



## **Family Carers and the Life Time Care and Support Scheme**

### **Submission from Carers NSW to the NSW Government on the paper 'Lifetime care and support: Assisting people with catastrophic injuries from motor vehicle accidents'**

#### **1. Introduction**

The Lifetime Care and Support (LTCS) Scheme is a welcome initiative by the NSW Government and the Motor Accidents Authority. We believe that this scheme has the potential to have positive effects for people catastrophically injured in motor vehicle accidents and their family carers and to help alleviate the pressure on the existing community care system to support people with disabilities living in the community. However we have some concerns about its implementation.

The key concerns that we will outline in this submission include:

1. The language used in the document pertaining to family carers;
2. The inclusion of carer support in the scheme; and
3. Issues of equity in the scheme.

#### **Carers in NSW**

Carers are relatives and friends who are caring for people with a disability, mental illness/disorder, chronic condition or who are frail aged. The support they provide is unpaid and they may balance this role with paid employment or receive a pension or benefit and live on a fixed income.

They represent the diversity of the whole population in terms of gender, age and cultural diversity. Although family carers are more likely to have worse health and lower income. The costs of disability are high, and unpaid family carers often bear the majority of these costs, which may include equipment, transport and fuel, pharmaceutical expenses, home modifications and generic community services.

Caring activities provided by unpaid family carers can range from full-time assistance with daily activities to intermittent supervision of people with impaired cognition such as that caused by brain injury. Some carers must leave or reduce hours of employment to provide full-time care.

The situation is most dire for those who cannot access sufficient or adequate formal services. Even for families receiving formal support, the level of informal support provided can still be

high and the costs significant. A family carer may still provide a substantial amount of support even if they receive some formal services.

### **Facts about carers**

There are approximately 750,000 carers in NSW alone, nearly 150,000 of whom are primary carers, meaning they provide the most informal support to a person with a disability, mental illness, chronic condition or who is frail aged.

Some of the negative physical effects of providing this care were reported in Australian data<sup>1</sup> from 2003. They included:

- 34% of primary carers felt weary and lacked energy;
- 29% felt their well-being had been affected;
- 29% frequently felt worried or depressed; and
- 10% had stress-related illnesses.

In total, 72% of all primary carers reported some physical or emotional effect from their caring role.

Further to the evidence from the ABS, a survey conducted by the Carers Association of Australia<sup>2</sup> found that, due to tasks associated with caring:

- 55% of carers surveyed reported tiredness or exhaustion;
- 34% reported upper body problems;
- 13% had high blood pressure or heart problems; and
- 10% had arthritis.

In terms of employment and financial circumstances<sup>3</sup>:

- 76% of carers in NSW are workforce age (18-64);
- 45% of carers and 64% of primary carers are not in the labour force;
- 44% of primary carers in Australia reported that their income had decreased or they had extra expenses after becoming a carer; and
- the median income for primary carers in NSW is only \$224 per week compared with \$435 for non-carers.

Catastrophically injured people are likely to require high levels of care and support, as shown in the LTCS plan. Family carers are therefore at a greater risk of adverse health effects even if they provide only a fraction of this support. As shown in a UK study<sup>4</sup>, carers providing twenty hours or more of care per week are at "greatest risk of poor health and adverse health changes because of their caring responsibilities". Most carers of people with catastrophic injuries would be in this category.

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<sup>1</sup> ABS (2003) 'Disability, Ageing and Carers, Australia: Caring in the Community' Cat. No. 4430.0.55.003

<sup>2</sup> Carers Association of Australia (2000) 'Warning – Caring is a Health Hazard: Results of the 1999 National Survey of Carer Health and Wellbeing'

<sup>3</sup> ABS (2003) 'Disability, Ageing and Carers, Australia: Caring in the Community' Cat. No. 4430.0.55.003

<sup>4</sup> Hirst M (2004) 'Health Inequalities and Informal Care', Social Policy Research Unit, University of York, UK. Accessible at [www.york.ac.uk](http://www.york.ac.uk)

We also know that carers feel significantly under-supported. Across Australia, 45% of all primary carers either had no fall-back carer or did not know if they had one. Almost a quarter (24%) report needing more assistance and 17% needed more respite.

Another UK study<sup>5</sup> found that it costs "three times as much to raise a child with a severe impairment as a non-disabled child" and that the most significant costs were on transport, toiletries, bedding, food, replacing damaged household items, special toys and equipment. The high costs of disability on household income also extend into adulthood as outlined in a recent Australian report on the costs of care<sup>6</sup>.

While the positive and rewarding aspects of caring are acknowledged, Carers NSW believes that there is a great need to improve living standards of carers across a range of areas including those mentioned above. Carers must have choices in all aspects of their caring role. We wish to ensure that carers are incorporated adequately in the LTCS scheme and suggest that the following measures need to be taken to ensure this occurs.

## **2. Concerns regarding the Scheme**

Carers NSW has a number of concerns that we will raise in this submission. These include the language used when referring to carers, support and inclusion of carers in the scheme, eligibility and equity, assessment, choice in care coordination and the adequacy of funding.

### **Carer language**

For the reasons given above it is vital that carers are recognised in any policy document or publication such as this one. We have previously expressed our initial concern about the language used in this document distinguishing carers from paid support staff. This concern will be reiterated in this submission, acknowledging that there has been a clear effort to incorporate family carers in this document (for instance in the strategies to support carers on page 11).

The LTCS plan distributed does not define what is meant by the term 'carer' and therefore is not clear whom the support is for. It is our concern that this confusion may result in inadequate recognition and assistance for carers by coordinators and support workers.

We note that primarily the term 'family' is used when referring to informal, unpaid care and in some instances the term 'carer' is used. As carer support strategies are referred to it would be much clearer to term family members requiring those supports as 'carers' or 'family carers'.

This is particularly important considering that the term 'carer' is sometimes used in place of 'care worker'.

The Australian Bureau of Statistics defines a carer as "a person of any age who provides any informal assistance, in terms of help or supervision, to persons with disabilities or long-term conditions, or older persons... This assistance has to be ongoing, or likely to be ongoing, for at least six months"<sup>7</sup>.

We recommend that future policy documents pertaining to the LTCS scheme provide clear definition of carers as unpaid, family members providing care and support and the roles that

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<sup>5</sup> Sharma, N (2002) 'Still Missing Out? Ending poverty and social exclusion: messages to government from families with disabled children', Barnardos, UK.

<sup>6</sup> Taskforce on Care Costs (2005) 'Creating Choice: Employment and the Cost of Care'

<sup>7</sup> ABS (2003) 'Disability, Ageing and Carers: Summary of Findings', Australian Bureau of Statistics, Canberra.

they may assume when a family member or friend is catastrophically injured. In addition the MAA should ensure that any further documents relating to the implementation of this scheme distinguish clearly between family carers and replace the term 'care worker' with 'support worker'. This is a more appropriate term because paid workers provide a range of supports to people with disability and their family carers to assist them to live as independently as possible.

### **Support for family carers**

Judie Stephens OAM, carer for her grandson Jackson, has outlined the difficulties faced by family members who become carers when someone is catastrophically injured in a motor vehicle accident. She has described the legal and financial battles that carers face in addition to the lifestyle adjustment of becoming a carer and taking on personal care and other essential tasks for an injured family member.

Carers NSW believes that, in developing a scheme for lifetime support, there needs to be further recognition of the needs of family carers such as Judie Stephens. We believe that the inclusion of a carer support strategy in the lifetime care and support scheme is essential. We recognise that respite care is included as a typical service to be provided following discharge and that the service provides breaks for family carers and is much valued. However a range of supports for carers are required. These should include<sup>8</sup>:

- Timely, accessible and relevant information that is culturally and linguistically appropriate and targeted to people whom it will reach;
- Emotional support to assist carers dealing with a range of changing emotions including guilt, fear, frustration, isolation, loss, anger, depression and anxiety;
- Education and training to equip carers with practical skills for management of the disability or condition and communication and coping skills;
- Effective and sufficient respite to give the carers substantial breaks from caring responsibilities;
- Practical assistance with a range of tasks associated with the provision of support to a family member; and
- Financial assistance.

Additional assistance is required for carers of people suffering from catastrophic injuries as there is often a significant period of shock and significantly heightened stress on the family. Many of these family members (often parents) will not have been carers previously and need to make rapid life changes and decisions. Often there is no support for carers prior to the discharge of their family member from hospital into their care.

While we recognise that support for carers has been included in the section 'Developing a Community Participation Plan' it is important that support for carers begins at an earlier stage than this. Further definition of the type of support must be considered so that health professionals, service providers and lifetime care coordinators involved in the scheme will have a clearer understanding of the support needs of carers and carers will understand what support is available to them.

Family members should have choices about whether or not they begin, continue or cease their caring role. This choice must be enabled by the flexibility of support services involved in

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<sup>8</sup> Adapted from Carers NSW (2003) 'Carer Support'

the scheme to adapt to changing carer and family situations, some of which have been highlighted in the case studies set out in the LTCS plan.

### **Inclusion of family carers**

Carers NSW welcomes the recognition of carers in the development of a Community Participation Plan. It is stipulated that the plan will 'be inclusive of carers at all stages and aim to support them in their caring role'. Once again, it is vital that coordinators, health professionals and service providers who come into contact with the person with a disability and their family carers have adequate training and information about the inclusion and support of carers.

It is critical that carers are included as part of the 'healthcare team' (as referred to on page 11 of the LTCS paper) as they are instrumental in providing health care and other supports<sup>9</sup>.

### **Eligibility and equity**

Carers NSW would like to reiterate concerns that have been raised by a number of organisations<sup>10</sup> concerning the equity of this scheme in terms of eligibility. Of primary concern is the exclusion of people who are injured in motor vehicle accidents outside of NSW. Currently this means that a NSW resident injured in another state will not be eligible under the scheme.

The inclusion of "at fault" people who are catastrophically injured in motor vehicle accidents is important from the perspective of carers as the responsibility and costs of supporting someone with severe disability usually fall onto family carers regardless of how that disability occurred.

This scheme has been developed in recognition of the high, lifetime support needs of people with this level of disability and the cost and coordination associated with supporting people with disability to live in the community. Yet the majority of people with disability and their family carers live in the community without this level of essential support. The NSW Government must now address the high level of unmet need for support services amongst other people with disability in the community.

### **Assessment and referral**

Once a person is assessed as eligible for support under the scheme, supports must be put in place immediately. We often hear from carers that there is a delay in assessment and a further gap between assessment and commencement of service provision. It is important that supports are in place in the period between injury and assessment and that service provision commences immediately after assessment. Any delay between discharge from hospital and the commencement of vital supports such as home and vehicle modifications can be significantly detrimental to the health and finances of unpaid carers.

It is important that care assessments take place in the home to ensure that a range of factors are taken into account when planning service provision and support for carers in that environment.

In cases where people are deemed ineligible for support, there should be a system for referral to other appropriate services for the person requiring support and their family carers. This process has not been made clear in the LTCS plan paper.

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<sup>9</sup> An Issue Paper on Carers and Health can be found on the Carers NSW website, [www.carersnsw.asn.au](http://www.carersnsw.asn.au)

<sup>10</sup> Including the Brain Injury Association and ACROD.

## **Care coordination**

The need for family carers to have choices about when and how much support they provide has already been emphasised in this submission. In light of this, the level of involvement provided by the care coordinator may fluctuate depending on the life circumstances of the family carer and stage of relationship between them and the person they support. There must be provision for the level of support provided by family carers to commence, increase, decrease or end during the lifetime of the person they support.

These issues will be particularly significant for ageing parent carers. Given that young men under the age of 30 are most likely to be catastrophically injured in motor vehicle accidents (p1 of discussion paper) their parents will most likely provide their informal support. As these parents age they will require, not only regular respite care and other services, but planning for future accommodation and support needs of their son or daughter when they can no longer provide support.

## **Funding and the LTCS Authority**

The development of standards for service providers (p15 of discussion paper) must be in line with existing standards, including the National Standards for Disability Services.

It is of high importance that the standard of care provided to people who would otherwise have received a settlement is not compromised. The level of care and support provided under the LTCS must be adequate, not minimal. Furthermore it must be recognised that under the scheme compensation will no longer be received for assistance performed on an unpaid basis (p17). Therefore supports for unpaid carers are a vital component of this scheme.

Best practice in carer support should also be taken into account when developing service standards for providers that are successful in tendering for the LTCS scheme service provision.

An adequate complaints mechanism must be established as part of the LTCS Act and LTCS Authority to ensure that people receiving support through the scheme and their family carers can raise concerns about service providers and make complaints, where necessary, without fear of losing services. Furthermore consideration should be made for exit or transition planning for families that do not feel their needs are being met under the scheme.

Finally the scheme needs to be reviewed at least annually after its commencement to ensure quality and continuous improvement.

### **3. Recommendations**

Carers NSW recommends:

1. That the language referring to unpaid family carers as opposed to paid support workers in the discussion paper and any further publications regarding the LTCS scheme be reviewed to ensure that there is an absolutely clear distinction between the two;
2. That sound principles and strategies for supporting carers are incorporated into this scheme and that service providers entering the scheme are adequately trained in carer support and inclusion;
3. That, where a family carer forms part of the care team for a catastrophically injured person, they receive adequate training for this role and are included and consulted and participate at every stage of the care plan;
4. That the MAA ensures lifetime care and support coordinators have the capacity to increase or decrease the level of support provided depending on the carer's wishes or decisions to provide varying levels of unpaid support;
5. That the scheme is sufficiently resourced to ensure that the ongoing support provides an adequate living standard for all receiving support under the scheme and their family carers;
6. That the LTCS Authority develops and adheres to standards for service providers that are consistent with current Disability Service Standards;
7. That the LTCS Authority include best practice in carer support in its research priorities;
8. That there is a review process in place that ensures at least annual review of the scheme after its commencement.
9. That the NSW Government significantly increases investment in generic community care services to ensure that other people with disability living in the community and their carers receive adequate lifetime care and support.