel Callinan, Director
Ms Rebecca Main, Principal Council Officer
Ms Christine Nguyen, Council Officer Assistant

Table of contents

	Chair's foreword	ix
	Executive summary	x
	Summary of recommendations	xvi
	Glossary and acronyms	xviii
Chapter 1	Introduction	1
	The Lifetime Care and Support Scheme	1
	The Committee's role	1
	Conduct of the inquiry	1
	Submissions	1
	Public hearing	2
	Questions on notice	2
	Structure of the report	2
Chapter 2	Overview of the Scheme	5
	The Scheme	5
	The Authority and the Advisory Council	6
	The Scheme process	6
	Eligibility	7
	Provisions	7
	The process	8
	Review and dispute resolution provisions	8
	Scheme utilisation	9
	Participants	9
	Financial matters	11
	Life Costing Model	11
	Premiums and the Medical Care and Injury Services Levy	12
	Case studies and participants comments	12
	Current success of scheme	15
	Future of the Scheme	16
	Committee comment	17
Chapter 3	Update from the First Review	19

	Recommendations from the First Review Report	19
	Interim participation of children	19
	Independent advice and advocacy	20
	Update on emerging issues from the First Review Report	22
	Accidents not covered by the Scheme	23
	Medical eligibility criteria	27
	Entry into the Scheme via the orthopaedics area	29
	Ability to opt-out of the Scheme and self-purchasing provisions for participants	29
	Estimated financial liabilities for the Scheme	30
	Interface with the Motor Accidents Compensation Scheme	30
	Supported accommodation	31
	Attendant care services	34
	Support for family carers	35
	Administration and resource burden for area health services and clinical staff	39
	Role of the LTCS coordinator	44
	Conclusion	49
Chapter 4	New issues for the Scheme	51
	Issues for the current Review	51
	Membership on the Lifetime Care and Support Advisory Council	51
	Revenue issues for area health services	54
	Definition of recreation and leisure activities covered by the Scheme	57
	Definition of families used by the LTCSA in applying guidelines	61
	Limited awareness of the Scheme	64
	Interim participation for people with spinal injuries	67
	Buy-in to the Scheme	68
	LTCSA Guidelines being ultra vires the Act	72
	Awarded damages being used in divorce settlements	75
	Future reviews	77
	Conclusion	77
Appendix 1	Submissions	79
Appendix 2	Witnesses at hearings	80
Appendix 3	Tabled documents	82
Appendix 4	Minutes	83

Tables and figures

Figure 1: Geographical breakdown of participants as at June 2009	9
Table 1: Scheme participants: injury type as at June 2009	10
Figure 2: Scheme participants: age group as at June 2009	10
Table 2: LTCS participants' care and support expenses, October 2006 to May 2009	11
Case study 3	13
Case study 4	13
Case study: Daniel Malouf, 17 years old	14
Case study: Ricki Lee Bell, 21 years old	14
Case study: Joel Spittles, 19 years old	14

Chair's foreword

This Second Review of the Lifetime Care and Support Authority (LTCSA) and the Lifetime Care and Support Advisory Council (LTCSAC) has been a positive experience for the Committee. We identified several years ago the desirability of a system of structured damages to meet the long-term care needs of people who are catastrophically injured in motor accidents and it is with satisfaction that we now see such a system running into its third year of operation. Overall, the Lifetime Care and Support Scheme is functioning effectively.

This Second Review has primarily focused on issues relating to the service provision for participants during acute care and rehabilitation and has recognised the start of a shift of participants moving from rehabilitation back to the community. The Committee examined issues such as supported accommodation and attendant care services for participants, support for family carers, buy in provisions for the Scheme, as well as the role recreation and leisure plays in rehabilitation and enhancing participants living circumstances.

A profoundly enlightening experience for the Committee occurred when we heard from participants and their family carers. This gave us a better understanding of how beneficial the Scheme is for them and also provided the opportunity for them to give feedback about the Scheme and the work of the Authority. The participants and the family carers gave heartening views on the benefits of the very existence of the Scheme to the ongoing support from service providers and the LTCSA. The Committee valued this input immensely and thanks the participants and their family carers for their time and effort.

The benefits of participant and family carer input to this Review has been brought through in a recommendation that consideration be given to participants being directly represented on the LTCSAC, the body that makes recommendations to the Minister regarding the Scheme. The LTCSA is open to this idea and the Committee has also recommended that a participant and family carer working group be created and facilitated by the Authority to support the participant representative on the LTCSAC.

We have also made recommendations on a number of issues including supported accommodation, impact on health resources of the Scheme, the role of the LTCS coordinator, recreation and leisure and identified the need to raise public awareness of the Scheme. The Committee will keenly observe how the Scheme will face the challenges of an increasing number of participants and a refocus on participants moving out of rehabilitation and back into the community in future annual reviews.

The input from a range of stakeholders including legal representatives, medical and rehabilitation staff, social workers, disability groups and participants and their carers has been very valuable for the Review. In addition, representatives of the LTCSA and LTCSAC gave us extensive information on the Scheme. On behalf of the Committee, I express our gratitude to all stakeholders for their significant contributions.

I thank my Committee colleagues for their informed and collaborative approach to the Review. I also express my thanks to the Committee secretariat for their highly professional support.



Hon Christine Robertson MLC
Committee Chair

Executive summary

Chapter 1 – Introduction

The Lifetime Care and Support (LTCS) Scheme is a NSW Government scheme administered by the Lifetime Care and Support Authority that provides treatment, rehabilitation and care for people who have been severely injured in a motor vehicle accident in NSW, regardless of who was at fault. The Scheme commenced operation on 1 October 2006 for children under the age of 16 and on 1 October 2007 for people aged 16 and over. It is funded by a levy collected through Compulsory Third Party (CTP) insurance.

Section 68 of the *Motor Accidents (Lifetime Care and Support) Act 2006* (NSW) requires a Legislative Council committee to supervise the exercise of the functions of the Lifetime Care and Support Authority (LTCSA) and Lifetime Care and Support Advisory Council (LTCSAC). This is the Committee's Second Review of the LTCSA and Lifetime Care and Support Advisory Council LTCSAC.

The Committee received submissions from a number of stakeholders and heard evidence from representatives of the LTCSA, the LTCSAC, the Greater Metropolitan Clinical Taskforce (GMCT), including the Brain Injury Directorate and NSW State Spinal Cord Injury Service, the NSW Bar Association, the Children's Hospital at Westmead and the Australian Association of Social Workers' Brain Injury Professional Interest Group.

The Committee also sought the input of participants and their carers to provide direct feedback to the Review about the treatment and care provided by the Scheme and their interaction with the Authority. Two participants and their family carers, as well as a carer of a third participant provided their experiences to the Committee at the public hearing.

Chapter 2 – Overview of the Scheme

Chapter 2 provides a brief overview of the LTCS Scheme and its administering body, the LTCSA. It also documents the utilisation of the Scheme to date and sets out Scheme expenditure to May 2009. Case studies provided by the LTCSA and the experiences of participants and their carers are documented in this chapter and are used to illustrate the treatment and care participants receive under the Scheme.

As at June 2009, there were 233 participants in the Scheme, of which 30 were children (under 16 years old) and the remaining 203 were adults. At the time of the Committee's First Review completed in October 2008 there were 76 participants. The majority of participants have a traumatic brain injury and/or spinal cord injury. The LTCSA advised that the overall number of participants is at the expected level. However, the Authority noted that the age profile is older than expected due to fewer children and a higher number of participants over the age of 60.

This chapter outlines the development of the Life Costing Model, a significant project related to the financial underpinnings of the Scheme. This model will allow the Authority to improve its estimation of the lifetime cost of individual participants, the cost of all participants, as well as calculating the cash flow requirements for the Authority. The Committee acknowledges the usefulness of the model and

the benefits this brings to running the Scheme. The Committee will consider how successful the model has been operating in its next review.

The Committee commends the LTCSA and the LTCSAC on the success of the Scheme to date and also the service providers, including medical practitioners and other clinical staff, for their role in aiding the smooth implementation of the Scheme. The valuable provisions the Scheme makes for lifelong treatment, rehabilitation and care services to people who are catastrophically injured in motor accidents in NSW, regardless of who was at fault in the accident, is acknowledged by the Committee. The early success of the Scheme is pleasing and the Committee considers it a potential model for other jurisdictions.

Chapter 3 – Update from the First Review

Chapter 3 provides an update on the Committee's First Review of the LTCSA and the LTCSAC completed in October 2008 and looks into the issues that require reconsideration by the Committee now that the Scheme has further matured.

In the First Review Report the Committee made two recommendations. The first related to the extending the interim participation of children in the Scheme. This is to make sure that a child who is less than three years old at the time he or she was severely injured will not have a final assessment for lifetime participation in the scheme until he or she has reached five years of age. This legislative amendment has been made.

The second recommendation related to independent advice and advocacy for participants. The Committee recommended that the LTCSA and the LTCSAC consider options for independent review of decisions and the provision of independent advice and advocacy for participants in the Scheme. In response, the NSW Government stated that there are mechanisms in place to allow for independent review of decisions. In addition, as part of a discussion paper process on advocacy for participants, the LTCSA advised that there already is a well established advocacy network that participants could access.

Stakeholders raised this issue again as part of the current Review. The main issue of concern related to how brain injured participants could exercise their right for an independent review of decisions made about their care and how these participants could access advocacy services. In response, the LTCSA commented that the Authority will include information in training sessions for service providers about how participants can access advocacy services and that the advocacy service will assist the brain injured participant as appropriate. The Committee remains concerned about the ability of brain injured participants to initiate contact with advocacy groups and encourages the LTCSA to further consider this issue. The Committee will revisit this issue in its next review.

A number of issues were raised in the First Review that were updated in this report, including, medical eligibility, entry into the Scheme via the orthopaedics area, opting-out of the Scheme, estimated financial liabilities for the Scheme, interface with the Motor Accidents Compensation Scheme, attendant care services and financial support for family carers. The majority of these issues will continue to be monitored in future reviews.

Stakeholders raised concerns regarding accidents not covered by the Scheme, and referred to the creation of a tiered system in the provision of treatment and care for people with catastrophic injuries caused by motor vehicle accidents or otherwise. The Committee heard concerns regarding whether people involved in pushbike accidents or those injured from projectiles thrown at motor vehicles

should be covered by the LTCS Scheme. The Committee notes these concerns and the possibility of a national insurance scheme that may incorporate those not covered by the LTCS Scheme.

For use in a future review, the Committee has recommended that research be conducted into the issue of people hit by a projectile whilst in a registered motor vehicle including, the number of incidents in NSW, nature and severity of injuries resulting from these incidents and the potential impact on the LTCS and Compulsory Third Party Schemes, if these incidents were to be covered.

Health practitioners brought the Committee's attention to the length of time taken to organise supported accommodation for participants and the impact this can have on hospital and rehabilitation wards accommodating the participants in the interim. The LTCSA is continuing to work on this issue and the Committee supports the GMCT recommendation for the relevant parties to continue to liaise and work together to find solutions for participants requiring supported accommodation. The Committee believes that the supported accommodation expert advisory group that has been established by the LTCSA could work more effectively to address this issue and recommends that the LTCSA examine the role and membership of the advisory group to improve its effectiveness.

Again, as in the First Review, clinical staff reported that the advent of the Scheme has seen a significant increase in administration for them in terms of completing paperwork for Scheme participants, which can distract from direct clinical time with patients. The Committee acknowledges that there is an increase in administrative work due to the Scheme but that the Authority reasonably requires detailed justification for expenditure of funds.

In response to these concerns, the Minister for Health advised the Committee that NSW Health will review the impact the Scheme has on health services' resources and that included in this review will be an assessment and analysis of the administrative demands of the Scheme. The Committee advised stakeholders of this review and asked if they had feedback to include in this review. The Committee forwarded the comments of the GMCT, the Department of Rehabilitation at the Children's Hospital at Westmead and the LTCSA to the Minister for Health for inclusion in the review.

In relation to this issue, the Committee recommends that NSW Health consider these comments as part of its review and that the results of the NSW Health review be forwarded to the Committee for its consideration.

Similar to the First Review, stakeholders raised issues relating to a general confusion of the role of the LTCS coordinator. The time at which the coordinator is introduced to potential participants and their families and inconsistencies relating to the application of the guidelines between different coordinators were also raised. The Committee acknowledges the integral role of the LTCS coordinator in providing a link between participants and their families and the Authority and heard positive feedback about the LTCS coordinators from the participants and their family carers.

There is still some confusion related to the role of the LTCS coordinator and the Committee encourages the LTCSA to continue to work with service providers to address this and to ensure Scheme participants and their families receive clear messages about the Scheme and its services. The Committee notes that the issue of consistency may be addressed through LTCS coordinator training.

The Committee recognises that, especially in the case of potential child participants, the introduction of the LTCS Scheme and the coordinator does need to be timed sensitively and recommends that the LTCSA consult with the treating rehabilitation team regarding the appropriate timing for the introduction of the LTCS coordinator in these cases.

The Committee acknowledges the issues raised by stakeholders and recognises that, overall, the Scheme is operating successfully and the concerns and issues raised by stakeholders examined in this chapter primarily relate to improving the Scheme and refining the work of the Authority.

Chapter 4 – New issues for the Scheme

Chapter 4 considers new issues for the Scheme. Stakeholders raised a number of issues that the Committee has committed to reviewing in future reviews as the Scheme further develops. These issues include the definition of families used by the LTCSA in applying the LTCS Guidelines, interim participation of people with spinal injuries, buy in provisions for people injured prior to the commencement of the Scheme and the LTCSA Guidelines being ultra vires or beyond the power of the *Motor Accidents (Lifetime Care and Support) Act 2006*.

An issue related to the administration burden of the Scheme canvassed in Chapter 3 is how revenue is returned to a particular public health unit for the provision of the service it provides to LTCS participants and how the additional time spent on administration for the Scheme impacts on revenue for the unit. The Committee has heard that in the case of some public health services, reimbursement may go to the area health service instead of the actual health unit.

The suggestion by the GMCT of a memorandum of understanding has merit and the LTCSA itself has raised the possibility of a ‘contract agreement’ to address this issue. The Committee notes that NSW Health will be considering the impact of the Scheme on health services resources and the Committee will await the outcome and results of that review. The Committee has requested that the results of the NSW Health review be made available to it. This issue will continue to be monitored and will be revisited in a future review.

The role of the LTCSAC is to advise the Minister on matters relating to the LTCS Scheme. While the Committee did not receive a great deal of evidence on this issue, it does seem appropriate for participants to be directly represented on the LTCSAC in order to ensure that participants are given a voice on the body that makes recommendations to the Minister regarding the Scheme. The Committee notes that the Authority also considered this to be a desirable outcome for the future and therefore recommends that the membership of the Advisory Council be reviewed and consideration given to including at least one participant representative.

In order to support the participant representative, the Committee recommends that the LTCSA should create and facilitate a small working group of representative participants and their family carers to examine participant and family carer issues, from which the representative could then report to the Advisory Council.

The significant contribution and role that allied health workers and professionals have within the Scheme was brought to the Committee’s attention during the Review. Based on this and the views of stakeholders in this regard, the Committee recommends that the membership review of the Advisory Council also consider including representatives of allied health workers and professionals.

Some stakeholders raised concerns regarding the definition of recreation and leisure activities used by the LTCSA when considering requests for funding for, or access to, these activities for LTCS Scheme participants. The Committee acknowledges that it is important for participants to have access to recreation and leisure activities in order to enhance their living circumstances.

The Committee notes that unless it is part of a rehabilitation program the LTCSA will only fund a participants access to that activity. If it is part of the rehabilitation program the LTCSA will fund the actual activity. The Committee recognises that covering the actual cost of recreation and leisure activities may have a financial impact on the Scheme, especially in the long term as lifetime participation increases.

However, the Committee understands the contribution these activities can make to the rehabilitation of participants including learning socialisation skills and recognises that it could be argued that most recreation and leisure activities form part of the psychosocial rehabilitation for participants in the Scheme. There is concern that some participants may not partake in recreation and leisure activities if the cost was to fall onto the participant and/or their family, and may therefore, miss out on opportunities to improve their life circumstances, especially for those participants who are not able to return to vocational employment or education as a result of the severity of injuries.

For these reasons, the Committee recommends that the LTCSA carefully examine the role that recreation and leisure has in the psychosocial rehabilitation of participants and the desirability of the LTCSA funding these activities, especially for those participants who are not able to return to vocational employment or education. In addition, the Committee recommends that the LTCSA, when interpreting the definition of recreation and leisure, take a broad approach so that, where appropriate, it includes unusual activities that may be of particular interest and therapeutic value to some participants, such as those activities described by participants who gave evidence to the Committee.

Another issue that came to the Committee's attention during its Review was the limited awareness of the LTCS Scheme. The GMCT highlighted the limited awareness of the Scheme by some service providers, especially those in rural and cross boarder locations. The Committee acknowledges the LTCSA efforts in raising awareness of the Scheme for those who will be directly involved, including health workers and other services providers and recommends that it ensure education campaigns are wider spread to address awareness issues in rural and cross border areas.

The Committee heard that participants and family members might find the initial confrontation with the Scheme's existence overwhelming. Potentially, the knowledge alone that the LTCS Scheme exists before they find themselves in the unfortunate circumstance of experiencing significant injury on the roads may help these families and participants. The Committee therefore recommends that the LTCSA consider conducting community awareness campaigns of the LTCS Scheme for the general public.

In addition, general public awareness of the Scheme would also contribute to greater understanding of the Scheme, leading to potential participants being identified more quickly and a general increase in the receptiveness to the Scheme by the community and those involved. A community awareness campaign also provides an opportunity to communicate the benefits of the existence of the Scheme and its positive role in helping people who are severely injured in motor accidents.

A final issue that was brought to the attention of the Committee by the LTCSA was that lump sum compensation awarded to accident victims for their future care was being treated as capital by the Family Court in divorce settlements. The Committee acknowledges the NSW Bar Association's advice on this issue. In particular, that the Family Court would determine each matter on the facts of the individual case and that legislative changes to create a blanket ban on such awards being taken into account by the Family Court may not have the desired impact. However, the Committee is mindful that the issue of awarded damages being used in legal settlements may have an impact on a person's ability to buy into the LTCS Scheme and requests that the Minister for Finance refer this issue to the NSW Attorney General for examination.

The Committee notes that there were a number of other issues raised by stakeholders that have not been covered in detail in this Review. It may be that these concerns emerge as more substantial issues as time goes on and may be examined by the Committee in one of the future reviews of the LTCSA.

As a whole the Scheme is functioning effectively and issues raised in this chapter, once addressed as per the Committee's recommendations, would see the Scheme and Authority continuing to develop on its positive path of delivering lifetime care and support for its participants.

The Committee recognises that future challenges will be encountered as the Scheme matures. The LTCSA has already identified the future challenge of the increasing number of participants moving from rehabilitation and back into the community and the change in focus for the Authority from treatment and rehabilitation to engaging participants in the community through recreation, leisure, school, vocational and employment related services.

The contributions made to this Review by stakeholders, participants and their carers, and the LTCSA are valued by the Committee and it looks forward to conducting its next review to continue to help the LTCSA improve the Scheme for its participants.

Summary of recommendations

- Recommendation 1** **27**
That the Minister for Finance request the Lifetime Care and Support Authority or the Motor Accidents Authority, as appropriate, to conduct research into the issue of people hit by a projectile whilst in a registered motor vehicle including:
- the number of incidents in NSW,
 - nature and severity of injuries resulting from these incidents and
 - the potential impact on the Lifetime Care and Support and Compulsory Third Party Schemes, if these incidents were to be covered.
- Recommendation 2** **34**
That the Lifetime Care and Support Authority examine the role and membership of the supported accommodation expert advisory group to improve its effectiveness.
- Recommendation 3** **44**
That the Minister for Health request NSW Health to:
- consider the comments of the Greater Metropolitan Clinical Taskforce, the Department of Rehabilitation at the Children’s Hospital at Westmead and the Lifetime Care and Support Authority as part of its review of the impact of the Lifetime Care and Support Scheme on health service resources, and
 - provide the results of its review to the Committee, once they become available.
- Recommendation 4** **49**
That the Lifetime Care and Support Authority, in the case of potential child participants, consult with the treating rehabilitation team regarding the appropriate timing for the introduction of the Lifetime Care and Support coordinator.
- Recommendation 5** **54**
That the Minister for Finance review the membership of the Lifetime Care and Support Advisory Council to consider including representatives of Lifetime Care and 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*.
- Recommendation 6** **54**
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.
- Recommendation 7** **61**
That the Lifetime Care and Support Authority:
- carefully consider the role that recreation and leisure has in the psychosocial rehabilitation of participants and reconsider funding the cost of recreation and leisure activities (and not just access to the activity), especially for those participants who are not able to return to vocational employment or education, and
 - when interpreting the definition of recreation and leisure, a broad approach be taken so that, where appropriate, it includes unusual activities that may be of particular interest and therapeutic value to participants.

Recommendation 8

67

That the Lifetime Care and Support Authority:

- ensure its education campaigns are wider spread to address awareness issues for service providers in rural and cross border areas and
- consider conducting community awareness campaigns of the Lifetime Care and Support Scheme for the general public.

Recommendation 9

77

That the Minister for Finance request that the NSW Attorney General examine the issue of awarded damages for the future care of injured people being used as part of divorce settlements and other legal settlements, and if appropriate, refer the issue to the Standing Committee of Attorney Generals.

Glossary and acronyms

The Authority	Lifetime Care and Support Authority
CTP	Compulsory Third Party (NSW)
LTCSA	Lifetime Care and Support Authority
LTCSAC	Lifetime Care and Support Advisory Council
LTCS Scheme	Lifetime Care and Support Scheme
The Scheme	Lifetime Care and Support Scheme

Chapter 1 Introduction

In this chapter the Committee outlines its role in reviewing the Lifetime Care and Support Authority (LTCSA) and the Lifetime Care and Support Advisory Council (LTCSAC) and describes the process of this Second Review of the LTCSA and LTCSAC.

The Lifetime Care and Support Scheme

- 1.1 The Lifetime Care and Support (LTCS) Scheme is a NSW Government scheme administered by the LTCSA that provides treatment, rehabilitation and care for people who have been severely injured in a motor vehicle accident in NSW, regardless of who was at fault. The Scheme commenced operation on 1 October 2006 for children under the age of 16 and on 1 October 2007 for people aged 16 and over. It is funded by a levy collected through Compulsory Third Party (CTP) insurance.²
- 1.2 Details of the structure of the LTCS Scheme are provided in Chapter 2.

The Committee's role

- 1.3 Section 68 of the *Motor Accidents (Lifetime Care and Support) Act 2006* (NSW) requires a Legislative Council committee to supervise the exercise of the functions of the LTCSA and LTCSAC. The Standing Committee on Law and Justice was appointed on 30 May 2007 to fulfil this function and report to the House at least once a year.³ This is the Committee's Second Review of the LTCSA and LTCSAC.

Conduct of the inquiry

- 1.4 The Committee resolved to commence this Second Review on 19 March 2009.

Submissions

- 1.5 The Committee continued the practice undertaken in the first review to call for public submissions by way of advertisements in major metropolitan newspapers. As with the last review, the Committee also wrote directly to a number of stakeholders inviting them to make a submission. At the Committee's request the LTCSA advertised the review through its E-Newsletter, which targets Scheme participants and service providers.
- 1.6 The Committee received 14 submissions. Those individuals and organisations who made a submission are listed in Appendix 1.

² Lifetime Care and Support Authority, *Annual Report, 2007-2008*, p 2

³ LC Minutes No 5, 30 May 2007, Item 3, p 81

Public hearing

- 1.7 The Committee held a public hearing on 26 June 2009 at which representatives from the LTCSA gave evidence, including Mr David Bowen, Chief Executive Officer, Mr Stephen Payne, Chief Financial Officer, Ms Suzanne Lulham, Director of Service Delivery, Mr Neil Mackinnon, Manager of Service Coordination along with Mr Richard Grellman, Chairman of the LTCSA Board and Mr Dougie Herd, Chairman of the LTCSAC.
- 1.8 The Committee also heard from a panel of witnesses representing the Greater Metropolitan Clinical Taskforce: Dr Adeline Hodgkinson, Chair, Brain Injury Rehabilitation Directorate; Dr Joe Gurka, Director at Westmead Brain Injury Rehabilitation Unit; Associate Professor James Middleton, Director, NSW State Spinal Cord Inquiry Service and Ms Jenni Johnson, Manager of Spinal Outreach, NSW State Spinal Cord Injury Service.
- 1.9 Representatives of the NSW Bar Association, the Children's Hospital at Westmead and the Australian Association of Social Workers' Brain Injury Professional Interest Group also appeared.
- 1.10 The Committee also sought the input of participants and their carers to provide direct feedback to the Review about the treatment and care provided by the Scheme and their interaction with the Authority. Two participants and their family carers, as well as a carer of a third participant provided their experiences to the Committee at the public hearing.
- 1.11 A full list of witnesses is provided in Appendix 2.

Questions on notice

- 1.12 Following the practice developed over the various reviews of the Motor Accidents Authority and the first review of the LTSCA, the Committee forwarded a number of written questions on notice to the LTCSA prior to the hearing. The questions were based on the LTCSA's *Annual Report 2007-2008*, LTSCA E-Newsletters, last year's review and issues raised in submissions.
- 1.13 The LTCSA provided detailed responses to the Committee's questions which other stakeholders, in turn, were asked to respond to in the hearing and in further questions on notice. This enabled significant depth of consideration of the issues.
- 1.14 The Committee expresses its thanks to all those who participated in this Review.

Structure of the report

- 1.15 This report is comprised of four chapters. This first chapter outlines the Committee's role in reviewing the LTCSA and LTCSAC and sets out the process undertaken by the Committee during this Review.
- 1.16 Chapter 2 provides a brief overview of the Scheme and the LTCSA. It also documents the utilisation of the Scheme to date and sets out Scheme expenditure to May 2009. The chapter uses a number of case studies to illustrate participants' treatment and care under the Scheme and concludes with comment on the success of the Scheme and its future challenges.

- 1.17** Chapter 3 provides an update on the Committee's recommendations from the first Review of the exercise of the functions of the LTCSA and the LTCSAC reported on in October 2008 and looks into the issues that require reconsideration by the Committee now that the Scheme has further matured.
- 1.18** Chapter 4 considers new issues raised by stakeholders during the current Review. Some of these issues the Committee noted as emerging issues from its first Review and have now become more apparent with the development of the Scheme. The chapter will also briefly outline issues that may be relevant for the Committee to consider in future reviews.
- 1.19** The Committee recognises that, overall, the Scheme is operating successfully and the concerns and issues raised by stakeholders primarily relate to improving the Scheme and refining the work of the Authority.

Chapter 2 Overview of the Scheme

This chapter provides a brief overview of the Lifetime Care and Support (LTCS) Scheme and its administering body, the Lifetime Care and Support Authority (LTCSA). It also documents the utilisation of the Scheme to date and sets out Scheme expenditure to May 2009. The chapter uses a number of case studies to illustrate participants' treatment and care under the Scheme and concludes with comment on the success of the Scheme and its future challenges.

More detail on the establishment and genesis of the Scheme can be found in Chapter 2 of the Committee's 2008 report on its first Review of the exercise of the functions of the Lifetime Care and Support Authority and the Lifetime Care and Support Advisory Council (hereafter referred to as the First Review Report).

The Scheme

- 2.1 The Scheme was established under the *Motor Accidents (Lifetime Care and Support) Act 2006* (hereafter referred to as the Act) and commenced on 1 October 2006 for people under the age of 16 and on 1 October 2007 for people aged 16 and over.⁴
- 2.2 The LTCS Scheme provides 'lifelong treatment, rehabilitation and attendant care services to people severely injured in motor accidents in NSW, regardless of who was at fault' in the accident. The Scheme covers catastrophic injuries including spinal cord injury, moderate to severe brain injury, severe burns and multiple amputations or permanent blindness.⁵
- 2.3 In comparison to the Motor Accidents Compensation Scheme, which provides monetary compensation for injury, the LTCSA coordinates and pays for the treatment and care services that are reasonable and necessary to meet the needs of participants.⁶
- 2.4 As stated in the LTCSA *Annual Report 2007-2008* (hereafter referred to as the Annual Report), the vision of the Scheme is to make sure 'people severely injured in motor accidents in NSW are treated with respect and dignity and have the maximum possible opportunities and choices in achieving quality of life.'⁷
- 2.5 Part 7 of the Act sets out how the Scheme is funded. Funding is provided through the Medical Care and Injury Services 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 Authority. The Act states that levy contributions must be set so as to fund the full cost of

⁴ Lifetime Care and Support Authority (LTCSA), *Annual Report, 2007-2008*, p 2

⁵ LTCSA, *Annual Report, 2007-2008*, p 2

⁶ 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* (hereafter referred to as the First Review Report), Report 37, October 2008, p5

⁷ LTCSA, *Annual Report, 2007-2008*, p 2

providing lifetime care and treatment to Scheme participants, and meet other Scheme expenses.⁸

The Authority and the Advisory Council

2.6 The LTCS Scheme is administered by the LTCSA, which is in turn advised and monitored by the LTCS Advisory Council (LTCSAC). The functions of the LTCSA are set out in the Act.

2.7 The LTCSA coordinates and funds the provision of care, treatment and rehabilitation for lifetime support and other services for participants. In addition, among other things, the Authority:

- monitors the operation of the Scheme and conducts research and collects statistics in relation to its operation
- advises the Minister on the administration, efficiency and effectiveness of the Scheme and publicise and disseminate information
- provides administrative support, advice and recommendations to the LTCSAC
- monitors and provides 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.⁹

2.8 The LTCSA has a Board of Directors consisting of the Chief Executive Officer of the Authority and four part-time directors.¹⁰ The Board has the function of determining the administrative policies of the Authority and, in exercising that function, it must ensure that, as far as practicable, the activities of the Authority are carried out properly and efficiently.¹¹

2.9 The LTCS Advisory Council's primary role is to monitor the operation of the services provided by the LTCSA by advising and making recommendations to the Authority on the LTCS Guidelines, and keeping them under review. In addition, the Council can provide advice to the LTCSA or the Minister on any matter relating to the Scheme that it considers appropriate.¹²

The Scheme process

2.10 This section briefly outlines eligibility for the Scheme, its provisions, the process of being part of the Scheme and the dispute resolution mechanisms. These mechanisms were dealt with in detail in the Committee's First Review Report.¹³

⁸ The Hon Della Bosca MLC, *NSWPD (Legislative Council)*, 4 April 2006, p 21919

⁹ *Motor Accidents (Lifetime Care and Support) Act 2006* (NSW), s 43

¹⁰ *Motor Accidents (Lifetime Care and Support) Act 2006* (NSW), s 34

¹¹ *Motor Accidents (Lifetime Care and Support) Act 2006* (NSW), s 39

¹² First Review Report, p13

¹³ First Review Report, pp7-12

Eligibility

- 2.11** To be eligible to participate in the LTCS Scheme, a person's injury must result from an accident involving a motor vehicle insured under the NSW Compulsory Third Party (CTP) Scheme, as prescribed by the *Motor Accidents Compensation Act 1999*.¹⁴
- 2.12** The LTCS Scheme does not cover injuries arising from use or operation of a motor vehicle that is not capable of registration, or the use or the operation of an unregistered and uninsured vehicle on private property.¹⁵
- 2.13** Eligibility for the Scheme is dependant on the type and severity of injury and is determined on the basis of medical assessment.¹⁶ There are different eligibility criteria in respect to spinal cord injuries, brain injuries, severe burns, multiple amputations and permanent blindness.¹⁷
- 2.14** Eligibility is a two-stage process as there is interim and lifetime participation in the Scheme. Eligibility for interim participation is assessed soon after injury and is for a period of up to two years for those over three years old. Interim participation for children under this age will continue until they reach the age of five years, after which lifetime participation will be assessed. This interim period exists because of possible recovery and improvements that may occur during that time.¹⁸
- 2.15** Lifetime participation is assessed before the expiry of the interim period.¹⁹ Because the Scheme is still maturing, as at June 2009, there were only four lifetime participants in the Scheme.²⁰ As the Scheme develops it is anticipated that this number will grow significantly as it is presumed that a majority of participants will remain in the Scheme for life.²¹

Provisions

- 2.16** The LTCSA pays for treatment, rehabilitation and care services that are reasonable and necessary to help meet the participants' needs and achieve their goals. 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 refer to personal or respite care, childcare, domestic assistance and educational or vocational support.²²

¹⁴ First Review Report, p7

¹⁵ First Review Report, p7

¹⁶ LTCSA, *Annual Report, 2007-2008*, p7

¹⁷ The Hon Della Bosca MLC, *NSWPD (Legislative Council)*, 4 April 2006, p 21921; LTCSA, *LTCS Guidelines*, Part 1 – Eligibility for participation in the LTCS Scheme, 28 September 2007

¹⁸ LTCSA, *Annual Report, 2007-2008*, p7 and *Motor Accidents (Lifetime Care and Support) Act 2006*, s5(A)

¹⁹ LTCSA, *Annual Report, 2007-2008*, p7

²⁰ LTCSA, Answers to pre-hearing questions on notice, Attachment 1, p1

²¹ First Review Report, p10

²² First Review Report, p9

The process

- 2.17** The First Review Report conducted by the Committee describes in detail the usual process of being accepted into the Scheme.²³
- 2.18** To enter the Scheme an initial notification process involves hospital staff, brain or spinal injury teams, or social workers assisting the injured person and their family to notify the LTCSA if they believe the injuries sustained may make the person eligible for the Scheme. Notification is made via either a phone call or by sending a completed Severe Injury Advice Form.²⁴
- 2.19** On receipt of this notification, a LTCS coordinator meets with the injured person and his or her family to explain the Scheme and the application process. A more detailed Application Form requests information about the motor accident, as well as a medical certificate completed by a treating specialist. The application is then assessed and the injured person and treating team are informed of the commencement date for interim participation.²⁵
- 2.20** All participants in the LTCS Scheme are assigned a LTCS Coordinator who will act as the primary point of contact between the participant, service providers and the LTCSA.²⁶
- 2.21** There are three types of plans that the coordinator will help the participant develop. The LTCS Plan is concerned with meeting the individual participant's current and future needs and aspirations, the Community Discharge Plan focuses on facilitating the move between hospital to home and the Community Living Plan outlines necessary services for the ongoing support of the participant. This last plan is regularly reviewed.²⁷

Review and dispute resolution provisions

- 2.22** The Act makes provisions for the LTCSA to review decisions regarding the eligibility and treatment, rehabilitation and care needs of applicants and participants.²⁸ Wherever possible, the LTCSA will try to resolve the issue informally, however, this might not be possible and a formal dispute may be lodged in writing. Independent assessors are used to resolve disputes.²⁹
- 2.23** The Authority reported to the Committee that there had been no disputes relating to eligibility or motor accident injury to date. There have been two disputes in relation to the treatment and care needs of two participants. One dispute relating to the approval of a road bicycle has been resolved with the use of a dispute assessor. The Authority indicated that the second

²³ First Review Report, pp 9-11

²⁴ First Review Report, p9

²⁵ First Review Report, p9

²⁶ First Review Report, p10

²⁷ First Review Report, p10

²⁸ *Motor Accidents (Lifetime Care and Support) Act 2006*, Parts 3 & 4

²⁹ LTCSA, *Resolving disputes about eligibility, A guide for applications to the LTCS Scheme*, September 2007 and LTCSA, *Resolving disputes about treatment and care needs, A guide for participants of the LTCS Scheme*, September 2007

dispute, relating to workplace modification, is likely to be resolved without the need for external assessment.³⁰

Scheme utilisation

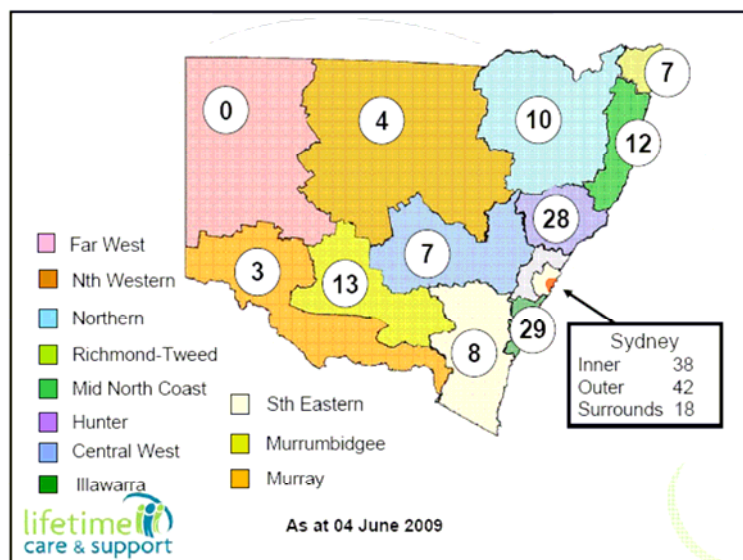
2.24 This section describes the participants in the Scheme including their sex, age, location, injury type and the role they had in the accident, for example, driver, passenger or pedestrian.

Participants

2.25 As at June 2009, there were 233 participants in the Scheme, 162 of whom were male and 71 female. Of the 233 participants, 30 were children (under 16 years old) and the remaining 203 were adults. Included in the 233 participants are two participants that are deceased.³¹ At the time of the Committee's First Review there were 76 participants.³²

2.26 Below is a geographical breakdown of the location of the participants provided by the LTCSA.

Figure 1: Geographical breakdown of participants as at June 2009³³



³⁰ LTCSA, Answers to pre-hearing questions on notice, p20

³¹ LTCSA, Answers to pre-hearing questions on notice, Attachment 1, p1

³² First Review Report, p16

³³ LTCSA, Answers to pre-hearing questions on notice, Attachment 1, p3

2.27 The type of injuries sustained by the participants is outlined in the table below.

Table 1: Scheme participants: injury type as at June 2009³⁴

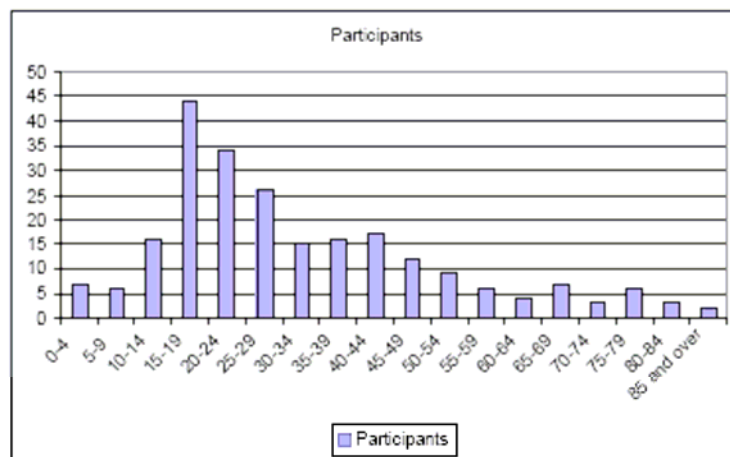
Injury type	Paediatric	Adult
Traumatic brain injury	25	155
Spinal cord injury	4	44
Traumatic brain injury & spinal cord injury	1	2
Multiple amputations	0	1
Severe burns (with spinal cord injury	0	1

2.28 Of the 30 child participants, their role in the motor accidents that caused their injuries was as follows: 16 passengers, 9 pedestrians, and 5 cyclists/other (including one driver).³⁵

2.29 Of the 162 adult participants, their role in the motor accidents that caused their injuries was as follows: 56 motorbike riders (including 4 pillion passengers), 61 drivers, 45 passengers, 37 pedestrians and 4 cyclists/other.³⁶

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

Figure 2: Scheme participants: age group as at June 2009³⁷



2.31 The LTCSA advised that the overall number of participants is at the expected level. However, the Authority noted that the age profile is older than expected due to fewer children and a higher number of participants over the age of 60. Also, the Authority indicated that the level of severity of the injuries has been higher than expected.³⁸

³⁴ LTCSA, Answers to pre-hearing questions on notice, Attachment 1, p3

³⁵ LTCSA, Answers to pre-hearing questions on notice, Attachment 1, p4

³⁶ LTCSA, Answers to pre-hearing questions on notice, Attachment 1, p4

³⁷ LTCSA, Answers to pre-hearing questions on notice, Attachment 1, p6

³⁸ LTCSA, Answers to pre-hearing questions on notice, p1

Financial matters

2.32 Detailed income statements and expenditure tables for the Scheme are provided in the Authority's Annual Report 2007-2008 and have not been reproduced here. However, in its answers to questions prior to the hearing the Authority provided a more current breakdown of actual expenditure from when the Scheme commenced until May 2009 (this does not include accrued expenses for which the Authority has yet to be invoiced by some service providers).

Table 2: LTCS participants' care and support expenses, October 2006 to May 2009³⁹

Expenses	\$'000
Attendant care	2,326
Hospital	10,216
Medical	5,974
Equipment	1,285
Home modifications	527
Vehicle modifications	46
Other	52
Total	20,427

Life Costing Model

2.33 During this Review, the Committee was advised of a current project related to the financial underpinnings of the Scheme: the Life Costing Model. This model will allow the Authority to estimate the lifetime cost of individual participants, the cost of all participants, as well as calculating the cash flow requirements for the Authority.⁴⁰

2.34 In terms of predicting how much it will cost to provide lifetime care and support for a participant, at the moment the Authority uses actuarial averages to project what a person's needs will be over life. However, as the Scheme matures, the Authority can begin to use actual information to achieve a better estimate of costs associated with the lifetime care and needs of participants.⁴¹

2.35 According to the Authority, currently the Life Costing Model gives it the ability to report on actual Scheme costs by participant and cost category and against budget and forecasts. Once completed and integrated with the Authority's financial system, the model will also enable the

³⁹ LTCSA, Answers to pre-hearing questions on notice, p1

⁴⁰ LTCSA, *Annual Report 2007-2008*, p11 and p15

⁴¹ Mr David Bowen, Chief Executive Officer, Lifetime Care and Support Authority, Evidence, 26 June 2009, p4

Authority to generate real-life historical analysis and forecasts/predictions of cost variations per participant, group and the overall Scheme.⁴²

- 2.36** Mr David Bowen, Chief Executive Officer of the LTCSA, indicated that, ultimately, the Life Costing Model will allow the Authority to put in the person's age, injury, the severity of the injury and the assessment of their care and needs (using the care-and-needs scales that clinicians produced for the Scheme) and the model will provide an estimate of the costs associated with the lifetime care and support for that person.⁴³
- 2.37** The Committee acknowledges the usefulness of the Life Costing Model to provide more accurate estimates of the lifetime costs of care for participants and the benefits this brings to running the Scheme. The Committee notes that the Authority has not provided a timeframe of when the Life Costing Model will be fully operational but will look into how successful the model has been operating in its next review.

Premiums and the Medical Care and Injury Services Levy

- 2.38** As mentioned earlier, the Scheme is funded through the Medical Care and Injury Services Levy paid by motorists when they purchase a CTP green slip insurance policy.
- 2.39** The Annual Report identifies a substantial surplus for 2007/2008 that has increased from last year to form equity of over \$160 million, and indicates that it is mainly due to a significantly lower than expected number of children participants. As a result of this the Board of the Authority has reduced the expected number of children for the next round of levy setting by 30%.⁴⁴
- 2.40** The Authority indicated that the number of children entering the Scheme each year has averaged 10 per year compared to an expected 20 to 35 per year. The Board's reduction in expected numbers reflects the trend in hospital data but still leaves an estimate above actual experience in case this trend is not long term. If the trend does continue the Authority advised that it will continue to reduce the projections and lower the levy.⁴⁵
- 2.41** The Authority advised that it has reduced the levy by 2.8% from 1 February 2009 to off-set increases in income due to higher CTP premiums. The Board has also determined to cut the levy by a further 5% early in 2009/2010.⁴⁶

Case studies and participants comments

- 2.42** The Committee sought de-identified case studies of actual Scheme participants to provide an indication of the treatment and care that participants are receiving under the Scheme and the

⁴² LTCSA, Answers to pre-hearing questions on notice, p5

⁴³ Mr Bowen, Evidence, 26 June 2009, p4

⁴⁴ LTCSA, *Annual Report 2007-2008*, p21

⁴⁵ LTCSA, Answers to pre-hearing questions on notice, p7

⁴⁶ LTCSA, Answers to pre-hearing questions on notice, p7

challenges faced by the Authority in providing that care. Two of the case studies are set out below.⁴⁷

Case study 3

Participant C is a 30 year old motor bike rider injured in a single vehicle accident in 2008. He sustained a complete thoracic spinal injury resulting in paraplegia. He received his acute care and rehabilitation in a Sydney spinal unit but lives in a large rural town in NSW. During rehabilitation the Authority commissioned an occupational therapist and a home modification project manager to assess the family home where he previously lived with his parents and partner. The final recommendation was to construct a suitable dwelling on the family owned residential property. While this has been in progress, the Authority has funded interim accommodation in the rural town.

Providing the necessary services to the participant has required comprehensive case management. Support from Sydney based spinal experts has been provided for the local service providers. The Authority has also funded the participant returning to Sydney for specialist medical appointments.

While the home modifications have been underway, the participant has continued to receive physical therapy and a vocational program. It is anticipated that one year following injury the participant and his partner will be in suitable permanent accommodation in their home town and preparing to start their own small business.⁴⁸

Case study 4

Participant D is a 38 year old pedestrian who sustained a very severe brain injury. He is now living in supported accommodation after 14 months in acute care and rehabilitation. He continues to require 24 hour care a day for all his basic needs. He has medical complications including severe spasticity and blood clots.

It was identified that the ability of the participant's family to support him at home would be very limited. The available services to meet all the requirements of a young person with high level care needs are limited. For this participant the Authority, together with his family and treating team, have supported a novel solution using services from several providers. The Northcott Society have provided suitable interim accommodation. The Community Integration Program from Royal Rehabilitation Centre provides accommodation management, therapy and attendant care services. The brain injury program is providing case management and medical oversight. In the longer term, housing will be provided by a community housing provider in an area close to his family. This solution brings together providers who in the past have not worked together. At this stage it requires careful monitoring but demonstrates the existence of expertise that can be brought together for an individual.⁴⁹

2.43 The Committee also invited participants and their carers to provide direct feedback to the Review about the treatment and care provided by the Scheme and their interaction with the Authority. Two participants and their family carers, as well as a carer of another participant

⁴⁷ LTCSA, Answers to pre-hearing questions on notice, pp3-5

⁴⁸ LTCSA, Answers to pre-hearing questions on notice, p4

⁴⁹ LTCSA, Answers to pre-hearing questions on notice, p5

provided their experiences to the Committee in person and their case studies as set out below.⁵⁰

Case study: Daniel Malouf, 17 years old

Daniel Malouf was a pedestrian who was struck down by a car in the Sydney CBD in December 2006. He sustained a brain injury as a result of the accident. He was in a coma for 10 days at St Vincent's Hospital and was then transferred for treatment to the Liverpool Hospital Brain Injury Unit. Within 24 hours after the accident, a social worker at St Vincent's Hospital informed his family that he may be eligible for entry into the Lifetime Care and Support Scheme. Daniel met the eligibility criteria and was accepted as the first participant of the Scheme in March 2007.

The Scheme has helped Daniel and his family immensely, his father John Malouf advising 'it has been very easy for us to be assimilated into it.' Daniel has received comprehensive care and support from the Scheme. The Brain Injury Unit taught him how to walk again, how to catch a train, handle money, and how to make everyday decisions. His case manager has helped through the arrangement of doctors' appointments, reimbursements for travel expenses, as well as organising driving lessons. Daniel will continue to receive care and support through the Scheme as he has been accepted as a lifetime participant due to the nature of his injuries.⁵¹

Case study: Ricki Lee Bell, 21 years old

Ricki-Lee Bell has been an interim participant of the LTCS Scheme since November 2008. She sustained a traumatic brain injury and was in an induced coma for 12 days at John Hunter Hospital after being thrown from a vehicle when the driver took off and did a U-turn over the median strip before the door was shut. Ricki-Lee's family was first approached by a social worker at the hospital who advised that she may be eligible to enter the Scheme. Ricki-Lee was a live-in patient at Newcastle's Hunter Brain Injury Unit for approximately two months and is currently continuing drop-in treatments three times a week. LTCSA has paid for all her medical expenses, including prescriptions, and travel expenses. Ricki-Lee will be assessed for lifetime participation before her two year interim period ceases.⁵²

Case study: Joel Spittles, 19 years old

Joel Spittles is an interim participant of the LTCS Scheme. Joel was 17 years old when his vehicle hit a tree in February 2008. He was the only person involved in the accident and was classed as an at-fault driver. Joel sustained a severe traumatic brain injury as well as some spinal injuries. Joel was in intensive care for 16 days, followed by three weeks in the neurosurgical section at the Royal North Shore Hospital. He subsequently continued his treatment at the Royal Rehabilitation Centre at Ryde.

⁵⁰ Evidence, 26 June 2009, pp38-50

⁵¹ Evidence, 26 June 2009, pp38-50

⁵² Evidence, 26 June 2009, pp38-50

The Lifetime Care and Support coordinator approached Joel's mother Zivana about three weeks into Joel's recovery to suggest he may be eligible for the Scheme. Zivana stated that the Scheme has been a relief for her family. Since entering the Scheme, Joel and his family have been provided with carers, cleaners as well as counselling services to help handle situations as they arise.

Joel has been provided with medical support including brain injury rehabilitation, speech therapy, occupational therapy, physiotherapy and has had his gym membership paid to help strengthen his back muscles. The LTCS Scheme has also provided recreational outings for Joel to practise his photography, and through this he has learnt skills such as how to plan a trip to the city, how to manage money and socialise with other people. The Scheme has helped to build up his confidence and develop skills he lost as a result of the accident. Joel will be assessed for lifetime participation in the Scheme before his two year interim period ceases.⁵³

Current success of scheme

2.44 Ricki-Lee Bell and Daniel Malouf, participants who appeared before the Committee, were positive about the Scheme, their case workers, coordinators and how it has helped them. Daniel Malouf commented that the Scheme had already given him so much that he felt he may have been imposing if he requested additional support for activities like driving lessons.⁵⁴

2.45 The family carers of the participants who appeared before the Committee also praised the Scheme and the work of the Authority.

2.46 Mr John Malouf, family carer of Daniel Malouf, a lifetime participant in the Scheme, commented that he was very appreciative of the establishment of the Scheme:

It has helped us immensely. It has been very easy for us to be assimilated into it. The assistance that Daniel has got to get to his doctors' appointments, the level and comprehensive care he has received—thank God it is there, is all I can really say. To me, as a carer, there have not been any negatives.⁵⁵

2.47 Similarly, Ms Zivana Spittles, family carer of Joel Spittles, participant in the Scheme, indicated to the Committee that the existence of the Scheme was a relief to her family:

It has been a relief for our family. Joel has received a lot of support, the same thing. He has had a lot of facilities offered to him ... Just the support that we get from the rehabilitation centre, because that is covered by Lifetime Care and Support, is amazing. It is the emotional support as well that we get ... It has been so helpful for us because we now keep positive and patient with our son. I cannot say a negative thing about it; it has given us our life back.⁵⁶

2.48 Also, service providers and medical practitioners commented on the benefits and overall success of the Scheme. Associate Professor James Middleton, Director, NSW State Spinal Cord Injury Service, acknowledged the success of the Scheme:

⁵³ Evidence, 26 June 2009, pp38-50

⁵⁴ Mr Daniel Malouf, Evidence, 26 June 2009, p45

⁵⁵ Mr John Malouf, Evidence, 26 June 2009, p39

⁵⁶ Ms Zivana Spittles, Evidence, 26 June 2009, p39

We would like to acknowledge that the Lifetime Care and Support Authority has achieved a remarkable amount in the short period of time to establish this scheme and all the necessary supporting policies, procedures, guidelines and systems that are required to implement and administer the scheme effectively. It is without doubt well-designed and going to set benchmarks for other jurisdictions.⁵⁷

- 2.49** The Brain Injury Rehabilitation Service at Westmead Hospital highlighted the positives of the Scheme including a greater percentage of their clients having access to rehabilitation services, access to support for families, the continuing review and evaluation of LTCS procedures and processes and the provision of the LTCS Newsletters to keep stakeholders informed.⁵⁸
- 2.50** Other stakeholders were also supportive of the Scheme. In its submission to the review Youthsafe advised that it “commends the role of the LTCSA and important developments over the last few years in managing serious injury due to road trauma, including the introduction of no fault provisions. This has been an area of significant need.”⁵⁹
- 2.51** Mr Richard Grellman, Chairman of the LTCS Authority Board, indicated to the Committee that from the Board’s perspective ‘we are feeling very pleased with the way that the Scheme is developing ... We are watching carefully, but for a very important and I think outstanding piece of legislation, early signs are very positive.’⁶⁰

Future of the Scheme

- 2.52** In terms of the future of the Scheme Mr Bowen stated that at this time “we are really trying to continue to alter, refine and simplify our systems to make it easy for both ourselves as well as our service providers and, at the end of the day, easy for our participants to understand as well.”⁶¹
- 2.53** Mr Bowen indicated that the challenges for the year ahead include rewriting and simplifying the Scheme’s Guidelines and also increasing the focus on community services and support for people when they return home as a significant number of participants will be moving through the acute care and rehabilitation phase and back into the community.⁶²
- 2.54** The Authority provided the following list of emerging challenges the Scheme will face in the immediate future:
- An increase in the number of participants over 65 years old: previously, these individuals would have been cared for by aged care services; they may be

⁵⁷ Associate Professor James Middleton, Director, NSW State Spinal Cord Injury Service, Greater Metropolitan Clinical Taskforce, Evidence, 26 June 2009, p18

⁵⁸ Submission 6, Westmead Hospital Brain Injury Rehabilitation Service, pp1-2

⁵⁹ Submission 5, Youthsafe, p3

⁶⁰ Mr Richard Grellman, Chairman, Lifetime Care and Support Authority Board, Evidence, 26 June 2009, pp7-8

⁶¹ Mr Bowen, Evidence, 26 June 2009, p16

⁶² Mr Bowen, Evidence, 26 June 2009, p17

inappropriately diagnosed as demented; and accessing brain injury services for these people is difficult because the units do not admit patients over 65.

- The need to seek advice from the Department of Community Services (DoCs) for a significant proportion of paediatric participants due to the circumstances they live in.
- Managing the treatment and care for participants with pre-existing mental health or drug and alcohol problems.
- Engaging participants in their community and accessing community based services as an increased number of participants are returning to the community and decreasing their need for specialised rehabilitation services.⁶³

2.55 The Committee notes that issues of concern raised during this Review by service providers, medical practitioners and carers and participants, such as the administration burden the Scheme places on clinical workers, the role of the LTCS coordinators and concerns relating to advocacy for participants, primarily relate to improving the Scheme and refining the work of the Authority. These issues along with other concerns will be canvassed in the following chapters.

Committee comment

2.56 The Committee commends the LTCSA and the LTCSAC on the success of the Scheme to date and also the service providers, including medical practitioners and other clinical staff, for their role in aiding the smooth implementation of the Scheme.

2.57 The Committee acknowledges the valuable provisions the Scheme makes for lifelong treatment, rehabilitation and care services to people who are catastrophically injured in motor accidents in NSW, regardless of who was at fault in the accident. The Committee is very pleased to see the early success of the Scheme and considers it a potential model for other jurisdictions.

2.58 The Committee supports 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.

⁶³ LTCSA, Answers to pre-hearing questions on notice, pp22-23

Chapter 3 Update from the First Review

The Committee reported on its first Review of the exercise of the functions of the Lifetime Care and Support Authority and the Lifetime Care and Support Advisory Council in October 2008 (hereafter referred to as the First Review Report). The First Review Report made two recommendations on particular matters and, due to the early stage of the Scheme, the Committee made commitments to reconsider a number of emerging issues raised in the First Review as part of this current Review.

This chapter will provide an update on the recommendations from the First Review Report and look into the issues that require reconsideration by the Committee, now that the Scheme has further matured. The Committee recognises that overall the Lifetime Care and Support (LTCS) Scheme is operating successfully and the concerns and issues raised by stakeholders primarily relate to improving the Scheme and refining the work of the Lifetime Care and Support Authority (LTCSA).

Recommendations from the First Review Report

- 3.1 The Committee made two recommendations in its First Review Report. The first recommendation related to the interim participation of children and the second recommendation related to independent advice and advocacy for participants.

Interim participation of children

- 3.2 The first recommendation in the First Review Report was:

That the Minister for Finance seek an amendment to the *Motor Accidents (Lifetime Care and Support) Act 2006* to provide that children less than three years of age when injured are not assessed for lifetime participation in the Lifetime Care and Support Scheme until they are aged at least five years.⁶⁴

- 3.3 The Committee agreed with the medical rationale that an extended period of interim scheme participation for children who are less than three years old at the time of the motor vehicle accident would ensure that their injuries fully stabilise before significant decisions are made about their projected lifetime care needs.⁶⁵
- 3.4 In the NSW Government response to the First Review Report, the Hon Joe Tripodi MP, Minister for Finance, advised that the Government supported the intent of this recommendation and that a Bill would be introduced to give affect to this legislative change.⁶⁶

⁶⁴ 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* (hereafter referred to as the First Review Report), Report 37, October 2008, p40

⁶⁵ First Review Report, pp38-40

⁶⁶ The Hon Joe Tripodi MP, Minister for Finance, Government Response to the Standing Committee on Law and Justice for the Review of the exercise of the functions of the Lifetime Care and Support Authority and the Lifetime Care and Support Advisory Council, 4 May 2009, p1

- 3.5** The Motor Accidents (Lifetime Care and Support) Amendment Bill 2009, that gave effect to this legislative change, was passed by Parliament and was assented to on 9 June 2009. In the Hon Penny Sharpe MLC's second reading speech for the Bill she advised that:

In making this change, the Government is acting on a recommendation made by the Standing Committee on Law and Justice in its first review of the new scheme ... The effect of this change will be to make sure that a child who is less than three years old at the time he or she was severely injured will not have a final assessment for lifetime participation in the scheme until he or she has reached five years of age.⁶⁷

Independent advice and advocacy

- 3.6** The second recommendation made by the Committee in its First Review Report was:

That the Lifetime Care and Support Authority, in liaison with the Lifetime Care and Support Advisory Council, formally consider the range of options for independent review of decisions and the provision of independent advice and advocacy in respect of applicants, interim participants and lifetime participants in the Lifetime Care and Support Scheme. This should include the development of recommendations as to the desirability of and the most appropriate mechanisms for each.⁶⁸

- 3.7** The Committee recognised that further consideration should be given to the most appropriate mechanisms for the review of decisions within the Scheme and to the desirability of an independent advice and advocacy service in order to ensure that participants enjoy adequate procedural rights.⁶⁹

- 3.8** In the NSW Government response to the First Review Report, Minister Tripodi commented that there are a number of mechanisms already in place to allow for the independent review of decisions regarding an injured person's eligibility for, and participation in the LTCS Scheme.⁷⁰

- 3.9** In addition, the Minister advised that the LTCSA was preparing a paper on the provision of advocacy services in the Scheme:

The Lifetime Care and Support Authority is currently preparing a paper on the provision of advocacy services in the Lifetime Care and Support Scheme in consultation with the Lifetime Care and Support Advisory Council and the various stakeholders who are involved in providing advice and advocacy to individuals with severe injuries ... The Lifetime Care and Support Authority anticipates that the paper will be submitted to the Lifetime Care and Support Advisory Council for approval by 30 December 2009.⁷¹

⁶⁷ The Hon Penny Sharpe MLC, *NSWPD (Legislative Council)*, 3 June 2009, p15594

⁶⁸ First Review Report, p55

⁶⁹ First Review Report, p55

⁷⁰ The Hon Joe Tripodi MP, Minister for Finance, Government Response to the Standing Committee on Law and Justice for the Review of the exercise of the functions of the Lifetime Care and Support Authority and the Lifetime Care and Support Advisory Council, 4 May 2009, p1

⁷¹ The Hon Joe Tripodi MP, Minister for Finance, Government Response to the Standing Committee on Law and Justice for the Review of the exercise of the functions of the Lifetime Care and Support Authority and the Lifetime Care and Support Advisory Council, 4 May 2009, p1

- 3.10** Stakeholders raised this issue again as part of the current Review. The main issue of concern for this Review related to how brain injured participants could exercise their right for an independent review of decisions made about their care and how these participants could access advocacy services.
- 3.11** The NSW Bar Association commented that:
- There is little point in conferring a right upon a brain injured claimant to have an administrative decision with a fundamental impact on their life independently assessed and reviewed if the claimant does not have the physical or mental capacity alone to exercise that legal right.⁷²
- 3.12** In their supplementary submission, the Association also commented that the NSW Government response to the Committee's recommendation in its First Review Report, does not address how a brain injured claimant is expected to be capable of exercising their right to a review.⁷³
- 3.13** Similarly, the Australian Lawyers Alliance commented that participants are vulnerable by virtue of their disabilities and therefore, access to independent legal advice is important:
- By virtue of their disabilities, participants or potential participants in the LTCS are inherently vulnerable and may not have adequate support from family and friends to ensure, for example, that assessments of their treatment and care needs are appropriate. For this reason, the Lawyers Alliance submits that adequate access to independent legal advice and assistance services is extremely important.⁷⁴
- 3.14** The Westmead Brain Injury Rehabilitation Unit also raised concerns with the dispute resolution process relating to the non-approval of services for brain injured participants. The Unit suggests that the process 'fails to take into account the significant cognitive, communication, psychological, psychosocial and insight difficulties resulting from severe brain injury.'⁷⁵
- 3.15** In addition, the Law Society of NSW advised that 'participants in the Scheme may not have family or friends capable of advocating on their behalf in a review of decisions affecting the care and support of the scheme participant.'⁷⁶
- 3.16** The Committee notes that the Authority released a discussion paper on advocacy in April 2009. As a result of this process, the approach endorsed by the LTCS Advisory Council is that there is already a well established disability advocacy network which participants can access. The LTCSA advised that this was the view put forward by the advocacy groups consulted in the discussion paper process.

⁷² Submission 1, NSW Bar Association, p2

⁷³ Submission 1a, NSW Bar Association, p1

⁷⁴ Submission 12, Australian lawyers Alliance, p2

⁷⁵ Submission 6, Westmead Brain Injury Rehabilitation Unit, p4

⁷⁶ Submission 13, Law Society of NSW, p2

- 3.17** The LTCSA stated that, due to the existing advocacy services, a new advocacy body is not necessary:

At this stage there is no need to create a new advocacy body but to inform participants of the existing advocacy services established by the Department of Families, Housing, Community Services and Indigenous Affairs. There is now information on the LTCS Authority's website about how to access an advocacy service and the Authority has developed a fact sheet that will be sent to participants and their carers about advocacy.⁷⁷

- 3.18** In response to submissions that raised concerns relating to brain injured participants accessing advocacy services, the LTCSA commented that the Authority 'will include information in training sessions for service providers about how participants can access advocacy services. Once a participant has made initial contact with an advocacy service, the advocacy service will assist the brain injured participant as appropriate.'⁷⁸

Committee comment

- 3.19** The Committee notes the concerns raised by stakeholders regarding access to advocacy services for participants, especially those with brain injuries, and the importance that such services are easily accessible when needed.
- 3.20** The Committee acknowledges the work the LTCSA has done in this area through its discussion paper and consultation process. The Committee notes that there are advocacy services already established that can be accessed by participants and that the Authority will advise participants of these services.
- 3.21** The Committee does remain concerned about the ability of brain injured participants to initiate contact with advocacy groups and would encourage the LTCSA to further consider this issue. The Committee will revisit this issue in its next review.

Update on emerging issues from the First Review Report

- 3.22** Due to the infancy of the Scheme during the First Review, the Committee gave an undertaking to monitor a number of issues emerging from the Scheme. This section will provide an update on developments in relation to these issues, which are as follows:
- Accidents not covered by the Scheme
 - Medical eligibility criteria
 - Entry into the Scheme via the orthopaedics area
 - Ability to opt-out of the Scheme and self-purchasing provisions for participants
 - Estimated financial liabilities for the Scheme
 - Interface issues with the Motor Accidents Compensation Scheme

⁷⁷ Lifetime Care and Support Authority (LTCSA), Answers to post-hearing questions on notice, Question 1, p1

⁷⁸ LTCSA, Answers to post-hearing questions on notice, Question 1, p1

- Supported accommodation for participants
- Attendant care services
- Support for family carers
- Administration and resource burden for area health services and clinical staff
- Role of the LTCS coordinator.⁷⁹

Accidents not covered by the Scheme

3.23 In the First Review the issue concerning potential gaps in the eligibility for the LTCS Scheme arose.⁸⁰ This relates to whether accidents involving certain motor vehicles would be covered by the Scheme. During the First Review, the LTCSA advised that accidents involving vehicles not capable of registration are ineligible to be covered by the Scheme, for example, accidents involving motorised bicycles, mini-bikes and quad bikes.⁸¹

3.24 As part of its current Review, the Committee asked the Authority if any new gaps in eligibility had been identified. The Authority indicated that there were no new gaps, but reiterated that the same groups of people identified in the First Review were not covered by the Compulsory Third Party (CTP) or LTCS Scheme. The Authority did, however, indicate that eligibility relating to motor accidents is not always straight forward. Ms Suzanne Lulham, Director of Service Delivery for the LTCSA, commented that they sometimes use forensic engineers and barristers to provide advice on the issue of eligibility:

A lot of time the question is; is that bike capable of being registered? We ourselves then get that information from them [applicants] and we send that off to a forensic engineer who will provide us with advice for that. Another example would be that we had a motorbike accident that actually happened at Oran Park, at one of the events they organise out there, and at first glance we thought that that person probably would not be eligible, but we sent it off to a barrister for some advice about whether that was a motor accident. That is, I guess, why we ask for those to come to us, because then we can direct the inquiries out to people who can provide the advice.⁸²

3.25 As noted in the First Review Report, accidents involving pushbikes and a person in a motor vehicle who is hit by a projectile (such as a rock) are also not eligible.⁸³ Stakeholders raised concerns during this current Review relating to whether people involved in pushbike accidents should be covered by the LTCS Scheme.

3.26 The Social Workers in Brain Injury Professional Interest Group recommended that the eligibility criteria for the LTCS Scheme be extended to include cyclists who have accidents on the road that do not involve motor accidents:

⁷⁹ First Review Report, pp27-66

⁸⁰ First Review Report, pp33-36

⁸¹ First Review Report, pp33-34

⁸² Ms Suzanne Lulham, Director, Service Delivery, Lifetime Care and Support Authority, Evidence, 26 June 2009, p7

⁸³ First Review Report, pp33-34

Cyclists who have accidents on the road that do not involve motor vehicles are currently not covered by the scheme leading to inequities between cyclists with catastrophic injuries in the longer-term support that they can access.⁸⁴

3.27 At the hearing, Dr Graham Simpson, Senior Social Worker at the Liverpool Brain Injury Rehabilitation Unit and member of the Social Workers in Brain Injury Professional Interest Group, relayed a colleague's comments on cyclists not being covered by the Scheme:

I will read out what a colleague supplied me with. This is a colleague who works in an acute major teaching hospital in Sydney. She wrote:

The anomaly is that cyclists, while utilising the road network, remain without access to the LTCS scheme unless struck by a motor vehicle that has third party coverage. That creates the anomaly that while they are meant to be equal users with equal rights under all other rules of the road they are excluded from access to the scheme. Cyclists are frequently registered within Cycle Australia at a State and national level and thus could easily be included by an extension of existing registration schemes. Sadly, I have encountered a cyclist who has sustained a high-level quadriplegia and because it occurred without fault being attributable to another party, he is without compensation or access to the true means of lifelong support.⁸⁵

3.28 Ms Diane Turner, Social Work Professional Leader at the Royal Rehabilitation Centre and member of the Social Workers in Brain Injury Professional Interest Group, advised the Committee of the broad accident compensation scheme in New Zealand and encouraged the Committee to consider the needs of other severely injured road users not covered by the LTCS Scheme:

Certainly in New Zealand there is the Accident Compensation Corporation that covers people who are injured in any way, shape or form in New Zealand. Our scheme, of course, is a lot more narrow than that but we were just wanting to encourage thought about the needs of other road users.⁸⁶

3.29 The NSW Bar Association was asked by the Committee to provide a legal perspective on the suggestion that cyclists should be covered by the Scheme. Mr Andrew Stone, Member, Common Law Committee of the NSW Bar Association, stated:

It involves difficult practical enforcement issues ... I am afraid the ultimate answer is to have a social welfare safety net that looks after them just as well as it looks after people who fall out of trees or who sustain spinal or brain injuries in all sorts of other ways. The dollars in this scheme can stretch only so far. Each time you take it a stretch further the money has to come from somewhere ... You asked in general terms what we should do about cyclists running over people. You should have better

⁸⁴ Submission 8, Social Workers in Brain Injury Professional Interest Group, p4

⁸⁵ Dr Graham Simpson, Senior Social Worker at the Liverpool Brain Injury Rehabilitation Unit and member of the Social Workers in Brain Injury Professional Interest Group, Evidence, 26 June 2009, p67

⁸⁶ Ms Diane Turner, Social Work Professional Leader and member of the Social Workers in Brain Injury Professional Interest Group, Evidence, 26 June 2009, p67

enforcement, predominantly with courier companies, around the Sydney central business district.⁸⁷

- 3.30** Mr David Bowen, Chief Executive Officer of the LTCSA, when asked to respond to the issue of Scheme coverage for cyclists suggested that the Government may have to consider providing coverage for people severely injured in pushbike accidents:

There have been a number of cases involving injuries to pedestrians from pushbikes ... It happens quite a lot in the city with bicycle couriers knocking over pedestrians. I am not aware of any other catastrophic injuries yet. Those people are not eligible to enter this scheme. Neither do they have a CTP claim because there is no CTP insurance ... If the number of pushbikes on the road increases and the opportunity for intersection with pedestrians increases ... I think it will be an issue that the Government will have to look at in providing some sort of coverage for pushbike riders as well along the lines of a green slip scheme. That would be a sensible way to go.⁸⁸

- 3.31** A further issue directly related to Scheme eligibility, raised during the current Review, is what some stakeholders referred to as the creation of a tiered system in the provision of treatment and care for people with catastrophic injuries caused by motor vehicle accidents or otherwise.

- 3.32** The NSW State Spinal Cord Injury Service reported that the implementation of the LTCS Scheme has resulted in a three-tiered system, where clients with similar levels of impairment may receive different levels of equipment and support depending on how they obtained their injuries.⁸⁹ In evidence, Associate Professor James Middleton, Director of the NSW State Spinal Cord Injury Service, explained the three-tiered system:

The three tiers we are talking about are now the Lifetime Care and Support Scheme, the public system and I guess other compensable schemes, whether that is workers compensation or DVA [Department of Veterans' Affairs]. There are three different systems occurring in parallel ... and a person will end up with different levels of equipment and availability of care.

Given that essentially all of the clients are all mixing in the same environment and are trying to be rehabilitated to the same high level, they all talk to each other. They all see and compare ... Clients are becoming increasingly aware of what they may or may not have access to because of the way they were injured and the scheme that they have ended up in. I guess that is the challenge for administering these things fairly and equitably.⁹⁰

- 3.33** Ms Martine Simons, Senior Social Worker at the Department of Rehabilitation at the Children's Hospital Westmead, also commented on the development of a tiered system. Ms Simons advised that while a patient is in hospital services can be provided equitably, regardless of how that person was injured. However, once the patient returns home 'in terms of our

⁸⁷ Mr Andrew Stone, Member, Common Law Committee, NSW Bar Association, Evidence, 26 June 2009, p37

⁸⁸ Mr David Bowen, Chief Executive Officer, Lifetime Care and Support Authority, Evidence, 26 June 2009, p13

⁸⁹ Submission 7, The NSW State Spinal Cord Injury Service, p2

⁹⁰ Associate Professor James Middleton, Director, NSW State Spinal Injury Service, Evidence, 26 June 2009, pp25-26

therapy and outreach, those services are still there. But in terms of access to other services, it really does become a two-tiered system.’⁹¹

- 3.34** Mr Dougie Herd, Chairman of the LTCS Advisory Council, clearly explained that a consequence of the LTCS Scheme is the development of a tiered system and that this would be an issue worth future consideration:

Somebody needs to have a look at the increasingly obvious fact that where and how one has one's accident or acquires one's disability has a consequence for the quality of the support that you would receive. I do not want to sound flippant but given that we are told when we are young that most accidents happen in the home, if you acquire a brain injury or break your neck or back at home, rather than at work or in a road traffic accident, you may not have as ready access to good-quality services as you would otherwise have ...I think that anomaly will come more and more to the forefront as the Scheme develops ... I think we have a duty together to look at those questions.⁹²

- 3.35** Mr Herd also commented on the issue of projectiles thrown at cars and whether accidents resulting from these incidents should be covered by the Scheme:

Wherever you break your neck, you break your neck and you will have a life-long need for support. I had not realised that if you are driving along a road in a motor car and somebody throws a brick off a bridge you are not covered, but if the car in front of you throws a brick in your windscreen you will be covered. I do not think it makes much difference to you where the brick came from. I guess we need to try to find a solution to that kind of problem. It is not specifically about the scheme but it certainly will emerge as an issue as a consequence of the Scheme's existence.⁹³

- 3.36** The Department of Ageing, Disability and Home Care (DADHC) advised the Committee that ‘a proposal is being developed by the National Traumatic Injury Insurance Scheme working group for a national scheme to extend service provision to people with catastrophic injuries who do not receive adequate compensation through insurance and who are not injured in a motor vehicle accident.’⁹⁴

- 3.37** The Committee notes that a national insurance scheme was raised as a solution providing long term support for people with a disability and those severely injured, who are not covered by an existing insurance scheme like the LTCS Scheme, in the report of the National People with Disabilities and Carer Council presented to the Commonwealth Government on 5 August 2009. The report is to inform the Commonwealth Government’s National Disability Strategy.⁹⁵

⁹¹ Ms Martine Simons, Senior Social Worker at the Department of Rehabilitation at the Children’s Hospital Westmead, Evidence, 26 June 2009, p59

⁹² Mr Dougie Herd, Chairman, Lifetime Care and Support Advisory Council, Evidence, 26 June 2009, p16

⁹³ Mr Herd, Evidence, 26 June 2009, p16

⁹⁴ Submission 14, Department of Ageing, Disability and Home Care, p1

⁹⁵ *Shut Out: The experience of people with disabilities and their families in Australia*, Media Release, the Hon Bill Shorten MP, Parliamentary Secretary for Disabilities and Children’s Services, 5 August 2009.

Committee comment

- 3.38** The Committee is mindful of the comments made by stakeholders regarding the development of a tiered system resulting from the implementation of the LTCS Scheme. The Committee also notes the comments made in relation to people involved in pushbike accidents not receiving the lifetime care that LTCS Scheme participants receive, even though cyclists are road users too.
- 3.39** The Committee also notes DADHC's comments and the Commonwealth Government's National Disability Strategy regarding the possibility of a national insurance scheme that may cover those catastrophically injured but not eligible for the LTCS Scheme, such as those involved in pushbike accidents and injured from projectiles thrown at motor vehicles. The Committee will monitor these issues as the Scheme matures.
- 3.40** The Committee did note in its First Review Report that it would seem fair for people hit by a projectile whilst in a motor vehicle to be covered by both the CTP and LTCS Scheme.⁹⁶ The Committee received little evidence on this issue during this review but will ask the LTCSA or the Motor Accidents Authority, as appropriate, to conduct research into this issue, including the number of incidents in NSW, nature and severity of injuries resulting from these incidents and the potential impact on the LTCS and CTP Scheme if these incidents were to be covered. The results of this research can be used to help the Committee consider this issue in a future review.

Recommendation 1

That the Minister for Finance request the Lifetime Care and Support Authority or the Motor Accidents Authority, as appropriate, to conduct research into the issue of people hit by a projectile whilst in a registered motor vehicle including:

- the number of incidents in NSW,
- nature and severity of injuries resulting from these incidents and
- the potential impact on the Lifetime Care and Support and Compulsory Third Party Schemes, if these incidents were to be covered.

Medical eligibility criteria

- 3.41** An additional Scheme eligibility issue that was raised in the First Review Report related to the medical eligibility criteria used to govern entry into the Scheme. In the First Review, the Greater Metropolitan Clinical Taskforce (GMCT) Brain Injury Rehabilitation Directorate suggested that the medical assessment tools used to assess criteria be evaluated. The LTCSA indicated, at that time, that any evaluation of these assessment tools should take place after

⁹⁶ First Review Report, p36

more participants had entered the Scheme and had gone on to be assessed for lifetime participation.⁹⁷

- 3.42** As part of the current Review the Committee followed up on this issue and the Authority advised that, while an evaluation has not taken place, the medical tools used to assess potential participants are working well:

While the eligibility criteria for the Scheme have not been specifically evaluated, the early indicators are that the criteria are working well. The Functional Index Measure (FIM), which measures whether a person is independent in an activity or requires assistance, is the main assessment tool for eligibility to enter the LTCS Scheme. The measure was selected by the brain injury clinicians from the Adult and Paediatric Brain Injury Units. The Authority continues to be receptive to suggestions for other objective and reliable assessment tools as adjuncts or alternatives to FIM. To date no viable alternatives have been suggested.⁹⁸

- 3.43** The Authority advised that it will closely monitor the two year interim assessment of participants to determine if there are any participants requiring services into the long term who would not score the FIM required for lifetime participation.⁹⁹

- 3.44** The Authority further commented that, to date, the few participants that have had assessments for lifetime participation and have not been eligible to participate in the LTCS Scheme have not received services for at least six months and have no need for services into the future. In addition, the LTCSA advised that people who are not able to participate in the LTCS scheme on a lifetime basis have the same access to services as other injured people. Also, approximately, 50 per cent of these people will have a CTP claim and the remainder would rely on publicly funded services.¹⁰⁰

- 3.45** In this current Review, the Department of Rehabilitation at the Children's Hospital at Westmead raised concerns regarding the limitations in using the WeeFIM assessment tool in determining lifetime participation in the Scheme for children with brain injuries and suggests the need for additional tools to aid in this assessment. The Department suggests the additional use of the new assessment tool the Paediatric Care and Needs Scale (PCANS) for 5-18 year olds, once it becomes available.¹⁰¹ The LTCSA advised that the testing of this tool for reliability and validity is one of the Authority's current research projects.¹⁰²

- 3.46** The Committee notes that the issue of medical eligibility criteria was not raised in evidence or submissions from the GMCT Brain Injury Rehabilitation Directorate during this current Review. The Committee also acknowledges the comments made by the LTCSA in relation to how well the medical assessment tools have been working to date and that it will monitor the

⁹⁷ First Review Report, p34

⁹⁸ LTCSA, Answers to pre-hearing questions on notice, Question 3, p2

⁹⁹ LTCSA, Answers to pre-hearing questions on notice, Question 3, p2

¹⁰⁰ LTCSA, Answers to post-hearing questions on notice, Question 4, p2

¹⁰¹ Submission 9, Department of Rehabilitation, The Children's Hospital Westmead, pp10-11 and Department of Rehabilitation, The Children's Hospital Westmead, Answers to questions on notice, pp1-2

¹⁰² LTCSA, Answers to pre-hearing questions on notice, Question 44, p26

two year interim assessment of participants to become lifetime participants using this tool and the testing of alternative medical assessment tools for children. At this stage, this appears to be a satisfactory resolution to this issue.

Entry into the Scheme via the orthopaedics area

- 3.47** During the First Review, the Committee noted and the Authority acknowledged that the orthopaedic system is a weaker area for entry into the Scheme. The LTCSA indicated that people with orthopaedic injuries would not usually meet the eligibility criteria for Scheme entry. However, it may be that a person with a brain injury is admitted to an orthopaedic ward and the brain injury may not be diagnosed until some time after. Once the injured person is referred to a specialist in brain injury or brain injury unit, the LTCSA would then be notified.¹⁰³
- 3.48** The Committee followed up on this issue with the Authority in this Review and in response the Authority advised that it has continued to conduct education sessions on the LTCS Scheme targeting social workers in hospitals in order to ensure all those eligible for the Scheme can gain entry in a timely way.¹⁰⁴
- 3.49** The Committee acknowledges that the LTCSA is addressing this issue. The Committee recognises the importance of educating hospital staff about the Scheme and further considers the issue of education and community awareness in the following chapter.

Ability to opt-out of the Scheme and self-purchasing provisions for participants

- 3.50** During the First Review, the Committee heard from the Law Society of NSW that it had concerns that participants should be able to opt out of the Scheme, if they so wish, and that the absence of provisions for this fails to respect the rights of participants. The Society also commented that self-managed care or purchasing provisions, as set out in the Act, are not the same as being able to fully opt-out of the Scheme.¹⁰⁵
- 3.51** In response, the Authority focussed on the option of self-managed care advising that it was developing the processes to implement subsection 6(3) of the *Motor Accidents (Lifetime Care and Support) Act 2006* that specifically provides for the LTCSA to enter into an arrangement with a participant to enable them to self-manage their care.¹⁰⁶
- 3.52** The Committee followed up on this issue during the current Review and was advised by the Authority that it is identifying participants who are competent and capable and may be interested in exploring self-management, such as participants with spinal cord injuries. Also the Authority commented that it is currently discussing the option of self-management with a participant who lives in Holland.¹⁰⁷

¹⁰³ LTCSA, Answers to pre-hearing questions on notice, Question 4, pp2-3

¹⁰⁴ LTCSA, Answers to pre-hearing questions on notice, Question 4, pp2-3

¹⁰⁵ First Review Report, pp40-41

¹⁰⁶ First Review Report, pp40-41

¹⁰⁷ LTCSA, Answers to pre-hearing questions on notice, Question 38, p23

- 3.53** The Committee notes that in its submission to this current Review the Law Society of NSW again raised the issue of allowing participants to opt out of the Scheme, if they so wish.¹⁰⁸ As was stated in the previous review, no disability or other groups have raised this as an issue with the Committee to date. The Committee understands the principle underlying the Law Society's concerns and will continue to carefully monitor this issue in future reviews.

Estimated financial liabilities for the Scheme

- 3.54** The Committee recognised in its First Review Report that a significant issue for the Scheme and the Authority is the use of actuarial estimations for projecting the financial liabilities of the Scheme. This relates to estimations for funding the Scheme to ensure that the Authority can fund the lifetime care and support for participants.
- 3.55** Due to the infancy of the Scheme, the Committee was advised that it was necessary to rely on actuarial estimations to work out these costs. However, as noted in the previous chapter, the LTSCA is implementing the Life Costing Model and as the Scheme matures it can now use actual information to achieve a better estimate of costs associated with the lifetime care and needs of participants.¹⁰⁹
- 3.56** The Committee notes that the Life Costing Model will allow the Authority to better estimate the lifetime cost of individual participants and the cost of all participants, as well as calculating the cash flow requirements for the Authority. The Committee will continue to monitor the use of this model in future reviews.

Interface with the Motor Accidents Compensation Scheme

- 3.57** In the First Review the Committee sought clarification on how LTCS Scheme participants' CTP claims are dealt with after issues were raised by the Insurance Council of Australia, including whether the insurance company or the Authority paid for particular expenses. The Authority advised that it was clarifying with insurers the definition of treatment, care and rehabilitation expenses.¹¹⁰
- 3.58** The Authority indicated that approximately half of the LTCS Scheme participants will also have a CTP claim. The LTSC Scheme pays for all the participant's treatment, rehabilitation and care expenses. The CTP insurer will compensate the claimant for their other expenses and losses arising from the injury including lost income and the loss of future earning capacity.¹¹¹
- 3.59** The issue of which scheme will pay for what expenses was not raised during this current Review. The Committee notes that the Insurance Council of Australia indicated to the

¹⁰⁸ Submission 13, p2

¹⁰⁹ Mr David Bowen, Chief Executive Officer, Lifetime Care and Support Authority, Evidence, 26 June 2009, p4

¹¹⁰ First Review Report, p37

¹¹¹ First Review Report, pp37-38

Committee that it did not wish to make a submission to this Review.¹¹² The Committee acknowledges that these issues may well be resolved as the Scheme has now had an opportunity to operate along side the CTP Scheme.

Supported accommodation

3.60 In the First Review Report, the Committee noted a number of emerging issues in respect of the provision of services to Scheme participants including concerns related to the availability of supported accommodation for participants. At that time, the LTCSA was looking to address this issue.¹¹³ Stakeholders in this current Review again raised the issue of supported accommodation for participants.

3.61 The Westmead Brain Injury Rehabilitation Unit raised concerns with the length of time taken to organise the provision of supported accommodation for participants and noted that prior to the LTCS Scheme, participants had a number of more immediate options available to them to pursue:

Prior to the LTCS, patients who had an accepted CTP claim had a number of options open to them when attempting to secure accommodation e.g. buy a home with advanced settlement money or modify an existing home with there being no apparent ceiling on modification costs so long as they could be justified. Our experience since the advent of the LTCS is that there is a paucity of solutions available for people with supported accommodation needs when they do not have a CTP claim. Patients are spending longer in hospital because of lack of timely options. LTCS's current policy of not purchasing homes for people and setting limits on what it will spend on modifications is contributing to long delays in solving accommodation options for participants.¹¹⁴

3.62 The GMCT also raised the issue of the length of time taken to organise supported accommodation for participants. The GMCT commented that some participants remain in acute rehabilitation wards for some time after their rehabilitation goals are achieved or are discharged to local hospitals to manage the issues without specialist support, instead of being placed in supported accommodation facilities.¹¹⁵

3.63 The GMCT noted that the supported accommodation expert advisory group, established by the LTCSA, has not convened for some time and described developments in this area as 'ad hoc and individual rather than within an identified framework with a process for bridging the gaps.'¹¹⁶

¹¹² Correspondence from Mr John Driscoll, General Manager Policy, Insurance Council of Australia, to Chair, 1 May 2009

¹¹³ First Review Report, p45

¹¹⁴ Submission 6, Westmead Brain Injury Rehabilitation Unit, pp5-6

¹¹⁵ Submission 10, Greater Metropolitan Clinical Taskforce, p3

¹¹⁶ Submission 10, p3

3.64 In evidence, Dr Adeline Hodgkinson, Chair of the Brain Injury Rehabilitation Directorate, GMCT, stated that accommodation is an ongoing issue for participants in terms of providing the actual home itself and therefore, solutions are slow:

Accommodation is an ongoing issue. There are solutions being proposed but, as Dr Gurka said, some of the solutions are very slow to move to resolution. One of the critical things is not the funding available to support the person in a home but the home itself. That is either a modified home or a home that can later develop into a group home. At Liverpool we are fairly disadvantaged in that probably the majority of our patients come from areas of social deprivation and want to return to their accommodation and their immediate family but they may be areas that are not really good investment options for a supported accommodation service that might be looking to have some capital invested in homes which will grow. The land value in some of the poorer suburbs in south-west Sydney is low. There is not an attractive option to some accommodation services. So that is what we would see as the way to go for lifetime care and support to look more closely at provision of houses.¹¹⁷

3.65 The GMCT recommended that the gaps in accommodation continue to be addressed through the existing GMCT and LTCSA liaison meetings and the Interagency Agreement that involves the LTCSA, DADHC, Department of Housing and NSW Health.¹¹⁸

3.66 In response to these concerns, the Authority advised that it is currently using a range of supported accommodation models, including:

- Two participants with brain injuries requiring 24 hour care are currently residing in accommodation provided by the Northcott Society.
- Other supported accommodation is being provided by the Supported Housing Association and the Community Integration Program.
- Opportunities for further development are being explored with providers of this accommodation traditionally not used by the Brain Injury Units including the Community Integration Program at the Royal Rehabilitation Centre.
- People with spinal cord injuries are being transitioned in accessible accommodation found on the rental market and the Authority funds the attendant care.¹¹⁹

3.67 As noted in the previous chapter in Case study 4, the LTCSA is working at providing tailored solutions for participants. The Authority advised that, in this case study, as there are limited services to meet the requirements of a young person with high level care needs, it has been working together with the participant's family and treating team to come up with an appropriate solution utilising several providers. This includes:

- interim accommodation provided by the Northcott Society,

¹¹⁷ Dr Adeline Hodgkinson, Chair, Brain Injury Rehabilitation Directorate, Greater Metropolitan Clinical Taskforce, Evidence, 26 June 2009, p28

¹¹⁸ Submission 10, p4

¹¹⁹ LTCSA, Answers to pre-hearing questions on notice, Question 22, p14

- a community integration program organised by the Royal Rehabilitation Centre, including accommodation management, therapy and attendant care services
- case management and medical oversight provided by the brain injury program
- long term housing which will be provided by a community housing provider in an area close to the family.¹²⁰

3.68 On a related accommodation issue, the Physical Disability Council of NSW raised the issue of appropriate accommodation for participants. In particular, the Council was concerned that young participants were potentially being accommodated in aged care facilities.¹²¹

3.69 In terms of young participants being accommodated in aged care facilities, Ms Lulham, of the LTCSA, advised the Committee that there is one young participant who is being accommodated in a nursing home mainly due to geographical reasons:

We have one 25-year-old woman in a nursing home in Coffs Harbour. When she went there we gave the family an undertaking that as soon as we had another participant in that area we would look at other alternatives. The nursing home she is in is one of the exempt nursing homes, so she has her own room, an en suite and a lounge room. We are purchasing about another 40 hours of care a week on top of the nursing home stuff, including 28 hours of community access. We have also purchased a fair bit of equipment for her. We perhaps could have provided other options for her, but the family wanted her to go back to Coffs Harbour.¹²²

3.70 Ms Lulham further advise that when another participant requires accommodation in the area other options can be reviewed.¹²³ Mr Bowen indicated that this is an 'area where, in addition to dealing with individual participants, we think we will have to do some needs analysis and we might have to assist in the construction of homes to accommodate young people outside nursing homes.'¹²⁴

Committee comment

3.71 The Committee acknowledges that the LTCSA is continuing to address the issue of supported accommodation for participants. The Committee notes the concerns of the GMCT in relation to the time taken to organise supported accommodation for participants and the impact this can have on hospital and rehabilitation wards accommodating the participants in the interim.

3.72 The Committee supports the GMCT recommendation for the relevant parties to continue to liaise and work together to find solutions for participants requiring supported accommodation. The Committee believes that the supported accommodation expert advisory group that has been established by the LTCSA could work more effectively to address this issue and recommends that the LTCSA examine the role and membership of the advisory group to improve its effectiveness.

¹²⁰ LTCSA, Answers to pre-hearing questions on notice, p5

¹²¹ Submission 11, The Physical Disability Council of NSW, pp5-6

¹²² Ms Lulham, Evidence, 26 June 2009, p11

¹²³ Ms Lulham, Evidence, 26 June 2009, p11

¹²⁴ Mr Bowen, Evidence, 26 June 2009, p12

Recommendation 2

That the Lifetime Care and Support Authority examine the role and membership of the supported accommodation expert advisory group to improve its effectiveness.

Attendant care services

3.73 In the First Review Report, the Committee noted issues relating to attendant care services that are provided to participants in the LTCS Scheme.¹²⁵ Again, stakeholders in this current Review raised the issue of attendant care services, in particular, the length of time to organise this care and the quality of the care.

3.74 As with the issue of supported accommodation, the Westmead Brain Injury Rehabilitation Unit raised concerns with the length of time taken for attendant care services to be organised for participants, which can impact on their length of stay in hospital:

One of the most significant issues facing participants in the post acute recovery and rehabilitation phase is the time it takes for care to be implemented from the time of referral to the attendant care agency to the actual implementation of care in the home.¹²⁶

3.75 The Unit also raised concerns regarding the carers ability to facilitate independence in brain injured participants and maximise their engagement in activities to the capacity of their ability. The Unit commented that:

One of the main objectives of care provision under a rehabilitation philosophy is to facilitate independence in the participant and maximise the participant's engagement in activities to the capacity of their ability. Our experience is that many carers struggle with this aspect of care as their tendency is to allow themselves to be directed by the participant in what they do for them. A cognitively and behaviourally impaired participant is often unable to make appropriate choices about their care and often needs prompting to prevent them from regressing into dependent or unsafe behaviours.¹²⁷

3.76 The Unit suggested that a greater understanding of how cognitive and behavioural issues impact on a participant and what the expectations are on carers when dealing with these participants is needed. The Unit commented that it is willing to provide this training to attendant carers, however, the LTCSA has been reluctant to agree to the funding of this education by the Unit as it believes it to be the role of the care agency, from where the attendant carers are recruited, to train its staff in core brain injury skills.¹²⁸

¹²⁵ First Review Report, pp44-45

¹²⁶ Submission 6, p6

¹²⁷ Submission 6, p6

¹²⁸ Submission 6, p6

- 3.77** The Unit recommends that the LTCSA liaise with the Attendant Care Industry Association (ACIA) regarding the establishment of improved education programs in traumatic brain injury and that the LTCSA be agreeable to specialised service providers giving education to attendant carers on relevant core skills appropriate for the care of the participant.¹²⁹
- 3.78** In response to these concerns, the LTCSA stated that it takes six weeks to set up an attendant care program for one participant, that is, to recruit and train attendant care workers. The LTCSA conducted a forum in April 2009 for attendant care providers and other service providers, including care needs assessors, to stress the importance of forward planning and to take into account how long it takes to establish an attendant care program. The forum will be repeated in November 2009.¹³⁰
- 3.79** The Authority advised that, to ensure participants are receiving a quality service that meets their individual needs, it is undertaking a number of initiatives including:
- An audit of attendant care providers, which will also provide recommendations for performance improvement in attendant care services.
 - As part of the Authority's grant program, it has provided \$181,600 to the ACIA for the Attendant Care Association Quality Certification program. The project is aimed at achieving the development of the Certification Program for attendant care in NSW.¹³¹
 - The ACIA has now developed and trialled its attendant care standards and have enrolled attendant care providers in its certification program.¹³²
 - It is a condition of attendant care providers' contracts with the Authority that they enrol in the ACIA's certification program.¹³³

Committee comment

- 3.80** The Committee recognises the concerns of stakeholders regarding the issue of attendant care services, including the length of time to organise this care and the quality of the care. The Committee notes that the LTCSA has taken a number of steps to improve the delivery and quality of these services, including conducting forums, audits and involvement in the ACIA certification program. The Committee will revisit the issue in its next review.

Support for family carers

- 3.81** The First Review outlined general concerns from Carers NSW that related to ensuring sufficient support was available for family carers of LTCS participants. The Authority noted these concerns.¹³⁴

¹²⁹ Submission 6, p6

¹³⁰ LTCSA, Answers to pre-hearing questions on notice, Question 17 p11

¹³¹ LTCSA, Answers to pre-hearing questions on notice, Attachment 3, p3

¹³² LTCSA, Answers to pre-hearing questions on notice, Question 31, pp 18-19

¹³³ LTCSA, Answers to pre-hearing questions on notice, Question 31, pp 18-19

¹³⁴ First Review Report, pp45-46

- 3.82** During this Review, the specific issue of financial support for family carers of LTCS participants was raised. Currently, the LTCSA pays for family support for its participants. This can include counselling, childcare, cleaning services and travel and accommodation when accompanying participants.¹³⁵
- 3.83** The LTCSA Guidelines clearly state that the employment of and, therefore direct 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 Authority does note that in some rare circumstances, for example, in rural and remote areas this may be necessary as attendant care can be limited.¹³⁶
- 3.84** In evidence, Mr Bowen acknowledged that the nature of the family relationship is that family members want to provide the necessary care. However, based on advice from the disability community and case managers, the Authority has taken the position that it will provide for all of the participants care and needs using professional care agencies and will not pay family members to become carers (except in the rare circumstances noted above).¹³⁷
- 3.85** Mr Bowen explained the intent behind this decision is to maintain a functional family relationship:

The intent behind it is to maintain a family relationship—a spousal relationship or a parent-child relationship, which will involve some elements of support and care in any event, but not to turn that into an injured person-carer relationship—to try to provide for those care needs outside the family so the family can remain functional as a family. There may well be circumstances, and we can certainly contemplate them, where there will be no choice but to use a family member as a carer, but it is certainly not the preference. That was strong advice we got from people who work in the area and the broader disability community.¹³⁸

- 3.86** Mr Herd, Chairman of the LTCS Advisory Council, commented that whilst superficially it may seem attractive to compensate family carers, the impact on the family relationship could be detrimental. He explained:

From all the evidence that any of us can glean from anywhere it is just a mistake. It seems superficially attractive to a family that might find itself in dramatically changed circumstances: a breadwinner loses her role; a loved one finds themselves looking after a member of their family, which makes it more difficult for them to find work. It looks like a good option to pay the family member from what looks like a well-resourced, dare one say rich, public service organisation in the form of an authority, but it does not anticipate the changes that will take place in the relationship.¹³⁹

- 3.87** Mr Herd continued:

¹³⁵ LTCSA, Answers to pre-hearing questions on notice, Question 40 & 41, pp 23-24

¹³⁶ Lifetime Care and Support Authority, *Lifetime Care and Support Guidelines*, 28 September 2007, Part 8, p7552

¹³⁷ Mr Bowen, Evidence, 26 June 2009, p9

¹³⁸ Mr Bowen, Evidence, 26 June 2009, p9

¹³⁹ Mr Herd, Evidence, 26 June 2009, pp 9-10

The creation of that financial nexus between the loved ones has such potential to disrupt and destroy normal family relationships that it is a grave error. However, it is not one that is immediately clear; it becomes clear five, 10 or 15 years down the line when the normal family relationship has been destroyed and the only thing that keeps people together is the fact that somebody is getting \$25,000 or \$40,000 a year by virtue of being in a relationship with somebody. That is no basis on which to maintain the relationship. That is not to say that the economic circumstances of these families are easy ones, but solving the financial problems of the family by turning a family member into a paid member of the staff of a loved one is not a solution to their problem.¹⁴⁰

- 3.88** Ms Lulham provided advice on when exceptions would need to be made to this policy, for example for families living in remote areas:

We have written a policy that says there are certain circumstances in which we can do it, but they are rare and exceptional. I guess the ones that we could perhaps think about are people in rural or remote areas where it would be very hard to attract carers. In some circumstances we may pay for some of the care to be delivered by a family member. I think we would be almost negligent to expect one person to be providing care for someone who needs 24-hour care. That is shift care and you need trained carers. We have said that in the rare circumstances where this happens the family member needs to be employed by the attendant care agency. They need to be trained and they need to have their own workers compensation coverage and have all the occupational health and safety issues dealt with, as with any other carer.¹⁴¹

- 3.89** Family carers of Scheme participants, who spoke with the Committee, had differing views on payment for the care that they provide for their children. Mr John Malouf, family carer of Daniel Malouf a lifetime participant in the Scheme, said he has never sought payment for being Daniel's carer and noted that he had a lot of family support available, so that it was not an issue for their family.¹⁴²

- 3.90** Ms Zivana Spittles, family carer of Joel Spittles an interim participant in the Scheme, also stated that she has never received payment for being carer. Ms Spittles highlighted for the Committee the issue family carers face in allowing professional carers come in and take on the caring responsibilities:

You just want to protect them [child] all the time, and no-one is going to be able to understand what they have been through and how they think and feel. But there are a lot of very caring people out there ... We did have carers allocated to us to spend time with Joel, but that was a positive thing because you do need a break. It is very intense and it is very emotionally draining.¹⁴³

- 3.91** Ms Spittles commented that in the beginning some form of carer payment may have been practical, as the family did struggle financially and, as a result, she did return to work:

¹⁴⁰ Mr Herd, Evidence, 26 June 2009, pp 9-10

¹⁴¹ Ms Lulham, Evidence, 26 June 2009, p10

¹⁴² Mr John Malouf, Evidence, 26 June 2009, p41

¹⁴³ Ms Zivana Spittles, Evidence, 26 June 2009, pp 41-42

Originally in the beginning it would have been good to be paid because I took many, many months off work, and we did struggle financially with that. It would have been great to have received some payment. I had to go back to work, and that is when the carers really stepped up. But then it was a relief to have that break as well. It is a kind of a Catch-22. It is hard to let go of that person once they have been injured like that.¹⁴⁴

- 3.92** Ms Denise Young, Program Clinical Manager at Bathurst Hospital and member of the Social Workers Brain Injury Professional Interest Group, saw both sides of the issue of payments for family carers:

I can see the issue both ways. I can kind of understand why people say it is good to have outside people come in. But I can see that there might be a benefit [for payment] in the early days. I think sometimes the people who are not working are the ones who seem to wear a lot of burden of the care in the early days. They do not have to make the decision about going back to work, but the others may need to go back to work and they certainly do. It is very individual.¹⁴⁵

- 3.93** Ms Young also commented that, while family support is positive for participants, outside help can advance the progress of some participants:

Sometimes the relationships with family members are vital to keep the person moving and progressing. Other times you need that independent but outside person who is not emotionally attached to the person to be able to do the encouraging and the family member can then be a family member or a supporter in that network, rather than the person who has to wave the big therapy stick in the same way.¹⁴⁶

- 3.94** Ms Turner, of the Social Workers Brain Injury Professional Interest Group, advised the Committee that it can be a matter of choice for some families and indicated the availability of the Commonwealth carers allowance:

I think the issue is choice. We have provision in Australia for people to get carers payments, if they are a carer. Carers allowances, of course, are not means tested. But I found that some families do want to choose to do that, whether it is for a shorter or a longer period of time. It would be great if there was provision in the scheme for people who made that choice to have the option to do that. If someone is caring for a relative with a brain injury, particularly someone who also has a significant physical injury, then they forfeit the opportunity to get paid employment. So they can be significantly financially disadvantaged. Some families prefer to do that and other families prefer to have paid carers. The issue of privacy, of course, is important. But there is not that capability within the scheme at the moment.¹⁴⁷

¹⁴⁴ Ms Spittles, Evidence, 26 June 2009, pp 41

¹⁴⁵ Ms Denise Young, Program Clinical Manager, Bathurst Hospital, Member of Social Workers Brain Injury Professional Interest Group, Evidence, 26 June 2009, p65

¹⁴⁶ Ms Young, Evidence, 26 June 2009, p65

¹⁴⁷ Ms Turner, Evidence, 26 June 2009, p65

Committee comment

- 3.95** The Committee recognises the significant emotional and financial impact that being a family carer can have on the family unit. The Committee notes Ms Spittles' comments on how it may be practical to receive payment at the beginning of such a difficult situation. However, the Committee heeds the comments made by the LTCSA, the Advisory Council and social workers of the potential negative impact of the LTCS Scheme funding family members to be carers.
- 3.96** The Committee also acknowledges that there is the Commonwealth carers allowance that could be available to the family carers of participants and encourages the LTCSA to advise family carers of the availability of this allowance when appropriate.

Administration and resource burden for area health services and clinical staff

- 3.97** In the First Review, the Committee heard from clinical staff about the increased amount of administration required by the Scheme and the burden this places on area health services. The Authority commented that it would review documentation and procedures.¹⁴⁸
- 3.98** The Committee followed up on whether the review of the documentation and procedures has been completed. The Authority advised that the procedures for requesting treatment, rehabilitation and care have been reviewed and as a result the format of forms has been standardised.¹⁴⁹
- 3.99** A number of stakeholders involved in the current Review again raised the issue of the administration and resource burden for clinical staff in terms of completing paperwork for Scheme participants.
- 3.100** The Hunter New England Spinal Cord Injury Service commented that the required documentation from the Authority is long and complex and that 'clinicians feel the documentation takes away time from providing direct clinical work.'¹⁵⁰
- 3.101** A rehabilitation provider also made similar comments relating to the length, complexity and repetitiveness of paperwork required for the Scheme.¹⁵¹
- 3.102** The Westmead Brain Injury Rehabilitation Unit raised the issue that, although there has been a review of forms and processes, the amount of time spent on these has not significantly changed:

Although there has been a review of forms and processes by the authority, the amount of time all staff, especially case managers, occupational therapists and social workers spend on meeting the needs of the Authority remains very high to the extent that clinical time and intensity of therapy for patients has been compromised ... To protect

¹⁴⁸ First Review Report, pp47-48

¹⁴⁹ LTCSA, Answers to pre-hearing questions on notice, Question 13, pp8-9

¹⁵⁰ Submission 2, Hunter New England Spinal Cord Injury Service, p1

¹⁵¹ Submission 4, Name suppressed by request of author, p2

the clinical time therapy staff needs to give patients, it is becoming crucial for our service to have additional resources to assist with LTCS matters.¹⁵²

- 3.103** The NSW State Spinal Cord Injury Service also indicated that from a health provider perspective, ‘clinicians report the significant burden now imposed by the bureaucratic requirements of LTCS involving increased paperwork to complete lengthy and repetitive forms distracting them from direct clinical responsibilities of providing rehabilitation to patients.’¹⁵³
- 3.104** In addition, the Department of Rehabilitation at the Children’s Hospital at Westmead provided an example of how the small group of severely injured children, who are Scheme participants, represent a small proportion of their caseload, yet are currently requiring a larger proportion of service provision to fulfil the significant administrative requirements of the LTCSA, in addition to their clinical rehabilitation needs. The Department further commented that ‘despite ongoing feedback and efforts of the LTCSA to streamline their processes the amount of paperwork and documentation remains onerous and laborious.’¹⁵⁴
- 3.105** Associate Professor Middleton acknowledged that there had been some improvement with the standardisation of forms but provided an example of how long and complex it can be to request equipment and services from the Scheme:

I acknowledge that there have been improvements. Some of the positive things include the standardisation of forms ... In the opinion of clinicians it is disproportionate to the need ... For example, a request went in from a physiotherapist for what we would deem six seemingly related items and was told that they all had to come on different forms and they were all sorts of different forms—some had to be on the community care plan, some had to be on equipment requests, some had to be on service requests ... From the impact of this the clinical teams have responded by creating templates, cutting and pasting a lot of the justification. It still needs to be customised in some senses, but even with that process in place, it still takes 20 to 30 minutes to complete a simple form. Very complex forms, for instance care requirements, can take an hour or an hour and a half.¹⁵⁵

- 3.106** Ms Juanita Noronha, Case Manager, Department of Rehabilitation at the Children’s Hospital Westmead, provided the example that ‘it took a case manager almost a day to write a care needs assessment request for attendant care for a child who really only needed five hours a week attendant care services ... It took her that long to gather the information, collate the request and actually do the form.’¹⁵⁶
- 3.107** The GMCT indicated that ‘there appears to be excessive bureaucracy burdening clinicians with increased paperwork, and lengthy and repetitive forms, distracting them from direct

¹⁵² Submission 6, p3

¹⁵³ Submission 7, p1

¹⁵⁴ Submission 9, p1 and p12

¹⁵⁵ Associate Professor Middleton, Evidence, 26 June 2009, p23

¹⁵⁶ Ms Juanita Noronha, Case Manager, Department of Rehabilitation at the Children’s Hospital Westmead, Evidence, 26 June 2009, p55

clinical time with patients.¹⁵⁷ The GMCT goes on to suggest that a memorandum of understanding be established to address this issue.¹⁵⁸

- 3.108** Ms Lulham, of the LTCSA, commented that the requirement to complete the paperwork is due to the scrutiny the Authority is under to account for its expenditure and justify the significant amounts of money required for the provision of services:

Yes, there is an increase in paperwork for people, but there is an increase in work generally. Recently we reviewed all our processes and forms and made changes. I say that acknowledging that people will continue to be required to fill in forms and complete paperwork. We are under scrutiny ourselves in what we spend money on. When people request services we ask that there is some justification for those requests. We have tried to make it as simple as possible, some of the claims that come to us are fairly small, but most of them range between \$30,000 and \$60,000 worth of services. So we feel that there needs to be a reasonable amount of justification for those services.¹⁵⁹

- 3.109** Ms Lulham also stated that workload has increased due to the increase in the number of participants in the Scheme:

One reason why the work has increased is that the number of people who can now access a wider range of services has doubled. Actually, there is double the volume probably of people who can now access private and not-for-profit services that could not before. That is a significant workload issue for them. I guess it is fair to say that the private sector has probably responded to that more easily because, if there is an increased workload and increased money to purchase the services, they can put people on. That has not been as easy for the public sector brain injury and spinal cord injury unit.¹⁶⁰

- 3.110** The Authority notes that while some providers have complained about the paperwork required in requesting and justifying services, others have had little difficulty in meeting these requirements.¹⁶¹

- 3.111** The Committee wrote to the Hon John Della Bosca MLC, Minister for Health, to seek information on the impact of the Scheme on NSW Health and on area health services' resources. The Minister for Health advised the Committee that NSW Health intends to conduct a review of the impact of the Scheme on health service resources at the close of the 2008/2009 financial year. Further to this 'the Department will be sure to include assessment and analysis of the administrative demands of the Scheme in this review.'¹⁶²

¹⁵⁷ Submission 10, p2

¹⁵⁸ Submission 10, p3

¹⁵⁹ Ms Lulham, Evidence, 26 June 2009, p14

¹⁶⁰ Ms Lulham, Evidence, 26 June 2009, p14

¹⁶¹ LTCSA, Answers to pre-hearing questions on notice, Question 13, p8 8-9

¹⁶² NSW Health, Answers to questions on notice, Question 4, p5 and Question 5, p6

- 3.112** The Minister indicated that the results of this review are likely to be available in the first half of the 2009/2010 financial year and would be made available to the Committee.¹⁶³
- 3.113** The Committee advised the stakeholders who raised concerns with the administrative burden that NSW Health will be conducting this review and asked them to provide feedback on what they would like to see included in the review.
- 3.114** The GMCT raised a number of questions it would like to see covered in the NSW Health review including:
- Are area health services (AHS) submitting their claims for reimbursements to LTCSA in a timely manner?
 - Are AHSs clear about what LTCSA expectations are for the services they are paying for?
 - Are AHSs aware of the impact the LTCSA requirements and expectations have had on the workload of clinicians undertaking these assessments and completing the documentation?
 - Have AHSs used the LTCSA payments/reimbursements to boost clinician and support staff resources in order to manage the additional workload of caring for LTCS participants and fulfil the LTCSA requirements?
 - Are AHSs aware that if they do not provide the services LTCSA requires, LTCSA is likely to seek these services elsewhere?
 - Have AHSs put in place regular channels of communication with LTCS to ensure difficulties are addressed in a timely manner and solutions to these difficulties are developed jointly?¹⁶⁴
- 3.115** The Brain Injury Rehabilitation Directorate (BIRD) of the GMCT also provided the Committee with the following comments on the NSW Health review:
- The NSW BIRD issues for returning revenue to units and ensuring workforce capacity are essential additions to a NSW Health review of the impact of the Scheme and the assessment of administrative demands. In addition, it would be helpful if the review was time limited and involved representative BIRD staff in the review process and developing the recommendations and action plans arising from the review.¹⁶⁵
- 3.116** The Department of Rehabilitation at the Children's Hospital Westmead commented that the NSW Health review is an excellent opportunity to consider the impact of the Scheme on health service resources and requested that NSW Health should:
- ... collect both quantitative and qualitative data from BIRP [Brain Injury Rehabilitation Program] programmes. For example, in the Rehabilitation Department database we keep information on time spent undertaking various clinical and

¹⁶³ NSW Health, Answers to questions on notice, Question 4, p5

¹⁶⁴ Greater Metropolitan Clinical Taskforce, Answers to questions on notice, Question 3, pp1-2

¹⁶⁵ Brain Injury Rehabilitation Directorate, Greater Metropolitan Clinical Taskforce, Answers to questions on notice, Question 3, p3

administrative tasks by all members of the multidisciplinary team and associated support staff. This information could further clarify the overall burden that LTCS has had on our service.¹⁶⁶

- 3.117** The LTCSA indicated that it is keen to assist and participate in the NSW Health review of the impact of the Scheme on health resources. The Authority commented that it is ‘paying over \$900 a day per participant for a rehabilitation bed and would like to clarify what services are included in this rate and how rehabilitation units can be resources to meet the increased need for services generated by the LTCS participants.’¹⁶⁷
- 3.118** The issue of returning revenue from the LTCSA to area health services, briefly mentioned in this section, is canvassed in more detail in the following chapter.

Committee comment

- 3.119** It is clear that there is an increase in administrative work due to the LTCS Scheme and that the Authority reasonably requires detailed justification for expenditure. While the increase in administration work is necessary and inevitable, it also appears to be having an onerous impact on service providers and one that may impact negatively on patient care. The Committee recognises that this is an important issue for stakeholders.
- 3.120** The Committee welcomes the Minister for Health’s comments that NSW Health will review the impact the Scheme has on health services’ resources and that included in this review will be an assessment and analysis of the administrative demands of the Scheme. In early August, the Committee forwarded the comments of the GMCT, the Department of Rehabilitation at the Children’s Hospital at Westmead and the LTCSA to the Minister for Health for inclusion in the review.
- 3.121** The Committee recommends that NSW Health consider the comments of the GMCT, the Department of Rehabilitation at the Children’s Hospital at Westmead and the LTCSA as part of its review. The Committee also recommends that the results of the NSW Health review be forwarded to the Committee so that it can consider the outcomes as part of its next review.
- 3.122** The Committee will consider the impact of the increased administration for the Scheme on all service providers in its next review.

¹⁶⁶ The Department of Rehabilitation at the Children’s Hospital Westmead, Answers to questions on notice, Question 3, p5

¹⁶⁷ LTCSA, Answers to post-hearing questions on notice, Question 9, pp4-5

Recommendation 3

That the Minister for Health request NSW Health to:

- consider the comments of the Greater Metropolitan Clinical Taskforce, the Department of Rehabilitation at the Children's Hospital at Westmead and the Lifetime Care and Support Authority as part of its review of the impact of the Lifetime Care and Support Scheme on health service resources, and
 - provide the results of its review to the Committee, once they become available.
-

Role of the LTCS coordinator

- 3.123** The First Review Report commented on the ambiguity of the role of LTCS coordinators in relation to the role of clinical staff and case managers. The Authority noted this as an area of concern and has attempted to address the issue through training and educating all parties involved in the Scheme.¹⁶⁸
- 3.124** During the current Review, stakeholders raised similar issues relating to a general confusion of the role of the LTCS coordinator, the time at which the coordinator is introduced to potential participants and their families and inconsistencies relating to the application of the guidelines between different coordinators.
- 3.125** The NSW State Spinal Injury Service suggested that there is a need for clarification and role delineation between the role of clinicians as managers of patient care and the role of the LTCS coordinators as the administrators of the Scheme. The Service commented that 'some coordinators are micromanaging at the clinical level and directing care delivery through the approval or non-approval of recommendations made by clinicians.'¹⁶⁹
- 3.126** The Department of Rehabilitation at the Children's Hospital Westmead stated there is confusion regarding the role of the LTCS Coordinator when a hospital case manager is involved. The Department commented:
- There appears to be a duplication or overlap that is not always clearly negotiated between parties and not always understood by participants. This has led to separate recommendations about interventions being made by the [LTCS] coordinator which do not reflect the current care plan, confusion from families and other community rehabilitation providers regarding how community rehabilitation needs are to be met and at time mixed messages regarding how rehabilitation services are to be obtained.¹⁷⁰
- 3.127** Dr Hodgkinson, of the GMCT, advised the Committee that the new role of the LTCS coordinator has been challenging to integrate into some existing service procedures and communication lines:

¹⁶⁸ First Review Report, pp49-51

¹⁶⁹ Submission 7, p2

¹⁷⁰ Submission 9, p7

I think the difficulty with the lifetime care coordinator's role is that it is a new role. It is not a direct parallel of what we, as clinical teams, are familiar with in terms of the case manager or the rehabilitation adviser for an insurance company who took a different role. This is a role where there is much closer involvement at a level and an expectation that they will meet regularly with the participant and that is done separate from the clinical team, and I think some of the issues arise in that the participants themselves and their families do not necessarily understand the roles of the lifetime care coordinator as separate from a clinical team, so they will raise clinical issues with the lifetime care coordinator who then feels obliged to do something, and then that puts pressure on him, what he then has to respond to, and there is not always the smooth communication and direction back to the clinical team to address those issues.¹⁷¹

- 3.128** In terms of a solution, Dr Hodgkinson suggested that, as each service manages communication and liaison issues differently, they will need to negotiate and resolve the issues on an individual service basis:

Each service has managed the communication issue differently, but what we established early on was a regular monthly meeting with the lifetime care coordinator to specifically address those issues, but that is starting to break down now partly because we have many more coordinators to deal with and so it becomes a harder thing to organise a meeting with four or five coordinators and then the number of cases we are involved with, so we will have to revisit that structure and talk to the lifetime care coordinators to try to resolve issues.¹⁷²

- 3.129** The issue of when the LTCS coordinator is to be introduced to a patient or patient's family was raised by the Department of Rehabilitation at the Children's Hospital Westmead. The Department stated that it has 'significant concerns about the potential detrimental impact on the family to a psychologically premature introduction to the Scheme.'¹⁷³

- 3.130** The Department explained this situation as follows:

Our clinical experience has shown that families remain in crisis state for some time following a motor vehicle accident and thus they require sensitive and timely provision of information ... Families have expressed that they have felt overburdened with requirements to meet extra people and deal with issues that are not vital to their understanding of their child's immediate needs while they are still in the acute stages of rehabilitation.¹⁷⁴

- 3.131** Ms Noronha, of the Department of Rehabilitation, advised that parents of severely injured children are hopeful that their child will get better and that the introduction of the possibility of lifetime care needs to be handled sensitively. Ms Noronha commented:

[A]t this time of crisis families often look for hope. They are hopeful that their child will get better and their child will be well and able to leave the hospital. At that point in time starting to talk about a Lifetime Care Scheme, in the view of the Rehabilitation

¹⁷¹ Dr Hodgkinson, Evidence, 26 June 2009, p20

¹⁷² Dr Hodgkinson, Evidence, 26 June 2009, p20

¹⁷³ Submission 9, p7

¹⁷⁴ Submission 9, p5

Department or the coordinator, may be pessimistic or negative rather than seen as something that is reassuring and helpful.¹⁷⁵

3.132 The Department suggests that the treating inpatient team should decide the appropriate timing of the introduction of the LTCS coordinator to ‘ensure that the needs of the child and family are met in a well-timed, sensitive manner that reflects the psychological, social and emotional status of the family in regard to their comprehensive rehabilitation.’¹⁷⁶

3.133 A further issue raised by stakeholders regarding the role of the LTCS coordinators was that of inconsistencies relating to the application of the LTCS Guidelines by different coordinators. For example, Associate Professor Middleton, of the NSW State Spinal Injury Service, stated:

In general, there are well-developed guidelines; however, difficulties arise due to the inconsistency between different coordinators in terms of interpreting and applying the guidelines and then communicating them to clinicians.¹⁷⁷

3.134 Associate Professor Middleton provided examples of inconsistencies between approvals by different LTCS coordinators:

Even simple things like taxi vouchers will be approved by one coordinator, but not by another coordinator. Overnight accommodation for family members might be approved or not approved. They are simple examples. Some more complex examples relate to recreation and exercise and other things. There is a feeling by the clinicians that sometimes coordinators intervene in the clinical decision-making process and take some decisions themselves.¹⁷⁸

3.135 Associate Professor Middleton noted that the increase in Scheme participants and increase in coordinators has contributed to this issue of inconsistency and suggested further training and communication mechanisms to address the issue:

... possibly as the scheme grows there are more coordinators and I think it does create more problems because there is not necessarily a direct involvement in clinical decision making and understanding ... It might be that there is some value in looking at communication mechanisms and ways of developing, and I think possibly training and education of the coordinators around health issues, the organisational structures, and I think there is some room for Health to improve as well, but I think we do need to look at better mechanisms to enhance communication and facilitate the understanding because certainly at the moment there can be misunderstandings created just by the lack of direct involvement or an adequate way of liaising.¹⁷⁹

3.136 The family carers of LTCS participants, that the Committee heard from, indicated positive views on their dealings and contact with their LTCS coordinators. Mr John Malouf advised that:

¹⁷⁵ Ms Noronha, Evidence, 26 June 2009, p52

¹⁷⁶ Submission 9, p5

¹⁷⁷ Associate Professor Middleton, Evidence, 26 June 2009, p19

¹⁷⁸ Associate Professor Middleton, Evidence, 26 June 2009, p24

¹⁷⁹ Associate Professor Middleton, Evidence, 26 June 2009, p19

Marie [LTCS coordinator] was very involved with us in the early stages as Daniel was just qualifying and just after qualifying. We had a number of meetings with doctors and social workers trying to come up with a plan from the family's point of view of what Daniel would need. Marie was very involved at that point. Once that was pretty much established, then everything folded back to the caseworker and that information was delivered that way.¹⁸⁰

3.137 Ms Spittles commented that the LTCS coordinator her family has is very caring and supportive:

Our coordinator is Rosie Kettlewell. As I said, I met her at Royal North Shore Hospital. She came across as, and is, a very caring individual. She has a lot of understanding about brain injuries. When you are dealing with government officers you tend to hit a brick wall. To speak to someone so understanding and responsive to questions and our needs was amazing. Rosie also took the time to visit the hospital on a number of occasions. She also visited the brain injury unit and sat through our meetings, so she always knew what was happening with Joel and how he was progressing. She also took the time to ring us at home to see how we were going. On at least two or three occasions she happened to ring when I was very upset and emotional about what we were going through. She took the pain away, said the right things and put me back on track by explaining why some of the behaviour we were experiencing was happening. I found that very beneficial. My husband went back to work full time within a week of the accident. As I said, we were struggling and a lot fell on my shoulders, and she was aware of that.¹⁸¹

3.138 In response to these concerns, the LTCSA provided the Committee with an outline of the role of the LTCS coordinator. The LTCS coordinator:

- Is the Authority's representative in a wide range of frontline situations including hospitals, schools, private healthcare providers and government agencies.
- Is able to provide information and advice about the Scheme to people with injuries, their families and services providers.
- Monitors and provides information about the quality, reliability and availability of services being delivered to Scheme participants.
- Reports on service gaps and engages assistance to meet identified needs and are the case file owner in the Authority to ensure that the Authority meets administrative requirements.
- Is also responsible for ensuring that contractors, such as attendant care providers, meet their contractual obligations.
- Will continue to be the contact for participants at the Authority, as participants move beyond their early treatment and rehabilitation phase.¹⁸²

3.139 The Authority advised that all Scheme participants have a LTCS coordinator and reiterated the key role of oversight and coordination of services:

¹⁸⁰ Mr John Malouf, Evidence, 26 June 2009, p46

¹⁸¹ Ms Spittles, Evidence, 26 June 2009, p47

¹⁸² LTCSA, Answers to pre-hearing questions on notice, Question 18c, p12

For some, the involvement has been in the background but for many the role has provided the oversight and coordination of services that is an essential component of delivering services to people with complex needs. This is often in addition to services from a case manager and other providers as they cannot act as a representative of the Authority. LTCS coordinators are involved with other providers and the relationship works effectively to meet participant's needs.¹⁸³

3.140 In terms of involvement and liaison with area health services and hospital staff, the LTCSA indicated that 'the involvement of LTCS coordinators in hospitals varies and is dependent on each service's protocols. LTCS involvement at each site has had to be negotiated individually and this negotiation continues.'¹⁸⁴

3.141 In response to stakeholder concerns, Mr Neil Mackinnon, Manager of Service Coordination for the LTCSA, acknowledged there are inconsistency issues:

Referring to consistency, I think we have been inconsistent. That is very much about the newness and the rate of change that we have gone through in the past two years—from having some basic principles to now having fairly detailed guidelines. That whole process of developing guidelines meant that a variety of approaches were taken until we arrived at one that we thought worked...

Some of those differences can be within units and between teams. At least initially I try to have a coordinator per unit to try to bed things down. We have gone past that now; we have 230 people in the scheme and coordinators now have quite a mix of new people. They also visit a number of units. The need for us to be consistent and for us to make things fairly straightforward for the coordinators is increasing. But we cross a whole range of services that have different operating procedures.¹⁸⁵

3.142 Mr Mackinnon stated that in relation to the time at which a LTCS coordinator approaches a potential participant's family 'it is important for us to be engaged early with people to tell them about the scheme because we are the only ones who have a more intricate knowledge about the scheme.'¹⁸⁶

Committee comment

3.143 The Committee notes that, continuing on from the First Review, there is still some confusion related to the role of the LTCS coordinator, which could be due to the infancy of the Scheme, the continuing growth of the number of participants and therefore the number of LTCS coordinators. The Committee notes that the issue of consistency may be addressed through LTCS coordinator training. The Committee encourages the LTCSA to continue to work with service providers to clear up this confusion and ambiguity to ensure Scheme participants and their families receive clear messages about the Scheme and its services.

3.144 The Committee does acknowledge the integral role of the LTCS coordinator in providing a link between participants and their families and the Authority. The Committee recognises that,

¹⁸³ LTCSA, Answers to pre-hearing questions on notice, Question 18c, p12

¹⁸⁴ LTCSA, Answers to pre-hearing questions on notice, Question 18c, p12

¹⁸⁵ Mr Neil Mackinnon, Manager, Service Coordination, LTCSA, Evidence, 26 June 2009, p12

¹⁸⁶ Mr Mackinnon, Evidence, 26 June 2009, p12

especially in the case of potential child participants, the introduction of the LTCS Scheme and the coordinator does need to be timed sensitively. The Committee recommends that the LTCSA in the case of potential child participants, consult with the treating rehabilitation team regarding the appropriate timing for the introduction of the LTCS coordinator.

Recommendation 4

That the Lifetime Care and Support Authority, in the case of potential child participants, consult with the treating rehabilitation team regarding the appropriate timing for the introduction of the Lifetime Care and Support coordinator.

Conclusion

- 3.145** The Committee recognises that, overall, the Scheme is operating successfully and the concerns and issues raised by stakeholders examined in this chapter primarily relate to improving the Scheme and refining the work of the Authority. The Committee acknowledges the issues raised by stakeholders and values their time and contribution put into the Committee's review process and their efforts for improving the Scheme for participants.
- 3.146** The Committee recognises that even though the Scheme has matured since the last review, there are still issues that will require monitoring in future reviews as the Scheme continues to develop. An increase in participants from 76 interim participants from the First Review, to the 233 participants, including four lifetime participants at the time of this current Review, and the estimated growth of the Scheme by 125 people per year¹⁸⁷ will inevitably require the Authority to refine its work and resolve new issues as they arise.
- 3.147** The Committee is pleased to be able to conduct annual reviews of the LTCS Scheme and Authority to aid the Authority and Advisory Council to improve the Scheme for participants. The ability to follow these emerging issues through and to report on their resolution or improvements is valuable.
- 3.148** The next chapter will specifically canvas new issues raised by stakeholders during this current Review.

¹⁸⁷ LTCS E-News: Lifetime Care and Support Newsletter, Issue 27, 18 June 2009, p2

Chapter 4 **New issues for the Scheme**

This chapter will look at the new issues raised in the current Review that relate to the functioning of the Lifetime Care and Support (LTCS) Scheme and the work of the Lifetime Care and Support Authority (LTCSA) and the Lifetime Care and Support Advisory Council.

Some of these issues may have been noted in the Committee's First Review of the exercise of the functions of the Lifetime Care and Support Authority and the Lifetime Care and Support Advisory Council Report and have become more apparent with the development of the Scheme. The chapter will also briefly outline issues that may be relevant for the Committee to consider in future reviews.

Issues for the current Review

4.1 Stakeholders raised the following new issues during this current Review:

- Membership on the Lifetime Care and Support Advisory Council
- Revenue issues for area health services
- Definition of recreation and leisure activities covered by the Scheme
- Definition of families used by the LTCSA in applying LTCS Guidelines
- Limited awareness of the Scheme
- Interim participation for people with spinal injuries
- Buy-in to the Scheme for people injured prior to the commencement of the Scheme
- LTCSA Guidelines being "ultra vires" the Act, or limiting the Act
- Awarded damages being used in divorce settlements.

Membership on the Lifetime Care and Support Advisory Council

4.2 The role of the Lifetime Care and Support Advisory Council (LTCSAC) is to advise the Minister on matters relating to the LTCS Scheme.¹⁸⁸ Section 45 of the *Motor Accidents (Lifetime Care and Support) Act 2006* sets out the membership of the Advisory Council:

- (1) The Advisory Council is to consist of the following 8 members:
 - (a) 2 health practitioners appointed by the Minister after consultation with the Australian Medical Association (NSW) Limited and such other associations of health practitioners as the Minister considers appropriate,

¹⁸⁸ Lifetime Care and Support Authority (LTCSA), *Annual Report, 2007-2008*, p5

- (b) 2 persons appointed by the Minister after consultation with such organisations concerned with the treatment and care of injured persons as the Minister considers appropriate,
- (c) 2 persons appointed by the Minister after consultation with such organisations representing the interests of severely injured persons as the Minister considers appropriate,
- (d) 1 person of the Minister's own choosing, who is to be the Chairperson of the Advisory Council,
- (e) the Chief Executive Officer of the Authority.¹⁸⁹

4.3 In evidence, the suggestion for the inclusion of participant representatives and social worker representatives on the LTCSAC was introduced.

4.4 When asked if there were any legislative changes that could be made to the Scheme, Mr David Bowen, Chief Executive Officer, LTCSA, commented that a participant representative on the LTCSAC would be a desirable outcome for the future:

I think it will be appropriate as the Scheme develops and we build up a body of participants. We have been talking about how we can empower other participants, not only to manage their own affairs but as a group to give some feedback. I think having a participant representative on the Advisory Council would be a desirable thing to achieve in the future.¹⁹⁰

4.5 Dr Graham Simpson, Senior Social Worker at the Liverpool Brain Injury Rehabilitation Unit and member of the Social Workers in Brain Injury Professional Interest Group, advised the Committee that social workers as a group were not represented on the LTCSAC.¹⁹¹

4.6 Ms Diane Turner, Social Work Professional Leader at the Royal Rehabilitation Centre and a member of the Social Workers in Brain Injury Professional Interest Group, commented that it was regrettable that social workers were not represented on the Advisory Council.¹⁹²

4.7 Ms Denise Young, Program Clinical Manager at Bathurst Hospital and also a member of the Social Workers Brain Injury Professional Interest Group, outlined the significant and varied role of social workers in relation to the LTCS Scheme:

First of all, we social workers play a part in informing people, or certainly the family members of injured people, about the existence of the scheme and help test their eligibility by making sure that applications are lodged with all the associated relevant material ...

¹⁸⁹ *Motor Accidents (Lifetime Care and Support) 2006*, s45. For the membership list of the Lifetime Care and Support Advisory Council refer to the LTCSA's *Annual Report, 2007-2008*, p5

¹⁹⁰ Mr David Bowen, Chief Executive Officer, Lifetime Care and Support Authority, Evidence, 26 June 2009, p4

¹⁹¹ Dr Graham Simpson, Senior Social Worker at the Liverpool Brain Injury Rehabilitation Unit, Social Workers in Brain Injury Professional Interest Group, Evidence, 26 June 2009, p66

¹⁹² Ms Diane Turner, Social Work Professional Leader at the Royal Rehabilitation Centre, Social Workers in Brain Injury Professional Interest Group, Evidence, 26 June 2009, p66

One of our other roles is that we want to ensure that rehabilitation coordinators within the appropriate rehabilitation service where the person goes are allocated and that there is liaison opened with the right lifetime care and support case coordinator ... we have quite a significant role in developing community discharge plans, care needs assessment and community living plans, and also liaising with other care agencies if they have to be involved, and making sure it all comes together for the plan.¹⁹³

- 4.8** Ms Young also advised the Committee on the social workers role with family members and friends, as well as providing direct support for participants in the Scheme:

Another really important area of our work is with family members. So we have to make sure that their needs and issues are addressed... Finally, we work to help the person themselves, family members and other workers to ensure that the person with the injury becomes as full as possible a participant in the life of their family and in their community. I suppose what I am saying is that social workers have not only a practical role but we have a significant role in the whole issue of relationships and the way in which the person recovers, and that the family, in which they are a strong part, and the social network continue to be able to function appropriately.¹⁹⁴

Committee comment

- 4.9** While the Committee did not receive a great deal of evidence on this issue, it does seem appropriate for participants to be directly represented on the LTCSAC in order to ensure that participants are given a voice on the body that makes recommendations to the Minister regarding the Scheme. The Committee notes that the Authority also considered this to be a desirable outcome for the future. The Committee is therefore of the view that the membership of the Advisory Council should be broadened to include at least one participant representative.
- 4.10** The Committee is also of the view that, in order to support the participant representative, it would be appropriate for the LTCSA to create and facilitate a small group of representative participants and their family carers, such as a participant and family carers working group, to examine participant and family carer issues, from which the representative could then report to the Advisory Council.
- 4.11** In addition, the Committee recognises the significant contribution and role that allied health workers and professionals have within the Scheme. Based on this and the views of stakeholders in this regard, the Committee believes that the membership of the Advisory Council should also include an allied health representative.
- 4.12** Therefore, the Committee recommends that the Minister for Finance review the membership of the Lifetime Care and Support Advisory Council to consider including representatives of Scheme participants and allied health workers and professionals and, if necessary, seek an amendment to the *Motor Accidents (Lifetime Care and Support) Act 2006*. The Committee also recommends that the LTCSA create and facilitate a participant and family carers working group that can support the participant representative to the LTCS Advisory Council.

¹⁹³ Ms Denise Young, Program Clinical Manager, Bathurst Hospital, Social Workers in Brain Injury Professional Interest Group, Evidence, 26 June 2009, p62

¹⁹⁴ Ms Young, Evidence, 26 June 2009, p62

Recommendation 5

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

Recommendation 6

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.

Revenue issues for area health services

- 4.13** Stakeholders, in particular representatives from public health services, raised concerns with how revenue is returned to that particular health unit for the provision of the service it provides to LTCS participants and how the additional time spent on administration for the Scheme impacts on revenue for the unit.
- 4.14** Currently, service providers invoice the LTCSA for the services they provide to LTCS participants. The LTCSA then reimburses the service provider. However, the Committee has heard that in the case of some public health services this reimbursement may go to the overarching area health services instead of the actual health unit, for example, an individual brain injury rehabilitation unit at a particular hospital.¹⁹⁵
- 4.15** NSW Health advised that the administration of revenue gained via the LTCS Scheme is governed by a number of policy directives, for which compliance is mandatory. In addition, NSW Health commented that:

Systems for administering LTCS Scheme revenue have been developed locally. Anecdotal evidence suggests there may be some uncertainty about processes relating to the administration of LTCS accounts ...The Department of Health will work with area health services to investigate options for enhancing systems for administering revenue from the LTCS Scheme.¹⁹⁶

- 4.16** In evidence, Dr Adeline Hodgkinson, Chair of the Brain Injury Rehabilitation Directorate, Greater Metropolitan Clinical Taskforce (GMCT), advised that the funding from the LTCSA goes into the general funding pool for area health services and does not target rehabilitation units:

Lifetime care is something that has the potential to draw money into health services to meet that current gap. The difficulty is that lifetime care funding goes into the general

¹⁹⁵ Dr Joe Gurka, Director, Brain Injury Rehabilitation Service Westmead, Greater Metropolitan Clinical Taskforce, Evidence, 26 June 2009, p22

¹⁹⁶ NSW Health, Answers to questions on notice, Question 1, pp2-3

revenue of Health and it then becomes dispersed as the chief executive officers of each area health service choose. Nothing directly targets that funding to rehabilitation.¹⁹⁷

- 4.17** Dr Joe Gurka, Director, Brain Injury Rehabilitation Service Westmead, GMCT, advised the Committee that each area health service deals with revenue in a different way:

Every area health service deals with revenue in a different way. Some revenue comes back to units and some revenue does not go back to units directly. What is going back to units is not necessarily coming back as real money that they can expend; it is just coming to meet a revenue target that might be unrealistically set. By default, what happens is that a lot of the lifetime care revenue is paying for public hospital services non-participants in the scheme. It is a huge issue that needs to be reviewed.¹⁹⁸

- 4.18** The GMCT stated that unlike with the Motor Accidents Scheme, there are no funds to deal with service enhancements or increased workload issues associated with the LTCS Scheme, only a fee for service system with the LTCSA:

The prior DOH/MAA memorandum of understanding acknowledged the implementation costs to NSW Health and provided funds to support changes. LTCSA are providing NSW Health revenue on a fee for service basis and there is no link to access revenue for service enhancements. The statewide reduction in NSW Health staff numbers to manage budgets has compromised the NSW BIRD's ability to respond to the workload changes for the LTCS within current resources.¹⁹⁹

- 4.19** The GMCT recommends that the LTCSA and NSW Health consider a memorandum of understanding to address revenue issues.²⁰⁰ Dr Hodgkinson elaborated on the need for a memorandum of understanding:

A memorandum of understanding would allow lifetime care to be assured, and that the services for which they are paying and the expectation of a quality service would be delivered. Hopefully it would be combined with an assurance from Health that the funding provided would go towards rehabilitation services rather than being absorbed into the black hole of deficits.²⁰¹

- 4.20** Dr Gurka added that a memorandum of understanding should recognise the resources needed to deliver the necessary services:

Just to add to that, it is important for the memorandum of understanding to recognise the minimum standard of resources that our programs require in order to deliver the services that are being paid for. Therefore, how the revenue from lifetime care is handled will have to be looked at closely.²⁰²

¹⁹⁷ Dr Adeline Hodgkinson, Chair, Brain Injury Rehabilitation Directorate, Greater Metropolitan Clinical Taskforce, Evidence, 26 June 2009, p22

¹⁹⁸ Dr Gurka, Evidence, 26 June 2009, p22

¹⁹⁹ Submission 10, Greater Metropolitan Clinical Taskforce, p3

²⁰⁰ Submission 10, p3

²⁰¹ Dr Hodgkinson, Evidence, 26 June 2009, p22

²⁰² Dr Gurka, Evidence, 26 June 2009, p22

4.21 The Department of Rehabilitation at the Children’s Hospital at Westmead supports the GMCT’s proposal for a memorandum of understanding between NSW Health and the LTCSA. The Department commented that:

This memorandum of understanding would acknowledge that it is crucial to sufficiently fund the NSW Brain injury Rehabilitation Programs to meet the clinical and administrative requirements of the Scheme and to continue to provide high standard brain injury and spinal cord injury programmes.²⁰³

4.22 Ms Suzanne Lulham, Director of Service Delivery at the LTCSA, recognised that the funds are not always directed back to the unit that provides the service but to the area health services as a whole:

Although we pay for these services—for a participant who is in one of those beds, we would be paying \$28,000 a month—that money does not go back to the unit but back to the area health service. It means that they are getting an increased workload without getting that funding to meet an increased workload.²⁰⁴

4.23 Ms Lulham advised that some form of a ‘contract agreement’ may be useful in ensuring that the money goes back to the units that provide the service:

One of the things we would like to pursue further with them is the idea of having some sort of contract arrangement with them whereby the money that we use to purchase the services goes back to the units to expand the capacity to meet the demand.²⁰⁵

4.24 As mentioned in the previous chapter in relation to the issue of the administrative work required of the Scheme, the Hon John Della Bosca MLC, Minister for Health, advised the Committee that NSW Health intends to conduct a review of the impact of the Scheme on health service resources at the close of the 2008/2009 financial year.²⁰⁶ Stakeholder comments regarding the issue of revenue reimbursement to area health services have been forwarded by the Committee to the Minister for inclusion in the NSW Health review.

Committee comment

4.25 The Committee acknowledges the comments made by the GMCT in relation to how revenue is not always directed back to public health units that are providing the treatment, care and support to LTCS participants. The suggestion by the GMCT of a memorandum of understanding has merit. The LTCSA itself has raised the possibility of a ‘contract agreement’ to address this issue.

4.26 The Committee notes that NSW Health will be considering the impact of the Scheme on health services resources and the Committee will await the outcome and results of that review.

²⁰³ The Department of Rehabilitation at the Children’s Hospital at Westmead, Answers to questions on notice, Question 2, p4

²⁰⁴ Ms Suzanne Lulham, Director, Service Delivery, Lifetime Care and Support Authority, Evidence, 26 June 2009, p14

²⁰⁵ Ms Lulham, Evidence, 26 June 2009, p14

²⁰⁶ NSW Health, Answers to questions on notice, Question 4, p5 and Question 5, p6

The Committee has requested that the results of the NSW Health review be made available to it. This issue will continue to be monitored and will be revisited in a future review.

Definition of recreation and leisure activities covered by the Scheme

- 4.27** Some stakeholders raised concerns regarding the definition of recreation and leisure activities used by the LTCSA when considering requests for funding for, or access to, these activities for LTCS Scheme participants.
- 4.28** The LTCSA released a consultation paper titled *Leisure and recreation in the Lifetime Care and Support Scheme* in March 2009. This consultation paper has resulted in draft guidelines for access to leisure and recreation activities, which intend to provide guidance and information about what LTCSA will fund.²⁰⁷
- 4.29** The new draft guidelines state that the Authority will fund reasonable and necessary access to leisure and recreation, which includes additional assistance (for example, the presence of an attendant care worker) and adaptation or modification to equipment required (for example, modified roller skates) to participate in the activity due to the motor accident injury, but not the cost of the activity unless it is part of a rehabilitation program.²⁰⁸
- 4.30** The Westmead Brain Injury Unit highlighted the importance of recognising leisure as an important life role for most people and that catastrophic injury can significantly change a person's ability to pursue leisure interests. The Unit said 'we strongly believe the ability to engage in leisure activities, or any other life roles for that matter, contributes significantly to people's perceived quality of life.'²⁰⁹
- 4.31** The GMCT expressed the view that the definition of recreation and leisure used by the LTCSA is restrictive and suggests the need to recognise the importance of recreation and leisure services for LTCS participants as part of rehabilitation and socialisation for those who are not able to return to vocational employment or education as a result of the injury severity. The GMCT continued:
- There are limited opportunities for the LTCS participant with significant and permanent loss of skills to independently maintain and enhance their living circumstances, develop and sustain social and community relationship and participant in community life when employment and further education is no longer an option.²¹⁰
- 4.32** The GMCT suggested that the gaps in recreation and lifestyle support will continue to be raised through the existing GMCT and LTCSA liaison meetings.²¹¹

²⁰⁷ LTCSA, LTCS E-News, Issue 26, 1 June 2009, p2. The draft guidelines were open for comment until 3 July 2009. The Committee has not been advised of the current status of these guidelines.

²⁰⁸ LTCSA, LTCS E-News, Issue 26, 1 June 2009, p2

²⁰⁹ Submission 6, Westmead Brian Injury Rehabilitation Unit, p2

²¹⁰ Submission 10, pp3-4

²¹¹ Submission 10, pp3-4

4.33 Dr Hodgkinson further explained the role that recreation and leisure plays in patient rehabilitation:

The recently released draft guidelines in terms of leisure and recreation have taken a fairly restricted view of what we see as necessary in terms of facilitating recovery in our patients. One of the issues comes down to how we view leisure and recreation ... Although initially following a severe brain injury there may be a lot of physical and cognitive impairments, one of the lasting impairments or disabilities is psychosocial disability. This may be a person's personality has changed their ability to interact with people, their ability for form relationships; to plan how they would get through their day to a return to work is affected by their injury itself. So the use of leisure and recreation from our perspective, when we are proposing leisure and recreation we are looking at it broader than just filling up the person's day.²¹²

4.34 Dr Hodgkinson advised that recreation and leisure activities become part of psychosocial rehabilitation therapy:

We are using the structured activities that we then propose as part of a person's leisure and recreational program to achieve a psychosocial rehabilitation, to reduce the psychosocial impairment so that it becomes in itself a therapy... For example, we have been given the decision that someone who applied to go to a gym program, it was approved for a certain period of time while there were physical goals of fitness but once we needed to keep that in place as a structured activity that would facilitate that person's interaction with the community and engagement in the community, and therefore lessen psychosocial disability, it was refused because it was no longer a physical goal and in fact became a leisure and recreation goal and therefore it was not approved. I think it was a loss for that patient.²¹³

4.35 Dr Gurka stated that there are concerns with the new draft guidelines only funding access to the activity but not the actual cost of the activity itself:

They will fund any care support or equipment that is required to support recreation but they are quite strong that they will not fund the actual activity itself. I guess that is where we have a concern because, as Dr Hodgkinson said, probably the biggest, long-lasting disability from brain injury is psychosocial and social isolation, depression and all of those things that result. So the activity is seen as a therapeutic intervention to prevent those things and therefore we strongly feel that there should be funding.²¹⁴

4.36 The Committee heard from a few participants in the LTCS Scheme and asked them and/or their carers about their views on recreation and leisure activities and funding by the Scheme. Their comments indicated the importance of such activities and assisted the Committee to understand the kind of activities this issue involved. In relation to the proceeding discussion of those views in the next few paragraphs, the Committee notes that, under the terms of reference for the review, it does not have the authority to investigate individual participants non-approval for treatment or acceptance into the Scheme.²¹⁵

²¹² Dr Hodgkinson, Evidence, 26 June 2009, p27

²¹³ Dr Hodgkinson, Evidence, 26 June 2009, p27

²¹⁴ Dr Gurka, Evidence, 26 June 2009, p27

²¹⁵ The terms of reference for the review refer to page iv of this report.

4.37 The examples the Scheme participants and their carers have provided the Committee have been used to highlight the types of activities participants are interested in for recreation and leisure and does not in any way mean that the Committee recommends the LTCSA should or should not fund these particular activities sought by these participants.

4.38 Mr Rod McDonald, family carer of Ricki-Lee Bell an interim participant in the LTCS Scheme, advised the Committee that Ricki-Lee was interested in partaking in hip-hop dancing classes, as was suggested by her physiotherapist, to help improve her arm movements and a positive change from usual rehabilitation activities. However, this request was not supported by the LTCSA.²¹⁶ Ricki-Lee also commented that it would provide her with social interaction, which is limited for her at the moment.²¹⁷

4.39 Mr McDonald said that in the future they would want Ricki-Lee to increase her socialisation through leisure activities:

There is a thing called Headstart that is outside the brain injury service. I do not think Ricki is quite ready for anything like that, but that is something that we are looking into. When that does come around—like I said, it has only been eight months, so I am not sure whether lifetime care and support would support that because that is more of a social activity thing. They might go bowling, they might go to the movies once a week or they might go to the wetlands, but it is more of a socialising thing where they are getting out and meeting other people that have more than likely been through the same sort of experience.²¹⁸

4.40 Ms Zivana Spittles, family carer of Joel Spittles an interim participant in the Scheme, said that her son has an interest in photography and the LTCSA pays for extra travel time for him to pursue this, which has helped with his socialisation:

My son Joel was into photography, taking little shots every now and then before his accident. Because he had that interest, lifetime care and support paid extra travel time with his carers and they would always make that extra effort to take him somewhere special, go for a bushwalk or go to the city to take photos. In the whole process of doing that he was learning skills, he was learning how to plan a trip to the city, he was learning how to manage his money, he was interacting with the carer and other people he met along the way, so some of those little interests that they have certainly build up their confidence and give them back some skills that they have lost.²¹⁹

4.41 Ms Spittles also gave an example of a leisure activity that would help with her son's socialisation and speech therapy:

Joel is very much into rapping and he really, really wants to do a singing course, but I have not approached that as yet. We feel that would probably really benefit him. He has lost a lot of his friends. His social situation has certainly changed. With his lack of insight he can make some bad choices. To have a focus and something that he really likes would work very positively for him. I must say I have not pushed that. It has been mentioned at times with his case manager. That is a bit like the hip-hop dancing.

²¹⁶ Mr Rod McDonald, Evidence, 26 June 2009, p40

²¹⁷ Ms Ricki-Lee Bell, Evidence, 26 June 2009, p44

²¹⁸ Mr Rod McDonald, Evidence, 26 June 2009, p44

²¹⁹ Ms Zivana Spittles, Evidence, 26 June 2009, p45

It would really benefit Joel ... The rehab team is aware of that and they are trying to utilise that interest to benefit Joel's communication skills.²²⁰

4.42 Daniel Malouf, a lifetime participant in the Scheme, commented that he felt like he was maybe 'asking for too much when my case managers ask about organising stuff like driving lessons. I just think I am asking for too much because they have already given me so much.'²²¹

4.43 Mr Bowen, of the LTCSA, recognised that as the Scheme is in the development stage 'we are still grappling with issues like recreational support.'²²²

4.44 As stated earlier, the Guidelines propose that the LTCSA pay for access to recreation and leisure, for example, adapted equipment or an attendant care worker to assist with the activity, but not for the actual cost of the recreation or leisure activity unless it is part of a rehabilitation program.²²³

4.45 The LTCSA's consultation paper on recreation and leisure indicates there would be funding issues if the Scheme were to fund the actual cost of recreation and leisure activities. The paper states:

Leisure and recreational activities have not been provided for when costing the Scheme, as they are not listed in the Act as part of treatment, rehabilitation and care. This means that the Scheme is not funded to provide leisure and recreation. It is also noted that the Scheme is in its early years with a very small number of lifetime participants. Therefore, the long term impacts of implementing funding for leisure and recreation within the Scheme and the expected costs may not be known for many years.²²⁴

Committee comment

4.46 The Committee notes the GMCT concerns that the definition of recreation and leisure is restrictive and notes that unless it is part of a rehabilitation program the LTCSA will only fund a participant's access to that activity. If it is part of the rehabilitation program the LTCSA will fund the actual cost of the activity.

4.47 The Committee recognises that covering the cost of actual recreation and leisure activities may have a financial impact on the Scheme, especially in the long term as lifetime participation increases.

4.48 The Committee acknowledges that it is important for participants to have access to recreation and leisure activities in order to enhance their living circumstances. The Committee understands the contribution these activities can make to the rehabilitation of participants including learning socialisation skills and recognises that it could be argued that most

²²⁰ Ms Zivana Spittles, Evidence, 26 June 2009, p45

²²¹ Mr Daniel Malouf, Evidence, 26 June 2009, p45

²²² Mr Bowen, Evidence, 26 June 2009, pp3-4

²²³ LTCSA, Answers to pre-hearing questions on notice, Question 39, p23

²²⁴ LTCSA, Consultation paper: *Leisure and recreation in the Lifetime Care and Support Scheme*, March 2009, p2

recreation and leisure activities form part of the psychosocial rehabilitation for participants in the Scheme.

- 4.49** The Committee is concerned that some participants may not partake in recreation and leisure activities if the cost was to fall onto the participant and/or their family, and may therefore, miss out on opportunities to improve their life circumstances, especially for those participants who are not able to return to vocational employment or education as a result of the severity of injuries.
- 4.50** For these reasons, the Committee recommends that the LTCSA carefully examine the role that recreation and leisure has in the psychosocial rehabilitation of participants and the desirability of the LTCSA funding these activities, especially for those participants who are not able to return to vocational employment or education. In addition, the Committee recommends that the LTCSA, when interpreting the definition of recreation and leisure, take a broad approach so that, where appropriate, it includes unusual activities that may be of particular interest and therapeutic value to some participants, such as those activities described by participants who gave evidence to the Committee.

Recommendation 7

That the Lifetime Care and Support Authority:

- carefully consider the role that recreation and leisure has in the psychosocial rehabilitation of participants and reconsider funding the cost of recreation and leisure activities (and not just access to the activity), especially for those participants who are not able to return to vocational employment or education, and
 - when interpreting the definition of recreation and leisure, a broad approach be taken so that, where appropriate, it includes unusual activities that may be of particular interest and therapeutic value to participants.
-

Definition of families used by the LTCSA in applying guidelines

- 4.51** Some stakeholders raised concerns regarding the definition of families used by the LTCSA in applying the LTCS Guidelines for the approval of services for family members of participants. The types of family related services the LTCSA can consider funding include respite care, counselling, before and after school care and transport and accommodation costs.²²⁵
- 4.52** The Royal Rehabilitation Centre Sydney explained the importance of family support for participants and therefore, the need to carefully consider definitions such as ‘significant others’:

Our experience has indicated that support for family and significant others is priceless. This freely given support can assist individuals to remain motivated, to persist with therapy, to try new things, including participation in vocational training and return to work. Such support can therefore, maximise a person’s capacity to make the transition from being an in-patient following catastrophic injury to accessing and participating in

²²⁵ LTCSA, Answers to pre-hearing questions on notice, Question 41a, p23

community life. It is therefore, important that LTCS Case Coordinators interpret ‘family and significant others’ broadly ... and give agreement that emotional adjustment therapy may proceed.²²⁶

4.53 The Westmead Brain Injury Rehabilitation Unit advised that the Authority has been supportive of applications they have submitted requesting support for families in the way of respite, counselling, rental assistance and transport as ‘such support is crucial to the rehabilitation outcomes for the patient.’²²⁷

4.54 The Unit encourages the LTCSA to continue its support of the family unit as a vital component of the rehabilitation program of the person with the injury. Furthermore:

We encourage the LTCSA to interpret the phrase ‘families and significant others’ in a broad way to encompass the whole family, be it either primary, secondary and tertiary caregivers or those affected by the consequences of the brain injury.²²⁸

4.55 The Social Workers in Brain Injury Professional Interest Group is concerned that the phrase ‘families and significant others’ is being interpreted too narrowly by the LTCSA. It stated ‘by narrowly we mean that families are being defined in dyadic terms (eg spouse – injured partner; parents – injured adult child) ... specifically, it raises difficulties in seeking services for members of the extended family network who have needs directly related to the injury.’²²⁹

4.56 The Group recommends the use of the National Health and Medical Research Council (NHMRC) definition of ‘family’ as the template to ensure inclusive non discriminatory practice particularly for cultural and linguistic diverse families and indigenous families. The NHMRC definition for families includes ‘the immediate biological family, the family of acquisition and the family of choice and friends.’²³⁰

4.57 In addition, the Group suggested that LTCS coordinators receive training on:

- The impact of a person’s traumatic brain injury on the family as a system.
- Interventions required to address such impacts, including counselling for significant others (which includes parents, siblings, grandparents, children, and others as appropriate).
- What constitutes sufficient evidence from health professionals, clinicians and social workers to demonstrate ‘reasonable and necessary’ interventions for family and significant others.²³¹

4.58 In evidence, Dr Graham Simpson, Senior Social Worker at the Liverpool Brain Injury Rehabilitation Unit and member of the Social Workers in Brain Injury Professional Interest

²²⁶ Submission 3, Royal Rehabilitation Centre Sydney, p2

²²⁷ Submission 6, p2

²²⁸ Submission 6, p2

²²⁹ Submission 8, Social Workers in Brain Injury Professional Interest Group, p3

²³⁰ Dr Simpson, Evidence, 26 June 2009, p63

²³¹ Submission 8, p3

Group, advised the Committee that the term ‘family’ and ‘significant others’ can be interpreted too strictly by the LTCSA:

... the families and significant others perhaps are being interpreted too narrowly at times by the LTCSA. There is often a shorthanded way that health and rehabilitation staff will work with families, where they will latch on to a primary carer or one family member who is often at the hospital, and then really channel everything through that person ...When we actually look at whom they will supply or provide support for, when we make requests, sometimes there are questions around providing support for people beyond those narrow, immediate family members.²³²

4.59 Dr Simpson provided an example to illustrate the issue of how it can be difficult to get support for siblings due to the way the LTCSA define family:

In one of those cases, after quite a bit of advocacy, support of a limited nature was provided. This was in relation to a young man who was very close to the brother who had the traumatic injury. The way he responded to the injury was by acting out. He started to display some behavioural disturbance and he got into trouble with the police, but it was directly related to the anxiety and the distress he experienced with the injury of his brother. The social worker had substantial difficulty in getting the case coordinator to approve support in relation to treatment for that particular brother.²³³

4.60 Dr Simpson recognised that there are sometimes complicating factors for LTCS staff in approving family support requests, including that in some cases some family members may have pre-existing psychosocial difficulties and that in other cases certain relationships may be ambiguous or contested within the family system.²³⁴

4.61 On a related issue, the Group raised concerns with the type of interventions available for families and significant others being limited to counselling and behavioural interventions by the LTCSA:

The second thing is the concern that the sort of interventions for targeting families and significant others just fits under this frame of counselling and behavioural intervention. All the time there is a growing range of different interventions that have been developed, both within Australia and internationally, in terms of treating and supporting families and maintaining and supporting friendship networks.

We just feel that it would be useful if there could be some sort of expansion beyond just the terms "counselling" and "behaviour management". For example, in terms of maintaining social networks, there is now a lot of work being done around the social networking technology through Facebook, email and things like that. These can be critical issues in terms of the way that the people remain connected, because we know that social isolation is one of the biggest challenges that particularly people with brain injury face, but it does not fall easily under a counselling framework.²³⁵

²³² Dr Simpson, Evidence, 26 June 2009, p63

²³³ Dr Simpson, Evidence, 26 June 2009, p63

²³⁴ Dr Simpson, Evidence, 26 June 2009, p63

²³⁵ Dr Simpson, Evidence, 26 June 2009, p63

4.62 The solution put forward by the Group was to broaden the definition of counselling and behavioural interventions to encompass a range of other ways that support both families and friendship networks.²³⁶

4.63 In response to these issues, the LTCSA advised that it consistently interprets families and significant others broadly when considering requests for services:

The Authority recognises that families are unique to each individual participant and values the important role family plays following serious injury. As such, the Authority consistently interprets “families and significant others’ broadly when considering each request for service related to family support. This can be evidenced by a range of examples where the Authority has funded reasonable and necessary services to family members including: adjustment counselling to assist siblings; before and after school care; counselling for a de facto partner; support fund education to a participant’s sister and brother-in-law.²³⁷

4.64 The Authority also commented that ‘as families are unique in nature, the Authority is reliant on service providers to describe the impact of injury on the participant’s family functioning in order to identify if the requested services are reasonable and necessary in the circumstances.’²³⁸

Committee comment

4.65 The Committee acknowledges the concerns of the Royal Rehabilitation Centre, the Westmead Brain Injury Unit and the Social Workers in Brain Injury Professional Interest Group that, in some instances, the application of the definition of families and significant others by the LTCSA may be too narrow.

4.66 The Committee recognises the importance of supporting family relationships and the role these family relationships can play in rehabilitation of participants. The Committee notes the advice of the LTCSA that it does in fact interpret ‘family’ and ‘significant others’ broadly when considering each request for services related to family support. The Committee encourages the LTCSA to continue to do this.

4.67 The Committee notes the comments relating to the definition of counselling and behavioural interventions potentially being too specific to encompass other interventions that support family and friendship networks and will consider this issue in a future review.

Limited awareness of the Scheme

4.68 Another issue that came to the Committee’s attention during its Review was the limited awareness of the LTCS Scheme.

4.69 The GMCT commented that whilst there was an initial education campaign for likely service providers regarding the establishment of the Scheme, there continue to be situations where

²³⁶ Dr Simpson, Evidence, 26 June 2009, p63

²³⁷ LTCSA, Answers to pre-hearing questions on notice, Question 41a, p23

²³⁸ LTCSA, Answers to pre-hearing questions on notice, Question 41a, p23

non-specialised providers are not aware of the LTCS Scheme, the request and approval procedures and processes.²³⁹

4.70 The GMCT stated that these issues are of particular concern in rural or cross-border locations and suggest that further education and public awareness forums be conducted by LTCSA across NSW to target these locations and that print material about LTCS is made available at strategic locations, such as patient information stands.²⁴⁰

4.71 Dr Hodgkinson stated that the different levels of understanding of the Scheme depended on a persons involvement and that the awareness gap lays outside the rehabilitation teams:

At the direct service level with the rehabilitation teams dealing with the participants I think there is a relatively good understanding. There certainly is at a team level; if one person does not have all the information some others will have more information. There is the knowledge that is able to support participants and raise clearer expectations of what the scheme is there for and what it will deliver in the long term. I think the awareness gap is outside the direct rehabilitation teams. Within Liverpool Hospital the acute services remain uninformed. The social workers have attended detailed training provided by Lifetime Care and Support. I do not think it has in any way changed their understanding of what is available and it has certainly not changed their practices. They are not identifying people early and referring early to the scheme.²⁴¹

4.72 Ms Jenni Johnson, Manager Outreach Services, NSW State Spinal Injury Service, also stated that in most cases potential participants have not heard of the Scheme:

I think the clients themselves are overwhelmed by the Scheme when they come into the units. They have never heard of it and they do not understand what it means to them. The social workers actually take the brunt of the workload in interpreting the benefits of the Scheme to the individual. Whereas in the past the social workers might have concentrated on psychosocial adjustment issues, they are now spending a lot of time assisting the client to understand the scheme and the benefits of the Scheme. That is quite overwhelming for many people.²⁴²

4.73 Dr Hodgkinson suggested that the LTCSA needs to continue with the education programs it has already carried out and said 'they have already done some education but I think they might need to keep doing similar education.'²⁴³

4.74 Ms Lulham, of the LTCSA, outlined for the Committee the recent and ongoing education programs the Authority has been running in the past 12 months:

We have run sessions on what we call our scheme introductory training, which is for all service providers. It is a one-day workshop that starts about general information

²³⁹ Submission 10, p5

²⁴⁰ Submission 10, p6

²⁴¹ Dr Hodgkinson, Evidence, 26 June 2009, p21

²⁴² Ms Jenni Johnson, Manager Outreach Services, NSW State Spinal Injury Service, Evidence, 26 June 2009, p21

²⁴³ Dr Hodgkinson, Evidence, 26 June 2009, p22

about the Lifetime Care and Support Scheme and then how to request services and our processes. We run three or four of those each year and we are continuing to do that. We ran one yesterday. We also run ongoing training in FIM [Functional Independence Measure], which is the eligibility assessment tool, and the WeeFIM [Children's Functional Independence Measure]. We run about two of those workshops each year ... The CANs, the care and needs assessment tool, we use very much to help with our costings and our review of people. Training on that is run two or three times a year for all service providers.

We have also run three training sessions for our approved assessors—they are the assessors that do our assessment in the Scheme in the last four, five months. In the next week we are about to run training for our disputes assessors which is specifically around that decision making and their role within our Scheme. We have also run training sessions, and general information sessions, with a number of insurers and about their relationship with us. We have been out to the public hospitals social work departments and some of the neurological wards to run training sessions. We have been up to the Hunter occupational therapy group and run training sessions with them, the Brain Injury Association, the spinal cord injuries nurses' course and then there are other specialist interest groups like the occupational therapy spinal special interest group, their brain injury group, the physio spinal group and those sorts of ones as well. Some of it is planned and some of it is more on an ad hoc basis.²⁴⁴

- 4.75** The LTCSA advised it has not run any direct community awareness education programs to the general public:

We have not run any specific education or information sessions for people with injuries. The way we usually do it is rely on the service providers in the hospitals, the brain and spinal units in particular, to let us know. We would then send a coordinator out who would talk with the family and that person on a one-on-one basis. If that is not possible we have information prepared that they can read about it as well. Also now that we have been going for a little longer the social work department people also know more about us as well. That information would be much more on a one-to-one basis than in an information group.²⁴⁵

Committee comment

- 4.76** The Committee notes the GMCT comments relating to limited awareness of the LTCS Scheme for some service providers, especially those in rural and cross border locations. The Committee acknowledges the LTCSA efforts in raising awareness of the Scheme for those who will be directly involved, including health workers and other services providers.
- 4.77** The Committee heard that participants and family members might find the initial confrontation with the Scheme's existence overwhelming. Potentially, the knowledge alone that the LTCS Scheme exists before they find themselves in the unfortunate circumstance of experiencing significant injury on the roads may help these families and participants.
- 4.78** In addition, general public awareness of the Scheme would also contribute to greater understanding of the Scheme, leading to potential participants being identified more quickly and a general increase in the receptiveness to the Scheme by the community and those

²⁴⁴ Ms Lulham, Evidence, 26 June 2009, p6

²⁴⁵ Ms Lulham, Evidence, 26 June 2009, p7

involved. A community awareness campaign also provides an opportunity to communicate the benefits of the existence of the Scheme and its positive role in helping people who are severely injured in motor accidents.

- 4.79** The Committee recommends that the LTCSA ensure its education campaigns are wider spread to address awareness issues in rural and cross border areas. The Committee also recommends that the LTCSA consider conducting community awareness campaigns of the LTCS Scheme for the general public.

Recommendation 8

That the Lifetime Care and Support Authority:

- ensure its education campaigns are wider spread to address awareness issues for service providers in rural and cross border areas and
 - consider conducting community awareness campaigns of the Lifetime Care and Support Scheme for the general public.
-

Interim participation for people with spinal injuries

- 4.80** The NSW Bar Association suggested that there is no real need for people with certain spinal cord injuries to be accepted as interim participants or for that person to wait two years before being accepted as a lifetime participant, when there is no cure or possibility of improvement following a severed spinal cord.²⁴⁶

- 4.81** The Association commented that the two year interim period may have an impact on the time taken to finalise an agreement with a Compulsory Third Party (CTP) insurer for compensable rights:

Some spinal cord cases involve persons with compensable rights. In those circumstances there will be an entitlement to general damages and economic loss. A lawyer would be negligent in concluding agreement with a CTP insurer as to compensable rights until the paraplegic or quadriplegic client had been accepted as a lifetime participant in the Scheme. The Association is concerned that settlement of compensable rights could be potentially delayed pending a determination that the participant qualifies as a lifetime participant in the LTCS Scheme.²⁴⁷

- 4.82** The NSW State Spinal Cord Injury Service was asked to provide comment on this issue. The Service advised the Committee that there may be some merit in this proposal:

We feel that there is merit in the NSW Bar Association proposal to confirm the injured person's status as a lifetime participant earlier after injury, perhaps most appropriately at the time of discharge from inpatient rehabilitation. This would certainly apply to all person's with a complete neurological lesion (classified as having ASIA A impairment) with no potential for further recovery below the level of lesion.

²⁴⁶ Submission 1, NSW Bar Association, p3

²⁴⁷ Submission 1, p3

Very few people, in fact, make a full recovery after significant spinal cord injury, although we are seeing an increased proportion of person's with incomplete (partial) injuries that have significant potential to improve their function and level of independence over the first 12-18 months post-injury.²⁴⁸

- 4.83** The Authority has advised in response that sometimes spinal classification is not definitive earlier on and that the two year interim participation is appropriate. However, the Authority did note that in some cases it has agreed to bring forward the lifetime participation decision when asked by solicitors as, in these instances, the participants had complete spinal cord injury and would not recover.²⁴⁹

Committee comment

- 4.84** The Committee notes the concerns raised by the NSW Bar Association regarding the potential for delaying finalisation of their compensable rights for a spinal cord injured person while waiting for acceptance for lifetime participation in the Scheme. The Committee acknowledges the NSW State Spinal Cord Injury Service advice that only for complete spinal injuries should the shortening of the interim participation period be considered. The Committee recognises that the Authority appropriately addresses this issue when approached by solicitors on a case by case basis for participants with complete spinal cord injuries.

Buy-in to the Scheme

- 4.85** The Motor Accidents (Lifetime Care and Support) Amendment Bill 2009, that was passed by Parliament and was assented to on 9 June 2009, gave affect to a legislative change to enable a person who was injured in a motor accident before the commencement of the LTCS Scheme to use their awarded lump sum compensation to buy in to the Scheme.²⁵⁰
- 4.86** The Legislation Review Committee advised that this Bill amends the *Motor Accidents (Lifetime Care and Support) Act 2006* to provide that:
- Injured persons may be accepted as a lifetime participant in the Scheme under this buy-in arrangement so long as their injury would have made them eligible to participate in the Scheme had the motor vehicle accident occurred after the Scheme commenced.
 - The LTCSA will determine the buy-in amount to be paid by an injured person wishing to participate in the Scheme.
 - The buy-in payment is to be the amount required to fund the person's treatment and care needs resulting from the motor accident injury for his or her lifetime participation in the Scheme.²⁵¹

²⁴⁸ NSW State Spinal Cord Injury Service, Answers to questions on notice, p2

²⁴⁹ LTCSA, Answers to pre-hearing questions on notice, Question 42, p25

²⁵⁰ Motor Accidents (Lifetime Care and Support) Amendment Bill 2009, Schedule 1

²⁵¹ Legislation Review Committee, *Legislation Review Digest*, No 7, 1 June 2009, p44

- 4.87** The amended version of the section of the *Motor Accidents (Lifetime Care and Support) Act 2006*, Section 7A which will allow for the buy in, has not yet commenced.²⁵²
- 4.88** Mr Bowen, CEO of the LTCSA, explained that the reasoning behind the buy in provision was to provide an option for accident victims who have received an award of damages to have their lifetime care managed:
- The buy-in is just giving an additional option to a person who had received an award, to manage their care. It is a very difficult circumstance to contemplate what might be your lifetime needs if you are personally injured or, for example, for the parents of a child who is injured will continue to be met. The reality is ... that most awards of damage run out well before the person dies. There are some exceptions to that, but on average awards of damage run out in about 17 or 18 years ... This scheme gives the person an assurance that upon having bought in, they will have it for life and they will get all their needs met.²⁵³
- 4.89** The Law Society of NSW advised that it was not consulted about the detail of the Motor Accidents (Lifetime Care and Support) Amendment Bill 2009. The Society commented that its Injury Compensation Committee is currently considering the impact of this amendment.²⁵⁴
- 4.90** The NSW Bar Association commented that this new measure is meant to be fully funded. This means ‘the cost of buying in would be the real commercial cost of providing a lifetime of care.’ The Association went on to express the view that, in reality, lump sum compensation would be inadequate to cover the commercial cost of their future care. The reason, the Association stated, is the five per cent discount rate used in the *Motor Accidents Compensation Act 1999*.²⁵⁵
- 4.91** Further detail was provided by the Association to aid the Committee’s understanding of the discount rate and awarded damages:
- In calculating an award for damages the court is required to use a discount rate of five per cent as set out under section 127 of the Motor Accidents Compensation Act 1999. The discount supposedly represents the financial benefit to the recipient in having an upfront lump sum to cover future costs. A discount rate is usually calculated by references to: Investment return – inflation – tax paid.
 - The legal profession has been shown some early modelling from the LTCSA and it has assumed a six per cent return on investment and four per cent inflation – and therefore a net discount rate of two per cent.

²⁵² *Motor Accidents (Lifetime Care and Support) Act 2006*, see Historical Notes. Section 7A will commence on proclamation. The Committee understands that the section relating to the buy in provisions will commence after the methodology for buying into the Scheme and the associated guidelines have been finalised by the LTCSA.

²⁵³ Mr Bowen, Evidence, 26 June 2009, p3

²⁵⁴ Submission 13, Law Society of NSW, p2

²⁵⁵ Submission 1b, NSW Bar Association, p1

- Therefore, an accident victim receiving a lump sum calculated at a five per cent discount rate is not going to be able to afford the LTCSA buy in calculated at two per cent.²⁵⁶

4.92 The Association provided the following example to demonstrate the implications of the five per cent discount rate and hence the inadequate funds to buy into the LTCS Scheme:

If care, treatment and the like cost \$5,000 per week and the claimant/purchaser has a life expectancy of a further 30 years then the damages awarded (at 5%) will be \$4.1 million. The buy in price charged by the LTCSA (at 2%) will be \$5.9 million. There is a \$1.8 million between the compensation recovered and the buy in price.²⁵⁷

4.93 Mr Andrew Stone, Member of the Common Law Committee, NSW Bar Association, provided background on the how damages are awarded in terms of the discount rate:

When you are awarded a lump sum to cover future expenses it is not as simple as saying, "My costs are \$100 a week, or \$1,000 a week, multiply that by the number of weeks I have the need." Because you are getting the lump sum upfront they have to take into account first of all the investment return that you can make on the lump sum, less the effect of inflation and less the tax you are paying on the investment return ... The State of New South Wales has legislated that when you are compensated there is a 5 per cent discount rate. In other words, it assumes that your investment return less the rate of inflation leaves a gap of 5 per cent. That is not the true discount rate. The true discount rate is in the order of 1 to 2 per cent.²⁵⁸

4.94 Mr Ross Letherbarrow SC, Chair of the Common Law Committee of the NSW Bar Association, plainly stated that this would result in no-one buying into the Scheme.²⁵⁹

4.95 The NSW Bar Association commented that the main issue is the five per cent discount rate in the *Motor Accidents Compensation Act 1999*, which should be two or three per cent:

It has been long understood that accident victims run out of money. It is not necessarily because they spend it foolishly. A 5% discount rate chronically over estimates the return on funds invested. The common law discount rate in Australia (devised by the High Court) is 3%. In England the discount rate is even lower. The LTCSA have calculated that a proper commercial discount rate is 2%. Having a 5% discount rate means that accident victims are not properly compensated ... The discount rate used by the motor accident scheme should be 2% or 3%.²⁶⁰

4.96 Mr Stone advised that a legislative change to lower the discount rate is not a simple answer:

²⁵⁶ Submission 1b, p1

²⁵⁷ Submission 1b, p1

²⁵⁸ Mr Andrew Stone, Member of the Common Law Committee, NSW Bar Association, Evidence, 26 June 2009, pp34-35

²⁵⁹ Mr Ross Letherbarrow SC, Chair of the Common Law Committee of the NSW Bar Association, Evidence 26 June 2009, p35

²⁶⁰ Submission 1b, p2

In effect what you are doing is saying to the CTP insurer, who at the moment for the 30-year \$5,000 a week scenario has a liability of \$4.1 million, "Instead we would like you to pay \$5.9 million. We want you to pay \$1.8 million more." The reason you cannot do that is the insurers very cleverly insisted on, or obtained, a clause in the deed to the original 1988 Act, which is still binding on the 1999 Act, that says if the Parliament ever retrospectively legislates to increase their liability it is the State of New South Wales that pays the gap. You cannot do it.²⁶¹

4.97 Mr Stone said 'I do not think this problem can be retrospectively fixed without either the LTCS Authority subsidising the buy-in, which is fine as long as you do not say it is fully funded, because it is not, or accepting that people getting lump sum compensation cannot afford it.'²⁶²

4.98 The advice of the NSW Bar Association in relation to the buy in process was presented to the LTCSA for comment. The Authority advised that the CEO of the LTCSA has met with representatives from the NSW Bar Association, Law Society of NSW and the Australian Lawyers Alliance to discuss concerns about the buy in option. As a result:

The LTCSA has commissioned an experienced personal injury lawyer to review 10 to 15 cases where there has been a court verdict in a motor vehicle personal injury matter that provides details of the award by heads of damage. If sufficient information is available in the verdict as to care needs this will be used to deduce a lifetime care cost using the Authority's life cost calculator. In most cases, it is expected that the LTCSA will also need to access the insurer's file to get sufficient medical information to determine a lifetime cost. It is anticipated that the review will be completed by the end of November 2009 and the information used to construct a buy-in methodology to be incorporated into a guideline under the *Motor Accidents (Lifetime Care and Support) Act 2006*.²⁶³

4.99 In relation to the concerns that an accident victim's lump sum compensation would not be enough to buy into the Scheme, Mr Bowen, CEO of the LTCSA, commented that:

We would like to explore options to allow people perhaps to use something like equity in a home that they may have purchased with their award to buy into the Scheme so that they get the assurance of the lifetime care. The asset is then dealt with at the end of their life. But if they do not have the funds, no, there is no option to buy in.²⁶⁴

Committee comment

4.100 The Committee notes the NSW Bar Association's comments in relation to the inability for an accident victim's lump sum compensation to adequately cover the potential buy in price due to the five per cent discount rate set in section 127 of the *Motor Accidents Compensation Act 1999* and the two per cent discount rate used by the LTCSA to calculate a potential buy in price.

4.101 The Committee acknowledges that the LTCSA is conducting a review of court verdicts in motor vehicle personal injury matters with the results, available by the end of November, to

²⁶¹ Mr Stone, Evidence, 26 June 2009, p35

²⁶² Mr Stone, Evidence, 26 June 2009, pp35-36

²⁶³ LTCSA, Answers to post-hearing questions on notice, Question 10, p5

²⁶⁴ Mr Bowen, Evidence, 26 June 2009, p4

be used to construct a buy in methodology. The Committee will await the outcome of this review to see if this can be used to address the concerns and provide further information on the cost of buying into the Scheme.

- 4.102** In the Committee's next review it will again look at the buy in provisions and consider the issue of discount rates set out under the *Motor Accidents Compensation Act 1999*.

LTCSA Guidelines being ultra vires the Act

- 4.103** Some stakeholders raised the issue of the LTCSA Guidelines, which are applied when making an assessment of the treatment, rehabilitation or care needs of Scheme participants,²⁶⁵ being ultra vires (that is, beyond the power of) the *Motor Accidents (Lifetime Care and Support) Act 2006* (the Act). In effect, these stakeholders suggest the guidelines are limiting the Act's intent by setting provisions on what is reasonable and necessary.

- 4.104** The NSW Bar Association stated that section 6 of the Act provides that the LTCSA is to pay the treatment and care needs of a Scheme participant 'as are reasonable and necessary in the circumstances.'²⁶⁶ The Association indicated other relevant sections of the Act that relate to providing treatment and care and the provision for guidelines:

- Section 6(2) of the Act identifies a variety of treatment and care needs including medical treatment, rehabilitation, attendant care services, domestic assistance, respite care and education and vocational training.²⁶⁷
- Section 6(4) of the Act provides that the LTCS Guidelines may make provision for or with respect to determining which treatment and care needs of a participants in the Scheme are reasonable and necessary in the circumstances.²⁶⁸

- 4.105** The Association indicated that 'the LTCS Guidelines contain numerous provisions limiting a participant's entitlement to treatment and care.' Further to this, it states:

It is understandable that the Authority seeks to bring consistency to decision making through the creation of guidelines. However, Section 6 of the Act commits the Authority to pay for reasonable and necessary treatment and care ... The guidelines cannot restrict a statutory right. In legal terms, the guidelines are ultra vires the Act.²⁶⁹

- 4.106** An example provided by the Association is as follows:

Part 11 of the guidelines provides that the reasonable maximum costs, which can be reimbursed for overseas care, will be determined by reference to the amount of the care that the participant would have required had the care been provided in NSW. To illustrate with a hypothetical example, if the scheme participant lives in California having been injured while travelling in NSW then, upon return home, the Authority

²⁶⁵ < <http://www.lifetimecare.nsw.gov.au/default.aspx?MenuID=34> >(accessed 11 August 2009)

²⁶⁶ Submission 1, p3 and the *Motor Accidents (Lifetime Care and Support) Act 2006*, section 6

²⁶⁷ Submission 1, p3 and the *Motor Accidents (Lifetime Care and Support) Act 2006*, section 6

²⁶⁸ Submission 1, p3 and the *Motor Accidents (Lifetime Care and Support) Act 2006*, section 6

²⁶⁹ Submission 1, p4

will only pay for the cost of care had the visitor remained in NSW. It doesn't matter that careers might cost \$60 per hour in California – the Authority will only pay the \$30 per hour that care costs in NSW.²⁷⁰

4.107 Mr Stone provided a further hypothetical example in evidence:

The Act says that if you are in the Scheme you get your reasonable and necessary treatment expenses paid. The guidelines say: here is what we shall consider to be reasonable and necessary, and that might be a new wheelchair every five years. If you come along and say "I have a perfectly good and reasonable need for a wheelchair after four years" you would hope the authority would have the flexibility to say "Right, then you shall have one". If they do not, in reliance upon the guidelines, then in effect their action, based on the guidelines, is not supported by the Act. If it is reasonable and necessary to have a wheelchair after four years then it has to be paid and you cannot have guidelines, in effect, subordinate legislation, undermining the substantive legislation.²⁷¹

4.108 Two solutions to the notion that the Guidelines are ultra vires the Act were provided by Mr Stone:

The solution we advocate is to make the guidelines consistent with the Act. In other words, to pay for whatever is reasonable and necessary and not put these arbitrary restrictions in place. The other thing you can do, and I am obliged out of honesty to tell you this while I don't particularly want to, is if you insert a clause into the Act that says, "Reasonable and necessary is whatever we say it is", that fixes the problem. Of course, I do not favour that because I do not like having tucked away into guidelines, which are further from the review of Parliament, the potential for clauses that take away people's substantial rights and needs.²⁷²

4.109 The Australian Lawyers Alliance also raised concerns regarding the legal validity of the Guidelines under the Act as being ultra vires, or beyond power. The Alliance commented that:

There are many examples of unnecessary restrictions being placed on participants to claim costs that are reasonable and necessary given their personal circumstances. For example, the LTCSA reduces payments for air conditioning, by factoring in any other family members that may benefit. Therefore, ... a quadriplegic mother with three children will be able to recover only one-quarter of the costs of her air conditioner. This is clearly inequitable, as the participant has a reasonable and necessary need for an air conditioner to regulate her body temperature and this should not be reduced by virtue of the participant's home and family situation.²⁷³

4.110 The Alliance continued that 'while recognising that guidelines can create consistency in a scheme, the Lawyers Alliance submits that the LTCS should be flexible enough to take into account individual circumstances of a participant when determining appropriate treatment and care.'²⁷⁴

²⁷⁰ Submission 1, p4

²⁷¹ Mr Stone, Evidence, 26 June 2009, pp30-31

²⁷² Mr Stone, Evidence, 26 June 2009, p31

²⁷³ Submission 12, Australian Lawyers Alliance, pp2-3

²⁷⁴ Submission 12, p3

4.111 The Law Society of NSW ‘echoes the Bar Association’s concerns about the ultra vires nature of the LTCS Guidelines vis a vis the Act.’²⁷⁵

4.112 The Authority when asked if any of the ‘caps or prohibitions’ contained within the guidelines were ultra vires the Act, the LTCSA commented that:

The NSW Bar Association provided this feedback to the Authority on the draft Home Modification Guidelines. Their submission was taken into account when finalising the Guidelines and this issue was addressed. The Bar Association has also suggested that the restriction on overseas participants receiving payment of services capped to what they would be entitled to in NSW is ultra vires the Act. The Authority will seek advice on this, but also seeks a recommendation from the Committee that the Authority is only liable to pay what the person would have been entitled to if they lived in Australia.²⁷⁶

4.113 The LTCSA was asked for further information regarding participants of the Scheme who are living overseas and how services are delivered to them. In response the Authority indicated that:

LTCS scheme participants are currently living in Germany, England, France, Holland, Slovakia, Korea and New Zealand. The LTCSA has an agreement with the Accident Compensation Commission in New Zealand that they case manage participants living in New Zealand and provide access to services. Participants living in Europe have services provided through well established rehabilitation programs and the LTCSA pays for services as required. For some of these participants, the LTCSA is examining the option of transferring a sum of money for participants to manage their own needs. The LTCSA also uses internal health assistance companies who specialise in managing people with injury and illness overseas.²⁷⁷

4.114 In relation to the LTCSA requesting a recommendation from the Committee relating to capping payments to overseas participants, the NSW Bar Association commented:

With the greatest respect to the Committee, it cannot make a recommendation (that would be in any way guiding or binding on any court) that restrictive guidelines be preferred to substantive legislation. Presumably the Authority is seeking a recommendation regarding legislative amendments in relation to overseas participants ... The Association submits that a specific rationale for such an amendment should be provided...²⁷⁸

Committee comment

4.115 The Committee notes the concerns of the legal professional that through the application of LTCS Guidelines the definition in the Act of what is reasonable and necessary could be limited. The Committee understands that there is a need for guidelines to ensure consistency in the LTCS Scheme.

²⁷⁵ Submission 13, p1

²⁷⁶ LTCSA, Answers to pre-hearing questions on notice, Question 43, p25

²⁷⁷ LTCSA, Answers to post-hearing questions on notice, Question 5(c), p3

²⁷⁸ NSW Bar Association, Answers to questions on notice, Question 1, p2

- 4.116** The Committee recognises that the provision of reasonable and necessary treatment is fundamental to the operation of the Scheme. Through the Committee's ongoing review function, problems regarding the appropriate interpretation of what is reasonable and necessary will, no doubt, be brought to our attention in future reviews.
- 4.117** The Committee encourages the LTCSA to ensure that the LTCS Guidelines do not limit the definitions in the Act of what is reasonable and necessary in providing lifetime care and support for participants.
- 4.118** The Committee notes that the LTCSA is awaiting advice on whether it can only be liable to pay overseas participants what the person would have been entitled to if they lived in Australia. In terms of the LTCSA seeking a recommendation from the Committee on this issue, it has not received enough evidence reach a decision. The Committee acknowledges the NSW Bar Association's comments and will revisit this issue in a future review.

Awarded damages being used in divorce settlements

- 4.119** A final issue that was brought to the attention of the Committee by the LTCSA was that lump sum compensation awarded to accident victims was being treated as capital by the Family Court in divorce settlements.

- 4.120** Mr Bowen, of the LTCSA, further explained this issue:

... this was somewhat surprising but we found this in our own research when we were looking at the eligibility for the Scheme—awards of damages, including awards for future care, are treated as capital for tax purposes and for family law purposes. Unfortunately, it is not uncommon for there to be a marriage breakdown following a severe injury, and the award of damages that person may get is treated as capital by the Family Court. So the spouse will get a proportion of that ... Even if it is sitting aside, the Family Court does not accept an argument that this is money for the person's future care. It is treated as an asset of the marriage ... I have raised that with the legal profession, and I think that is something that they can look at as well.²⁷⁹

- 4.121** Mr Bowen agreed that having a system of lifetime care and support, rather than a lump sum payment, addresses this issue 'that is right, the individual does not have to worry about how they will invest it to look after their own care needs, let alone whether or not they can predict those care needs.'²⁸⁰
- 4.122** The NSW Bar Association was requested to provide advice on the issue of awards of damages, including awards for future care, being treated as capital for tax purposes and family law purposes, and treated as assets of a marriage for the purpose of divorce proceedings. The Association advised the Committee:

Property for the purpose of family law property settlement proceedings, for example, is widely defined. All property held by a party to a marriage at the time of a hearing may be the subject of an order for adjustment pursuant to section 79 of the *Family*

²⁷⁹ Mr Bowen, Evidence, 26 June 2009, p5

²⁸⁰ Mr Bowen, Evidence, 26 June 2009, p5

Law Act 1975. This applies irrespective of the time or source of the acquisition of the funds.

So far as damages at Common Law are concerned, the issue was settled by the High Court in *Williams v Williams* (1985) 10 Fam LR355, where it was held that when the property available for division between parties represents (or includes) an award of damages for pain, suffering and loss of amenity, it may be relevant in some situations, to have regard to the circumstances of that award, but there is no general presumption that the award should not be taken into account in determining what order for property settlement should be made.²⁸¹

- 4.123** The Association further advised that judges of the Family Court have a very broad discretion in dealing with a property settlement application:

Under section 79 (2) Family Law Act the Court is obliged not to make an order for the alteration of property interests unless it is satisfied that “it is equitable to do so.” Each matter will be very much determined by the Court on the facts of the individual case.

While generalities are dangerous and possibly misleading, it can be said that, in a case where there is significant other wealth from which a just and equitable property settlement can be awarded to the other party, then it is likely that the Court would leave a damages award, regarding it then as a separate category of property, with the party who received the award subject to any proper recognition to the contribution of the other party to a Griffith v Kerkemeyer damages component. On the other hand, if the pool of property consists of modest values outside of the damages award then it is likely to receive little discretionary judicial protection at all.²⁸²

- 4.124** When asked what can be done to ensure that awards for the future care of injured people are not part of divorce settlements or other legal settlements the Association advised:

This situation could only be avoided by an express amendment to the *Family Law Act* or other relevant legislation. However, given the myriad of different factual situations which can confront the Family Court, it is difficult to see how such a blanket amendment would result in fair outcomes in all circumstances. The current flexibility involved in the judicial approach of what is “just and equitable” may well be a fairer approach, taking into account the individual circumstances of the parties, than that which could be achieved by any particular form of legislative amendment.²⁸³

Committee comment

- 4.125** The Committee appreciates the LTCSA bringing this issue to the attention of the Committee and thanks the NSW Bar Association for providing advice on this issue. The Committee notes the Association’s comments that the Family Court would determine each matter on the facts of the individual case and that legislative changes to create a blanket ban on such awards being taken into account by the Family Court may not have the desired impact. However, the Committee is mindful that the issue of awarded damages being used in legal settlements may

²⁸¹ NSW Bar Association, Answers to questions on notice, Question 2, pp2-3

²⁸² NSW Bar Association, Answers to questions on notice, Question 2, p3

²⁸³ NSW Bar Association, Answers to questions on notice, Question 2, p3

have an impact on a person's ability to buy into the LTCS Scheme and requests that the Minister for Finance refer this issue to the NSW Attorney General for examination.

Recommendation 9

That the Minister for Finance request that the NSW Attorney General examine the issue of awarded damages for the future care of injured people being used as part of divorce settlements and other legal settlements, and if appropriate, refer the issue to the Standing Committee of Attorney Generals.

Future reviews

4.126 The Committee notes that there were a number of other issues raised by stakeholders that have not been covered in detail in this Review. It may be that these issues, some of which are listed below, may emerge as more substantial issues as time goes on and may be examined by the Committee in one of the future reviews of the LTCSA:

- Participant satisfaction with the Scheme, including participant surveys
- Geography issues for LTCSA in delivering services, treatment and care, for example, participants living, in rural areas, interstate or overseas
- Engaging participants in the community and return to work issues for participants
- Data collection for participants in the Scheme and what can be done with that information
- Possible provision of public transport cards for participants.

Conclusion

4.127 The Committee is pleased that, as a whole, the Scheme is functioning effectively. Issues raised in this chapter, once addressed as per the Committee's recommendations, would see the Scheme and Authority continuing to develop on its positive path of delivering lifetime care and support for its participants.

4.128 The Committee recognises that future challenges will be encountered as the Scheme matures. The LTCSA has already identified the future challenge of the increasing number of participants moving from rehabilitation and back into the community and the change in focus for the Authority from treatment and rehabilitation to engaging participants in the community through recreation, leisure, school, vocational and employment related services.

4.129 The Committee values the contributions made to this Review by stakeholders, participants and their carers, and the LTCSA. The Committee looks forward to conducting its next review to continue to help the LTCSA improve the Scheme for its participants.

Appendix 1 Submissions

No	Author
1	NSW Bar Association
1a	Supplementary submission: NSW Bar Association
1b	Supplementary submission: NSW Bar Association
2	Spinal Cord Injury Service, Hunter New England Area Health Service
3	Royal Rehabilitation Centre Sydney
4	Name Suppressed
5	Youthsafe
6	Westmead Brain Injury Rehabilitation Unit
7	NSW State Spinal Cord Injury Service
8	Social Workers in Brain Injury Professional Interests Group, Australian Association of Social Workers (NSW)
9	Department of Rehabilitation, The Children's Hospital at Westmead
10	Greater Metropolitan Clinical Taskforce (GMCT)
11	Physical Disability Council of NSW
12	Australian Lawyers Alliance
13	The Law Society of NSW
14	Department of Ageing, Disability and Home Care (DADHC)

Appendix 2 Witnesses at hearings

Date	Name	Position and Organisation
Friday 26 June 2009	Mr David Bowen	Chief Executive Officer, Lifetime Care and Support Authority
Room 814-815	Mr Dougie Herd	Chairman, Lifetime Care and Support Advisory Council
Parliament House	Mr Richard Grellman AM	Chairman, Lifetime Care and Support Advisory Board
	Mr Stephen Payne	Chief Financial Officer, Lifetime Care and Support Authority
	Ms Suzanne Lulham	Director, Service Delivery, Lifetime Care and Support Authority
	Mr Neil Mackinnon	Manager, Service Coordination, Lifetime Care and Support Authority
	Dr Adeline Hodgkinson	Chair, Greater Metropolitan Clinical Taskforce, Brain Injury Rehabilitation Directorate
	Dr Joe Gurka	Director, Greater Metropolitan Clinical Taskforce, Brain Injury Rehabilitation Service Westmead
	Associate Professor James Middleton	Director & Chair, Greater Metropolitan Clinical Taskforce, NSW State Spinal Cord Injury Service
	Ms Jenni Johnson	Manager of Spinal Outreach, Greater Metropolitan Clinical Taskforce, NSW State Spinal Cord Injury Service
	Mr Ross Letherbarrow SC	Chair, Common Law Committee, NSW Bar Association
	Mr Andrew Stone	Member, Common Law Committee, NSW Bar Association
	Mr Daniel Malouf	Participant
	Mr John Malouf	Family carer of participant
	Ms Zivana Spittles	Family carer of participant
	Ms Ricki-Lee Bell	Participant
	Ms Leanne Bell	Family carer of participant
	Mr Rod Macdonald	Family carer of participant
	Ms Martine Simons	Senior Social Worker, Department of Rehabilitation, Children's Hospital at Westmead

Date	Name	Position and Organisation
	Ms Juanita Noronha	Case Manager, Department of Rehabilitation, Children's Hospital at Westmead
	Dr Graham Simpson	Senior Social Worker, Brain Injury Professional Interest Group, Australian Association of Social Workers (NSW)
	Ms Diane Turner	Social Work Professional Leader, Brain Injury Professional Interest Group, Australian Association of Social Workers (NSW)
	Ms Denise Young	Program Clinical Manager, Brain Injury Professional Interest Group, Australian Association of Social Workers (NSW)

Appendix 3 Tabled documents

1. Document entitled 'Scheme surplus projection incorporating a 10% prudential margin and 3.5% levy reduction', tabled by Mr David Bowen, Chief Executive Officer, Lifetime Care and Support Authority, 26 June 2009.
2. Supplementary submission to the Second Review of the Lifetime Care and Support Authority, tabled by Mr Andrew Stone, Member, Common Law Committee, NSW Bar Association, 26 June 2009.
3. Confidential document, tabled by Ms Jenni Johnson, Manager of Spinal Outreach, Greater Metropolitan Clinical Taskforce, NSW State Spinal Cord Injury Service. 26 June 2009.

Appendix 4 Minutes

Minutes No. 29

Thursday 19 March 2009

Jubilee Room, Parliament House, Sydney at 9.00 am

1. Members present

Ms Robertson (*Chair*)

Mr Clarke (*Deputy Chair*)

Mr Donnelly

Mr Ajaka

Ms Hale

Ms Fazio (9:30 am)

2. ***

3. Deliberative meeting

3.1 Minutes

Resolved, on the motion of Mr Ajaka: That Minutes No. 26 and 27 be confirmed.

3.2 ***

3.3 ***

3.4 ***

3.5 Second Review of the LTCSA

Resolved on the motion of Ms Fazio: That:

1. The Committee commence its Second Review of the LTCSA and the LTCSA.
2. The Committee adopt the following timeline for the Second Review prepared by the Secretariat, with any necessary modifications made by the Secretariat in consultation with the Chair:

Advertise call for submissions	Wednesday 1 April 2009
Submission period	(5 weeks)
Submission due	Wednesday 6 May 2009
QON to LCSA	Friday 15 May 2009
QON returned	Friday 12 June 2009
Hearing	Friday 26 June 2009
Report deliberative	Monday 3 August 2009
Report tabling	Wednesday 5 August 2009.

3. The Second Review and the call for submissions be advertised in the *Sydney Morning Herald* and the *Daily Telegraph* on Wednesday 1 April 2009 and in other publications as appropriate.

4. That a media release announcing the Review and the call for submissions be published on 1 April 2009 to coincide with the publication of the call for submissions.
5. Written invitations to make a submission be sent to the following stakeholders identified by the Secretariat and any others identified by Committee Members and submitted to the Secretariat by Friday 27 March 2009:
 - Carers NSW
 - Disability Council of NSW
 - Greater Metropolitan Clinical Taskforce Brain Injury Rehabilitation Directorate
 - Insurance Council of Australia
 - Law Society of NSW
 - NSW Bar Association
 - NSW Motorcycle Council
 - People with Disability Australia Incorporated
 - Youthsafe.
6. The Committee hold a public hearing on Friday 26 June 2009 with representatives of the Lifetime Care and Support Authority and the Lifetime Care and Support Advisory Council and other witnesses determined by the Secretariat and the Chair in consultation with the Committee.
7. A questions on notice process be conducted whereby questions drafted by the Secretariat in consultation with the Chair be forwarded to the Chief Executive Officer of the Lifetime Care and Support Authority for response prior to the hearings.

4. ***

5. ***

6. **Adjournment**

The Committee adjourned at 6.00 pm until 23 April 2009.

Rachel Callinan
Clerk to the Committee

Minutes No. 30

Thursday 23 April 2009

Room 1102, Parliament House, Sydney at 9.25 am

1. **Members present**

Ms Robertson (*Chair*)
Mr Clarke (*Deputy Chair*)
Mr Donnelly
Mr Ajaka
Ms Hale
Ms Fazio

2. **Minutes**

Resolved, on the motion of Ms Hale: That draft Minutes No. 28 and 29 be confirmed.

3. ***

4. Second Review of the LTCSA and LTCSAC

Resolved, on the motion of Ms Hale: That the following item of correspondence be noted:

4.1 Correspondence sent

- 30 March 2009 – From Chair to Minister for Finance, Hon Joe Tripodi MP, advising that the Committee has commenced its Second Review of the LTCSA and LTCSAC.

5. *****6. Adjournment**

The Committee adjourned at 11.00am until 9.00am 18 May 2009.

Rachel Callinan
Clerk to the Committee

Minutes No. 31

Monday 18 May 2009

Room 1102, Parliament House, Sydney at 9.25 am

1. Members present

Ms Robertson (*Chair*)

Mr Clarke (*Deputy Chair*)

Mr Donnelly

Mr Ajaka

Ms Hale

Ms Fazio

2. Minutes

Resolved, on the motion of Mr Ajaka: That, on the advice of the Clerk to the Committee, Ms Robertson's name be removed from the last paragraph under the heading '5.1 Correspondence received'.

Resolved, on the motion of Mr Ajaka: That draft Minutes No. 30, as amended, be confirmed.

3. *****4. Second Review of the LTCSA and LTCSAC****4.1 Correspondence**

Resolved, on the motion of Mr Donnelly: That the following item of correspondence be noted:

Received

- 30 April 2009 – From Mr Driscoll, General Policy Manager, Insurance Council of Australia, to Chair, advising the Council will not be making a submission.

4.2 Publications of submissions

Resolved, on the motion of Mr Donnelly: That, according to section 4 of the Parliamentary Papers (Supplementary Provisions) Act 1975 and Standing Order 223(1), the Committee authorise the publication of Submission Nos 1-3 and Nos 5-12.

Resolved, on the motion of Mr Donnelly: That, according to section 4 of the *Parliamentary Papers (Supplementary Provisions) Act 1975* and Standing Order 223(1), the Committee authorise the publication of Submission No 4 with name suppressed at the request of the author.

4.3 Consideration of witnesses for hearing

Resolved, on the motion of Mr Donnelly: That representatives from the following organisations be invited to appear as witnesses, as well as any additional witnesses identified by the Secretariat in consultation with the Chair:

- Lifetime Care and Support Authority (LTCSA) and Advisory Council
- Greater Metropolitan Clinical Taskforce Brain Injury Rehabilitation Directorate
- NSW Bar Association
- NSW State Spinal Cord Injury Service
- Australian Association of Social Workers (NSW): Brain Injury Professional Interest Group
- Children's Hospital at Westmead: Department of Rehabilitation

5. ***

6. ***

7. Adjournment

The Committee adjourned at 5:15 pm *sine die*.

Rachel Callinan

Clerk to the Committee

Minutes No. 32

Friday 26 June 2009

Room 814-815, Parliament House, Sydney at 9.30 am

1. Members present

Ms Robertson (*Chair*)

Mr Clarke (*Deputy Chair*)

Mr Donnelly

Mr Ajaka

2. Apologies

Ms Hale

Ms Fazio

3. Public hearing – Second Review of the Lifetime Care and Support Authority

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:

- Mr David Bowen, CEO, Lifetime Care and Support Authority
- Mr Richard Grellman AM, Chairman, Lifetime Care and Support Advisory Board
- Mr Dougie Herd, Chairman, Lifetime Care and Support Advisory Council
- Mr Stephen Payne, Chief Financial Officer, Lifetime Care and Support Authority
- Ms Suzanne Lulham, Director, Service Delivery, Lifetime Care and Support Authority

- Mr Neil Mackinnon, Manager, Service Delivery, Lifetime Care and Support Authority.

Mr Bowen tendered the following document:

- Scheme surplus projection incorporating a 10% prudential margin and 3.5% levy reduction, Lifetime Care and Support Authority.

The evidence concluded and the witnesses withdrew.

The following witnesses were sworn and examined:

- Dr Adeline Hodgkinson, Chair, Brain Injury Rehabilitation Directorate, Greater Metropolitan Clinical Taskforce
- Dr Joe Gurka, Director, Brain Injury Rehabilitation Directorate, Greater Metropolitan Clinical Taskforce
- Associate Professor James Middleton, Director and Chair, NSW State Spinal Cord Injury Service, Greater Metropolitan Clinical Taskforce
- Ms Jenni Johnson, Manager of Spinal Outreach, NSW State Spinal Cord Injury Service, Greater Metropolitan Clinical Taskforce.

Ms Johnson tendered the following document:

- Example of a de-identified completed Lifetime Care and Support Authority equipment request form.

The evidence concluded and the witnesses withdrew.

The following witnesses were sworn and examined:

- Mr Ross Letherbarrow SC, Chair, Common Law Committee, NSW Bar Association
- Mr Andrew Stone, Member, Common Law Committee, NSW Bar Association.

Mr Stone tendered the following document:

- Supplementary submission to the Second Review of the Lifetime Care and Support Authority.

The evidence concluded and the witnesses withdrew.

4. Deliberative meeting

4.1 Minutes

Resolved, on the motion of Mr Ajaka: That draft Minutes No. 31 be confirmed.

4.2 Correspondence

Second Review of the Lifetime Care and Support Authority

The Committee noted the following items of correspondence received:

- 16 June 2009 – From the Hon Joseph Tripodi MP, Minister for Finance, to the Chair enclosing the response to questions on notice from the Lifetime Care and Support Authority.
- 24 June 2009 – From the Hon John Della Bosca MLC, Minister for Health, to the Chair enclosing the response to questions on notice from NSW Health.
- 25 June 2009 – From the Hon Minister Paul Lynch MP, Minister for Disability, to the Chair enclosing the response to questions on notice from the Department of Ageing, Disability and Home Care.

The Committee noted the following items of correspondence sent:

- 20 May 2009 – From Chair to Hon Joseph Tripodi MP, Minister for Finance, enclosing a prepared list of questions on notice to be returned to the Committee by Monday 15 June 2009 and advising of witnesses from the Lifetime Care and Support Authority to appear at the public hearing on 26 June 2009.
- 27 May 2009 – From Chair to Hon Paul Lynch MP, Minister for Disability Services, enclosing a prepared list of questions on notice to be returned to the Committee by 19 June 2009.
- 27 May 2009 – From Chair to Hon John Della Bosca MLC, Minister for Health, enclosing a prepared list of questions on notice to be returned to the Committee by 19 June 2009.
- 16 June 2009 – From Chair to Hon John Della Bosca MLC, Minister for Health, advising of witnesses from the Lifetime Care and Support Authority to appear at the public hearing on 26 June 2009.

4.3 Publication of submissions

Resolved, on the motion of Mr Ajaka: That, according to section 4 of the *Parliamentary Papers (Supplementary Provisions) Act 1975* and Standing Order 223(1), the Committee authorise the publication of Submission Nos 13 and 14.

4.4 Publication of pre-hearing questions on notice

Resolved, on the motion of Mr Donnelly: That, according to section 4 of the *Parliamentary Papers (Supplementary Provisions) Act 1975* and Standing Order 223(1), the Committee authorise the publication of the answers provided by the following:

- Lifetime Care and Support Authority to pre-hearing questions on notice
- The Hon John Della Bosca MLC, Minister for Health
- The Hon Paul Lynch MP, Minister for Disability.

4.5 Return of answers to questions taken on notice

Resolved, on the motion of Mr Ajaka: That, witnesses be requested to return answers to questions they take on notice during the hearing by Friday 17 July 2009.

4.6 Publication of tabled documents

Resolved, on the motion of Mr Donnelly: That, the Committee accept and publish, according to section 4 of the *Parliamentary Papers (Supplementary Provisions) Act 1975* and Standing Order 223(1), the following documents tendered during the public hearing:

- Scheme surplus projection incorporating a 10% prudential margin and 3.5% levy reduction, tendered by Mr David Bowen, CEO, Lifetime Care and Support Authority
- Supplementary submission to the Second Review of the Lifetime Care and Support Authority, tendered by Mr Andrew Stone, Member, Common Law Committee, NSW Bar Association.

Resolved, on the motion of Mr Donnelly: That the Committee accept the following document tendered during the public hearing by Ms Jenni Johnson, Manager of Spinal Outreach, NSW State Spinal Cord Injury Service, Greater Metropolitan Clinical Taskforce, and that it be kept confidential:

- Example of a Lifetime Care and Support equipment request form,

5. Public hearing – Second Review of the Lifetime Care and Support Authority

The following witnesses were sworn and examined:

- Mr Daniel Malouf, Participant
- Mr John Malouf, Family carer of Daniel Malouf
- Ms Zivana Spittles, Family carer of a participant
- Ms Ricki-Lee Bell, Participant
- Mr Rod McDonald, Family carer of Ricki-Lee Bell
- Ms Leanne Bell, Family carer of Ricki-Lee Bell.

The evidence concluded and the witnesses withdrew.

The following witnesses were sworn and examined:

- Ms Martine Simons, Senior Social Worker, Department of Rehabilitation at the Children's Hospital at Westmead
- Ms Juanita Noronha, Case Manager, Department of Rehabilitation at the Children's Hospital at Westmead.

The evidence concluded and the witnesses withdrew.

The following witnesses were sworn and examined:

- Dr Grahame Simpson, Senior Social Worker, Brian Injury Professional Interest Group. Australian Association of Social Workers (NSW)
- Ms Diane Turner, Social Work Professional Leader, Brian Injury Professional Interest Group. Australian Association of Social Workers (NSW).

The following witness was sworn and examined via teleconference:

- Ms Denise Young, Program Clinical Manager, Brian Injury Professional Interest Group. Australian Association of Social Workers (NSW).

The evidence concluded and the witnesses withdrew.

The public hearing concluded at 4.45pm. The public and the media withdrew.

6. Adjournment

The Committee adjourned at 4.45pm until Monday 29 June 2009 at 9.00am.

Rachel Callinan

Clerk to the Committee

Draft Minutes No. 34

Wednesday 26 August 2009

Room 1102, Parliament House, Sydney at 2.00 pm

1. Members present

Ms Robertson (*Chair*)
 Mr Clarke (Deputy Chair)
 Mr Donnelly
 Mr Ajaka

2. Apologies

Ms Hale
 Ms Fazio

3. Minutes

Resolved, on the motion of Mr Donnelly: That draft Minutes No. 32 and 33 be confirmed.

4. ***

5. Second Review of the LTCSA

5.1 Correspondence

The Committee noted the following items of correspondence received:

- 14 July 2009 – Answers to QON from NSW Bar Association
- 20 July 2009 – Answers to QON from GMCT
- 20 July 2009 – Answers to QON from NSW State Spinal Cord Injury Service, GMCT
- 27 July 2009 – Answers to QON received from The Children’s Hospital at Westmead
- 29 July 2009 – Answers to QON from Brain Injury Rehabilitation Directorate, GMCT
- 3 August 2009 – Answers to QON from the LTCSA (via Minister Tripodi).

The Committee noted the following item of correspondence sent:

- 4 August 2009 – From Chair to Minister for Health, forwarding information for consideration for the NSW Health review.

5.2 Publication of answers to questions on notice

Resolved, on the motion of Mr Ajaka: That, according to section 4 of the Parliamentary Papers (Supplementary Provisions) Act 1975 and Standing Order 223(1), the Committee authorise the publication of the answers provided by the following:

- NSW Bar Association
- GMCT
- NSW State Spinal Cord Injury Service, GMCT
- Brain Injury Rehabilitation Directorate, GMCT
- The Children’s Hospital at Westmead
- LTCSA.

5.3 Consideration of the Chair’s draft report

The Chair tabled her draft report entitled *Second Review of the Lifetime Care and Support Authority and the Lifetime Care and Support Advisory Council*, Report 40, which, having been previously circulated, was taken as being read.

The Committee proceeded to consider the draft report in detail.

Chapter 1 read.

Resolved, on the motion of Mr Donnelly: That Chapter 1 be adopted.

Chapter 2 read.

Resolved on the motion of Mr Ajaka: That chapter 2 be adopted.

Chapter 3 read.

Resolved, on the motion of Mr Ajaka: That Recommendation 1 be adopted.

Resolved, on the motion of Mr Donnelly: That Recommendation 2 be adopted.

Resolved, on the motion of Mr Ajaka: That Recommendation 3 be adopted.

Resolved, on the motion of Mr Donnelly: That Recommendation 4 be adopted.

Resolved, on the motion of Mr Ajaka: That Chapter 3 be adopted.

Chapter 4 read.

Resolved, on the motion of Mr Ajaka: That Recommendation 5 be adopted.

Resolved, on the motion of Mr Donnelly: That Recommendation 6 be adopted.

Resolved, on the motion of Mr Clarke: That Recommendation 7 be adopted.

Resolved, on the motion of Mr Clarke: That Recommendation 8 be adopted.

Resolved, on the motion of Mr Clarke: That Recommendation 9 be adopted.

Resolved, on the motion of Mr Clarke: That Chapter 4 be adopted.

Executive summary read.

Resolved, on the motion of Mr Ajaka: That the executive summary be adopted.

Resolved, on the motion of Mr Clarke: That the draft report be the report of the Committee and presented to the House, together with transcripts of evidence, submissions, tabled documents, answers to questions on notice, minutes of proceedings and correspondence relating to the inquiry, except documents kept confidential by resolution of the Committee.

Resolved, on the motion of Mr Ajaka: That the report be tabled in the House on 1 September 2009.

The Chair requested a letter of thanks be sent to the LTCSA regarding their contribution to the Review.

Mr Ajaka thanked the secretariat for its excellent work in preparing the report.

6. Adjournment

The Committee adjourned at 2.15 pm sine die.

Rebecca Main
Clerk to the Committee

