Carers
AUSTRALIA

# Submission to the Senate Inquiry into the Social Security Legislation Amendment (Improved Support for Carers) Bill 2009

*April 2009*

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**Title:** **CA Submission to the Inquiry into the Legislation Amendment (Improved Support for Carers) Bill 2009**
Date: April 2009
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## Introduction

Carers Australia welcomes the invitation to respond to the proposed Social Security Legislation Amendment (Improved Support for Carers) Bill 2009. We believe that legislation plays an essential part in the recognition and support of the role of carers in our society. The review of Carer Payment (child) that was undertaken throughout 2007, was welcomed by Carers Australia and those family carers who care for children with a disability, mental illness, terminal illness or chronic condition. The improvements that this legislation is designed to bring for these carers through the social security system are welcome.

There are clear benefits in the new legislation for carers of children with a disability or chronic or terminal illness. In the main, these are related to changes that are directly determined by the legislation, and not reliant on additional policy to ensure their delivery. These changes include: improved qualification provisions allowing for carers to qualify on the basis of short-term and episodic care; removal of limitations on hospital stays; automatic qualification for Carer Allowance with Carer Payment (child); and new provisions with regard to combined care for adults and children and new provisions for qualification in the case of terminal illness.

The amendments in the Bill have the capacity to improve the clarity and flexibility of carer support payments, but cannot be effective unless they deliver on the aims of the legislation in practice. We are mindful that 'the devil may be in the detail' in this process, many of the changes will rely on the elements that will function alongside the Amendment Bill and Social Security Act, including policy and implementation, service delivery and customer assistance processes. Further, without clarity, transparency and the continuation of the aims of the Amendment Bill in these processes, it is unlikely that the legislation alone will provide 'improved support for carers'.

The Taskforce Report into Carer Payment (child)[1], completed in November 2007, demonstrated that reforms are needed in the current assessment and qualification processes for the payment. A large number of the Taskforce's recommendations also cannot be addressed through legislation alone. While we welcome the current amendments, Carers Australia also anticipates further changes in the delivery and administration processes for Carer Payment (child) through FaHCSIA and Centrelink, that will be required going forward.

## About Carers Australia

Carers Australia is the national peak body representing those Australians who provide unpaid care and support to family members and friends with a disability, mental illness or disorder, chronic condition, terminal illness or who are frail.

Carers Australia's members are the Carers Associations in each state and territory that deliver specialist information, counseling and others services to carers in the community. Carers Australia is informed about carer issues through its member Carers Associations (the Network of Carers Associations) and its participation in national and international forums.

We believe that all carers are entitled to the same rights, choices and opportunities as other Australians in order to enjoy optimum health, social and economic wellbeing and to participate in family, social and community life, employment and education.

## About Australia's Carers

Australia has almost 2.6 million carers, and nearly 500,000 of these are primary carers – the people who provide the most care[2]. Carers are from all walks of Australian society and come into the caring journey at various stages throughout their life.

Of around 4 million Australians with a reported disability in Australia, almost one-third had a profound or severe limitation and of those 1.07 million live in private households. 79 per cent of people with a disability living in households received care from the close link between people with disabilities and carers.[3]

In 2003, there were 390,000 children (under 14) with a disability, of these 166,700 had a profound or severe core activity limitation.[4] 23% of primary carers were parents caring for a child.[5]

In the financial year 2007-08 130,657 people received Carer Payments (adult and child), 113,549 people received Carer Allowance (child).[6]

## Aims of the New Legislation

The explanatory document states the aim of the inquiry into the Amendment Bill: "To ensure that the new provisions adequately meet the needs of carers". The Bill aims to respond to the report from the Carer Payment (child) Taskforce, which found that "the criteria were too restrictive, the assessment process was too rigid, and produced inequitable outcomes". There is a need to ensure that these commendable aims are supported, and that the changes within the Bill provide real benefits for carers of children under 16. Carers are one of the most disadvantaged groups yet discovered[i] and it is essential that carers are not further disadvantaged by these changes.

Further, the government has stated that the introduction of the Bill aims to result in an additional 19,000 carers having access to the payment. It is likely that a proportion of these people will be existing income support recipients, who are on another pension or allowance.

The move to Carer Payment (child) may have significant benefits for these carers, but it is important this move will not have unforeseen negative impacts on the income of these carers. Further, it should be considered that simply rotating already existing income support recipients through the system would not extend this support to the carers in the community who may be in real need of government support yet are not currently receiving it.

## Qualification Provisions

### Automatic qualification for Carer Allowance

The automatic eligibility for Carer Allowance (child) for those approved for Carer Payment (child) (section 954B) will be a very welcome outcome of this legislation. The change will safeguard against current confusion that exists surrounding people's eligibility for both payments, and will

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[i] See Deakin University (2007) Australia Unity Wellbeing Index Survey, The Wellbeing of Australians: Carer Health and Wellbeing, Australia, Victoria

ensure that carers are able to easily access the full extent of support available to them. Currently, many carers are unaware of their entitlement to both payments.

> *However, the process that will see those carers already receiving Carer Payment access Carer Allowance, needs to be clarified. The explanatory memorandum for the Bill states that these individuals will not need to be* re-assessed *to qualify for Carer Allowance (see p.4). Guidelines are needed to establish whether these carers will however, still need to* apply *in order to access Carer Allowance under the new provisions. Should this be the case, every effort should be made to inform current carers of their ability to access Carer Allowance and ideally, Carer Allowance should be automatically credited to these carers.*

Those already qualified for Carer Payment (child) at the commencement date should not be required to apply for Carer Allowance, instead Carer Allowance payments should be automatically credited.

The further provision of the draft Bill that allows backdating of payments for individuals who claim for Carer Payment and are unsuccessful, but are later approved for Carer Allowance, (subsection 15A,1) is also extremely positive.

This improvement is both fair and reasonable and takes into account the need for carers to receive financial support as soon as possible following the application process and compensates for the time required to apply, assess for qualification and the subsequent time required for re-application.

## Episodic and short-term qualification

Amendments introducing better support for short term or episodic cases (section 197G) will be of real benefit to caring families.

Short-term qualification will be provided for a one off period of a maximum of six months, episodic qualification, for ongoing periods of 3-6 months. This is a vast improvement on previous arrangements, in which carers were unable to access payments for caring responsibilities lasting less than six months. These provisions will mean that people across a wider range of caring situations can be assured of receiving the support they need during highly stressful life events.

It is commendable that this support has also been made more flexible, and designed to avoid instances of carers being ‘cut-off’ from support prematurely. The protection against loss of payment for turning 16 while in episodic care through the continuation of payments for four months of the same episode (subsection 197H, 4) is an excellent provision.

> *Consideration however, needs to be given to the need for ongoing assessment and compliance measurements for those who qualify for episodic or short-term payments. The requirement for the carer to meet measures for ongoing qualification, and review processes will need to be reasonable, and not substantially more burdensome than the requirements of other situations under which carers qualify for payment.*

## Terminal illness and hospital support

The Amendment Bill has achieved a positive change through the changes to the assessment process for carers of terminally ill children (section 197E). Payments for those with a terminal illness will now be based on the average life expectancy for the condition. This measure is much more sensitive to the individual, and fair, in that it removes ambiguity and speculation involved in current assessments of terminal illness that may take into account the multitude of variables associated with individual life expectancy.

Further, we strongly support the extension of the definition of terminal illness from 12 to 24 months (subsection 197E, 1b ii). This extension reflects a realistic approach to life expectancy measures.

> "When the person I am caring for goes to hospital my job still goes on every day as I have to be there 24/7 as no one can communicate with the person I care for." (Carer of 19 years)

The changes designed to further support caring families in periods of hospital stays, by removing the previous cut-off period for payment set at 63 days in hospital per year, (section 198AA) are very positive.

This is a change that responds to the reality of caring situations and the amount of hospital involvement that may be required. There is no reason for carers to be excluded from payments because the care recipient is in hospital.

In many ways this acknowledges the involvement of carers in the hospital process, the continued need for informal care during this time and the continued impact of caring on the carer, even where the person's physical or medical needs are being met by hospital staff.

## Multiple Caring Responsiblities

> "I know I am not the only person caring for more than one person and I feel that it is very important to have it recognised and acknowledged that it is happening"
> (Carer of daughter and mother)

The Bill presents a clear improvement to the legislation by allowing combined care provided for adults and children to be taken into account in the assessment process (section 197D). The provisions ensure that people with multiple care responsibilities will be able to qualify on the basis of the combined care that they provide.

> *However, consideration should be given to the process of assessment by health professionals. Currently, one treating health professional provides the required assessment for Carer Payment (child). It should be considered that this may not be the most practical approach, particularly in cases where care is provided to two people whose current treating health professionals may differ. Multiple treating professionals should be able to contribute to the qualification process and provide assessments that more accurately reveal an overall picture of the caring situation.*

Assessments by *multiple* treating health professionals should be able to contribute to the qualification process, particularly in cases involving the combined care of more than one care recipient.

Where there are multiple carers, the allowance for shared custody/care arrangements for two or more children with a disability under the legislation (section 197F) is also a welcome improvement for carers and their families.

> *There is however still no provision for shared care of a single child who requires an intensive level of support. It is questionable that these provisions for two disabled children in a shared care arrangement adequately respond to the reality of many caring situations. Further, it should be considered that this provision may in fact act to discourage shared care arrangements in families of a single child with a disability or illness.*

The legislation could allow for shared care of a single child, where the level of care is intensive and the shared care arrangements are minimal.

The Taskforce Report identified that where there are multiple children, there is no clear guide regarding the way in which the care needs of the two children are measured as being equal to the care needs of one profoundly disabled child. This should be addressed in the new assessment process involving combined care for children and adults.

It should also be noted that the provisions of the Bill continue to cater only for shared care arrangements between parents on the basis of court-orders. Caring families are not made up solely of parents of children.

> *Consideration should be given to support in the legislation for care shared between other relatives on a more informal basis, which would provide greater recognition for the diversity of caring family situations.*

Qualification in situations where the care of children is shared between relatives other than parents should be supported in the Bill.

## Assessment Provisions

### The new Disability Care Load Assessment

The replacement of current assessment measures for Carer Payment (child) with the new Disability Care Load Assessment (section 38E), should be a positive change for carers, allowing greater flexibility in the qualifying criteria for Carer Allowance.

> *It should be considered that the replacement of the List of Recognised Disabilities with a new assessment tool may complicate the process. Certain carers will instead be asked to comply with the requirements of the new Disability Care Load Assessment, which may mean a lengthier process for carers of people with conditions, illnesses or disabilities, who would have otherwise qualified immediately as a result of the List of Recognised Disabilities.*

The list of recognised disabilities could be included as an alternative means of qualification under in the Disability Care Load Assessment determination.

The Disability Care Load Assessment tool is currently unavailable to the public. Until it is made available, it is difficult to know if the tool will be truly effective in practice. The current Child Disability Assessment Tool (CDAT) was developed using a consultation process, and it is hoped that a similar transparent process will undertaken in the creation of the new assessment tool. An open consultative process will ensure that the Disability Care Load Assessment is fair and equitable in assessing care requirements and eligibility. Measures of intensity of care in particular will need to be clearly defined, especially in the case of assessments of combined care responsibilities.

The Disability Care Load Assessment should be developed by way of a comprehensive consultation process.

### Assessments by 'treating health professionals'

One greatly beneficial provision is the introduction of the broader definition of 'treating health professional' (section 38F), which moves beyond the previous definition of 'medical practitioner'. Minister Macklin in her media statement of 18 March 2009, outlined that "The changes will also allow a range of health professionals including physiotherapists, registered nurses and Aboriginal health workers in remote areas to provide assessment - not just doctors and specialists."[7] This change will be particularly beneficial if the list of included health professionals is to resemble the list for used for the Adult Disability Assessment Tool (ADAT). It is hoped then, that this change will also result in greater parallel between the two levels of payment (child and adult) and improve the transition process.

The list of outlined health professionals able to carry out assessments should closely resemble the list outlined under the ADAT guidelines, and particularly include treating psychologists and psychiatrists, nurses, and Indigenous health workers.

## Provisions for Interactions with Other Payments

### Transition from payment child to payment adult

> "I feel like we don't fit into Centrelink's 'categories' very well. I was receiving Carers Allowance for my daughter when she was under 16, but have had to reapply recently when she turned 16. The application process is very difficult and off-putting and certainly makes me feel like giving up." (Carer for husband, daughter and son)

The interaction of the payment with other income support measures, particularly Carer Payment (adult) is an important part of any caring families' dealings with Centrelink and the income support process. The transition from child to adult payments can be a period of confusion and anxiety for carers, who may be particularly uncertain about the loss of payments as their child reaches 16, and indeed for many carers this does occur.

The new, staged approach to Carer Payment transitions introduced by the Bill (section 197K) will ease the tension of transition significantly and is a very positive change.

The transition to adult payments has been addressed by allowing child payments to continue for 3 months following the time at which the care recipient turns 16, or until a ADAT is completed. This will not only ensure that a steep change to payments is avoided, but will also encourage ADATs to be carried out promptly when they are required.

> *While this change is welcomed, there is also a greater need to consider whether another assessment (ADAT), is in fact necessary at this transition point. If carers have qualified for Carer Payment (child) using one set of assessment reports, surely these could be utilised to qualify them for ongoing payments. Given the rate of change of many care recipients' disabilities, this would be a reasonable measure. And given the amount of assessment processes that are required, any streamlining of the process would be beneficial.*

A carer's Centrelink assessments carried out within the last two years while receiving Carer Payment (child) could be approved for use to qualify carers for Carer Payment (adult), in place of a new ADAT assessment.

In aiming to promote improved transition between payments, it must also be noted that the revised eligibility criteria for the payment will in some ways lead to increased inconsistency between Carer Payment (child) and Carer Payment (adult).

For example Carer Allowance (child) is payable for multiple children (2+), whereas Carer Allowance (adult) only takes into account care provided for 2 adults. This transition will mean for some carers, the loss of any previously held Carer Allowance payments for more than 2 care recipients over 16. Examples such as this need to be more closely examined in aiming to improve the transition from child to adult payments. Differences in the Adult Disability Assessment Tool (ADAT) and the Disability Care Load Assessment may also mean that many carers risk loosing entitlements following the move to adult payments. A future review of Carer Payment (adult) would extend the significant positive outcomes of this review.

The ADAT should be reviewed for compatibility with the Disability Care Load Assessment.

## Further Carer Payment (child) Improvements to Support Carers

### Expected workforce participation and required care

Expectations regarding the amount and constancy of care that carers should be providing in order to qualify for payment, needs to be reconsidered at some stage. The Taskforce Report states that the Carer Payment (child) was originally designed to support those whose amount of care was equivalent to a working day, everyday, seven days a week. A definition of 'constant' care that suggests that carers donate all of their time to caring, sacrificing any opportunity for regular relaxation or the pursuit of interests, is not a reasonable expectation, particularly in a society that strives to promote work-life balance.

Many carers who may be able to participate in work during school hours would still experience the impacts of their caring role at work, away from the person for whom they provide support. For example, carers may be sleep-deprived, stressed, distracted, or constantly primed to respond to crises that require them to 'drop everything' at work. This could significantly impact on their ability to find and maintain employment but this is not considered under the current system.

Research has consistently shown that carers have the lowest health and wellbeing of any group yet discovered and this should be taken into account in assessing eligibility for Carer Payment (child). The caring role can be highly stressful and psychologically demanding, with emotional and psychological investment carrying over into times when carers are not directly providing care. These care needs can significantly impact on a carers ability to engage in substantial participation in the workforce.

## Required care measures and the psychological impact of caring

"I feel the thing which gets you down as a carer is the constancy of the situation. I go to bed every night listening for every call or movement and often wake thinking I have heard him call out only to come to his room and find him sleeping soundly. When you wake in the morning you wake to the same routine every day." (Carer of adult son)

"The Government should recognise that caring is physical and emotional and that supervision/ constant watchfulness can be as difficult as the physical tasks." (Female caring for a friend with Schizophrenia)

The Network of Carer Associations argued strongly in our submission to the review of the CDAT and ADAT that 'care load' needs to be conceptualised as broader than physical and personal care, and include the constant vigilance, supervision, encouragement, nurturing, and the ensuring of medication compliance that accompanies a large number of caring roles. The Amendment Bill provides a unique opportunity to include these aspects of caring in the new assessment process (Disability Care Load Assessment).

Currently the CDAT and Carer Payment Qualification process base measures of intensity of care on physical, social and medical support needs, but ongoing emotional and psychological investment by the carer is not given consideration. This is one of the most intensive elements of caring for many people. The addition of emotional and psychological support needs to the current measures of required care used in the Disability Care Load Assessment would be a clear improvement to the process.

The DCLA should include indicators of the psychological/emotional impact of caring as a measure of required care.

## Medical assessments and the role of health professionals

The new provisions of the Bill aim to measure the level of care required rather than categorising the care based on rigid medical criteria. However, the heavy reliance of the opinion of treating health professionals in the assessment process remains unchanged, and should be balanced with other measures of provided and required care. While the opinion of treating health professionals are important, significant problems with the medical professional assessment process have been evident in the past, and the new approach to Carer Payments should be designed to minimise these complications and reduce the need for appeals processes.

The recent Assessment of Claims for Disability Support Payment completed by the Commonwealth Ombudsman, raised several problems with the process of medical assessment. The report raised that treating professionals need to be provided with clear guidelines regarding the context in which their reports will be applied and the ways that assessments will affect their patients. They must be able to easily fill out forms and these forms should not be time-intensive. This report recommends a guide for health professionals to accompany forms and states that FaHCSIA has indicated it would support an information kit for health professionals. The report also highlights problems with the return of forms and suggests the need for Centrelink assessors to be made responsible for making contact with medical professionals to seek additional medical information or to ensure that sections of forms are completed correctly.

Health professionals should be supported by way of clear, efficient forms, information packs and support from Centrelink staff, to complete the required assessments correctly.

### Assessment of care recipient income

The assessment of the amount of income of the care recipient (required under section 197B-E, subsection 4c) raises concerns for the future security of care recipients, particularly with regard to Special Disability Trusts. Assurance must be given that any investment in Special Disability Trusts will not be taken into account when determining income or assets of the care recipient.

This could otherwise provide a disincentive for people using the Special Disability Trust system, which is designed to support others to plan for the future for people with a disability in the event that there is no longer a carer for the care recipient. Carers should not be discouraged from planning for the future for the person for whom they care in order to receive the income support that they require.

Special Disability Trusts should be exempt from all income/asset assessments related to Carer Payment (child) (under section 198N).

## Future Directions in Response to the Carer Payment (child) Review

These proposed legislative changes must be viewed as part of the broader process of Carer Payment (child) reform.

For example, this payment cannot be considered in isolation from Carer Payment (adult), particularly when many carers will go on to receive it. The beneficial changes achieved in this process should be extended to the process for Carer Payment (adult), for example, the measures of terminal illness and removal of limit on hospital stays. Future steps to align Carer Payment (adult) with Carer Payment (child) would improve the transition process, which is particularly important for many carers who will require income support over the life of their care recipient. Further, many care recipients are ‘dependants’ well into adulthood, reaching the age of 16 does not alter this fact and should not result in major upheaval for carers reliant on income support.

The process will also need to move beyond legislative improvements. Many of the recommendations of the Carer Payment (child) Taskforce Report cannot be adequately addressed in legislation. For example, those recommendations relating to the assessment process or criteria which will be determined by later policy, as well as those recommendations addressing workplace culture and the customer service ethic of Centrelink, which has been criticised in the report for deterring carers from applying.

It should be noted that Centrelink's role in informing carers of the new changes and providing ongoing assistance throughout the payment qualification process will be crucial to seeing real improvements to the carer payment system. For the amendments to be successful it is essential that all Centrelink staff understand the new provisions.

A wide array of policy-driven changes to processes would also have the potential to further improve the support of carers. For example, widely available 'dedicated complex claims assessment teams'; policy that outlines the frequency of payment reviews appropriate medical review cycles and reporting requirements; and review of the guidelines applying to carers of children with behavioural disorders (where qualification is not granted until age 6). Further policy will also determine much of the new Disability Care Load Assessment tool.

## Conclusion

Carers Australia supports the Social Security Legislation Amendment (Improved Support for Carers) Bill as a whole. The review has clearly identified the needs of carers with respect to the current Carer Payment (child) process and the proposed Bill responds to these issues. We still hold some reservations about certain elements that have the possibility of impacting negatively on carers, and these should be considered and corrected-for where feasible and appropriate.

There is a need to consider additions to the legislation and there must be clear direction about further ways by which carers with children will be supported and how these responses will be implemented. This will determine the effectiveness of the legislation in responding to the needs of this group of carers and providing 'improved support'.

# References

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[1] Australian Government (2007) Carer Payment (child): A New Approach— Report of the Carer Payment (child) Review Taskforce, Australia, Canberra

[2] Australian Bureau of Statistics (2004) 2003 Disability, Ageing and Carers: Summary of Findings, Australia, Canberra

[3] ibid

[4] ibid

[5] Australia Bureau of Statistics (2008) A Profile of Carers in Australia, Australia, Canberra

[6] Department of Families, Housing, Community Services and Indigenous Affairs (2008) FaHCSIA Annual Report 2007-2008, Australia, Canberra

[7] Macklin, J. (2009) Media Release: Carers to Benefit from Government Reforms, 18 March 2009