

Social Security Legislation Amendment (Improved Support for Carers) Bill 2009

**Submission to the
Community Affairs Committee**

April 20 2009



Palliative Care

V I C T O R I A

Specialist health care and practical support



Association for Children with a Disability
Information, Support & Advocacy for Families of Children with a Disability

The Carers Association Victoria, Palliative Care Victoria and the Association of Children with a Disability have actively participated in representing the needs of unpaid carers in work to amend the provision of Carer Payment (child). Submissions have been made to the Carer Payment (child) Review Task Force (2007); the FaHCSIA Evaluation of the Adult Disability Assessment Tool and the Child Disability Assessment Tool (2007); the House of Representatives Standing Committee on Family, Community, Housing and Youth's Inquiry into Better Support for Carers (2008) and the Pension Review (2008).

This submission is a joint response by Carers Victoria, the Association of Children with a Disability (Victoria) and Palliative Care Victoria to issues that have arisen in relation to the Social Security Legislation Amendment (Improved Support for Carers) Bill 2009.

Our organisations anticipate there will soon be further improvements in the support available to carers. These will result from the Pension Review, the Taxation Review and the House of Representatives Inquiry into Better Support for Carers.

Carer Payment (child)

1. Carer Payment provides income support to people who because of the demands of their caring role are unable to support themselves through substantial workforce participation. As such it is subject to an income and assets test.

Likely benefits of the Social Security Legislation Amendment (Improved Support for Carers) Bill 2009

Establishing eligibility

2. The amendments appear to provide a fairer means of establishing eligibility for Carer Payment (child). Assessment is to be based on the level of care (or care load) required, rather than on the rigid legislative definition of a profoundly disabled child, and the medical practitioner certification used previously. A Disability Care Load Assessment will replace the List of Recognised Disabilities (LORD) and the problematic Child Disability Assessment Tool. It will assess the level of care required.
3. In the past, many carers were precluded from receiving the payment, even though their care responsibilities appeared to be as great as those who qualified. The number accessing Carer Payment (child) was inappropriately low. The payment has had the far lowest rate of grant to application ratio (12%) than all other income support payments. The amendments anticipate that there will be a significant increase in eligible carers, through the reduction in past overly restrictive criteria. The rate of grant to application ratio will need to be carefully monitored.

Streamlining with Carer Allowance

4. The proposed streamlining of eligibility for Carer Payment (child) with automatic eligibility for carer allowance will avoid the need for separate applications and assessments. This is a beneficial change. It appears however that the Child Disability Assessment Tool will be retained as a separate mechanism for eligibility for Carer Allowance (child) only.

Provisions for hospitalisation

5. Changes will ensure that carers can qualify, or remain qualified for carer payment (child) while the child is hospitalised for unlimited days per calendar year. This will remove the earlier problem of cessation of Carer Payment when the limit of allowable days of hospitalisation was reached. It acknowledges that the care load borne by carers often continues when their child is hospitalised regularly or for long periods. (However, a carer participating in the care of an

adult in hospital will only remain qualified if hospital admission is limited to 63 days in a calendar year).

Multiple care responsibilities

6. The amendments acknowledge the complexity and demands of a significant number of care situations. Carer Payment (child) will in future be paid in relation to a carer who cares for a single child with a severe disability or medical condition, (subject to care load); to a carer who cares for 2 or more disabled children (subject to a cumulative care load score) or to a carer who cares for one or two children with a disability or medical condition who also cares for a disabled adult (subject to a cumulative care load score). These are desirable changes.

Shared or exchanged care

7. Complexity is also acknowledged in the provision, in the amendments, for separated or divorced parents to qualify if they exchange the care of 2 or more children with a disability or chronic illness (subject to care load) and are thus precluded from substantial workforce participation. The shared caring responsibilities need to be endorsed by the courts or articulated in an agreed parenting plan.

Short term and episodic care

8. Particularly pleasing are amendments (197 G) which make allowances to provide income security payments to support a carer involved in the short term or episodic care of a child. These changes potentially allow quick access to carer payment in extreme circumstances. Short term care allows eligibility for a one off event for up to 5 months. Episodic care refers to care provided on a recurring basis where each episode is expected to last for more than 3 months and less than 6 months. There is capacity for extension beyond those respective periods with certificates from a treating health professional.
9. These changes will appropriately extend the benefit of carer payment to a parent who has limited capacity to participate in employment due to their child's recurring illness and treatment, or accident and rehabilitation. This was previously unavailable for children with disabilities or illnesses of less than 6 months duration, often at great family cost.
10. There is provision in the proposed amendments for receipt of carer payment on a short term or episodic basis to move to a carer payment where care is required for 6 months or more. In addition, recipients of Carer Payment (child) can have eligibility extended for 3 months beyond 16 years; allowing time for completion of ADAT scores.

Terminal Illness

11. The amendments to the requirements of medical certificates about terminal illness are a great improvement. Section 197 E removes the requirement that a medical practitioner certifies that a child has a terminal condition and will not live for substantially longer than 12 months. This is replaced with a requirement to certify (less directly) that the average life expectancy of a child with the same or similar condition is not substantially longer than 24 months. It provides a more flexible and sensitive mechanism. Further comments about this are made below.
12. The automatic extension of carer payment for those eligible due to a child's terminal condition for 2 years beyond age 16 will also be beneficial.

Broadening the experts

13. The amendments also broaden those experts who can assess and certify eligibility for Carer Payment (child) beyond medical practitioners to treating professionals. This ensures that carers have greater choice in who may assist with their application and appraise their needs.

Issues of concern about the amendments

Assessing Care Load

14. It is difficult to appraise the likely impact of the amendments when there is no public access to the Disability Care Load Assessment Tool and its scoring arrangements. There needs to be transparency about the tool to be used. What will be needed to achieve an intense care load score, both in relation to the care of an individual child, or the cumulative scores for several children, or several children and an adult?
15. We note that the Disability Care Load (child) Determination will be subject to parliamentary scrutiny.
16. Similarly, we wonder how 'constant care' of a child under 16 will be defined. How is 'personal care' defined? We note that treating professionals are required to certify that a child will need personal care for 6 months or more under sections 197B, 197C, 197D, 197E, 197G. The network of carer associations and others argued strongly in its submission on the review of the CDAT and ADAT that 'care load' needs to be conceptualised as broader than physical and personal care. It needs to be inclusive of care which requires constant vigilance, supervision, encouragement, nurturing, and the ensuring of medication compliance. It needs to acknowledge the 'intensive care load' that

can be required for some children with autism, a mental illness or psychiatric disability and children with severe and challenging behaviours.

17. In addition, the care required for a child living with terminal illness includes four domains of care- the physical, psychological, social and spiritual. Thus it is important that care load is understood as being much broader than physical and personal care.

Short term and episodic care of children

18. We wonder if section 197 G (short term and episodic care of children) is sufficiently inclusive of children with a mental illness such as depression, anxiety or an eating disorder. For some, personal care is less important than the need for constant supervision and hyper vigilance to ensure the child's safety and well being are maintained and to manage their treatment. Will this form of 'intensive' care be appropriately measured in the Disability Care Load Assessment tool? We note that case examples included in the Explanatory Memorandum only illustrate care situations involving a child's accident/ injury or need for chemotherapy.
19. In addition, we recommend the insertion of a protective mechanism which allows a carer who is eligible for Carer Payment (child) in relation to a child with an episodic illness to retain eligibility for carer payment for up to 2 years. This will allow eligible carers to transition into and out of employment over a number of years to accommodate, for example, their child's hospitalisation, chemotherapy or periods of acute mental illness. It will avoid the necessity and stress of regular reassessment of eligibility for Carer Payment (child)

Certification of a child's terminal illness

20. Carers of a child living with a terminal illness have difficulty signing forms which include clauses such as 'not normally expected to survive for more than 24 months'. Many feel signing such forms consigns their child to die, or reduces their hope. As a consequence, many avoid applying for a needed Carer Payment.
21. Matters of loss and grief are long and difficult processes and it is important that families are supported sensitively. We believe the medical certification can be undertaken separately from the application for Carer Payment.

Financial assistance to families after a catastrophic event

22. The proposed amendments to Carer Payment (child) do not provide an appropriate arrangement for financial assistance to families in the adjustment period following a catastrophic event. We note that the one off Carer Adjustment Payments, which cease in December 2009, were able to provide financial assistance for families of children under 6 years where full time care

was required, after a catastrophic event. These included in some circumstances, the diagnosis of a terminal condition as a catastrophic event for the purposes of Carer Adjustment Payment.

23. While the amendments provide options for earlier access to Carer Payment (child) for short term and episodic events they appear to provide no options for short term financial assistance for families in the adjustment period after a child under 16 experiences a catastrophic event. In this period many families have a financial need and participation in employment may be constrained because of the child's care and support needs. We anticipate that the situations which gave rise to the need for Carer Adjustment payment will continue to arise. This is a major gap.
24. We consider a mechanism for short term financial assistance to families after a catastrophic event will still be required. It should be distinguished from the issue of income support.

Barriers for some complex families

25. It is likely that the amendments will exclude some complex multiple care situations from eligibility for Carer Payment (child). The amendments propose that eligibility can be reached through cumulative care load scores for one or several children and one adult. Some carers may be providing care for both parents and a child – or various other family constellations. It is important that barriers for exceptional care situations are minimised.

Shared and exchanged care

26. The amendments include options which appropriately promote an increased sharing of care between several individuals. They allow sharing the care or exchanged care for 2 or more children by divorced or separated parents. There is however, no provision to share the care of a single child who requires an intensive care load. The capacity for either parent to adequately participate in paid employment is likely to be limited.

Restricted capacity to undertake paid employment

27. Various case examples in the explanatory memorandum outline the circumstances of care situations where the carer is, or is not severely restricted from participation in employment.
28. However, participation in employment requires access to suitable child care before and after school and vacation care for children and adolescents with high care needs. While these options are available to working families with ordinary children, they are rarely accessible to carers of children or adolescents who require an intensive care load. Both lack of access to and the cost of alternative care for children with significant disabilities can make

participation in paid employment and job retention difficult. This must be taken into account in determining eligibility for Carer Payment.

29. Other reforms are required to support carer participation in the workforce. These include modifications to the disincentive of the 25 hour work, training and education rule for carer payment which discourages the combining of paid work and unpaid care; improved access to training and support, and improvements in the industrial relations arena, including extension of the right to request flexible work to all people with care responsibilities. These are beyond the scope of the current legislation amendments.

Importance of accessible information

30. The proposed amendments extend eligibility for carer payment (child) to a broader range of care situations. But simultaneously, they introduce a greater level of complexity to eligibility for the payment. It will be important to ensure clear and readily accessible information is available about revised eligibility. This should include general community information, information to key services providers; and information targeted to CALD and indigenous communities. Particular attention must be paid to reducing the barriers for carers from indigenous and culturally diverse communities in accessing Carer Payment (child). The up skilling of Centrelink staff will be crucial.

Arrangements for review of eligibility

31. While it may be inappropriate to legislate concerning the nature and timing of review of eligibility for Carer Payment (child) and Carer Allowance, a more appropriate review regime, consistent with the report of the Carer Payment (child) Review Task force must be urgently developed.

Different eligibility mechanisms

32. The revised eligibility for Carer Payment (child) will result in increased inconsistency with assessment and eligibility for Carer Payment and Carer Allowance (adult).
- It appears there will be 3 different forms of assessment – the Disability Care Load Assessment; the Child Disability Assessment Tool (retained for eligibility for Carer Allowance (child) alone), and the Adult Disability Assessment Tool.
 - There will be better options for establishing eligibility through cumulative care load for carers of children than carers of adults.
 - Access to Carer Allowance (adult) is restricted to a maximum of 2 disabled adults and excludes some families with more than 2 adult disabled children. Carer Allowance (child) can be paid with respect to each eligible child.
 - Stress and confusion will apply if a child with a terminal illness lives longer than age 18 as Carers Payment (adult) has a different terminal illness criteria. Carers Payment (Adult) states the adult is not expected to live

more than 3 months. Carers Payment (child) states that the child is not expected to live substantially longer than 24 months.

- Emerging and increasing anomalies will need to be quickly addressed to ensure smooth transitions from child to adult criteria and overall improvement in the payment system for all carers.