

27 November 2015

Department of Social Services  
Carer Payment and Carer Assessment  
PO Box 7576  
Canberra Business Centre ACT 2610

Dear Sir or Madam,

**Re: Improved Assessment Process for Carer Payment and Carer Allowance**

Thank you for the opportunity to make this submission in relation to the Improved Assessment Process for Carer Payment and Carer Allowance project.

**About National Legal Aid**

National Legal Aid (NLA) represents the Directors of the eight state and territory legal aid commissions (LACs) in Australia. The LACs are independent statutory authorities established under respective state or territory enabling legislation. They are funded by State or Territory and Commonwealth governments to provide legal assistance to disadvantaged people.

NLA aims to ensure that the protection or assertion of the legal rights and interests of people are not prejudiced by reason of their inability to:

- obtain access to independent legal advice;
- afford the appropriate cost of legal representation;
- obtain access to the federal and state and territory legal systems; or
- obtain adequate information about access to the law and the legal system.

**Background**

The Federal Government is reviewing the assessment process for Carer Payment (CP) and Carer Allowance (CA) for carers of both children and adults.

This submission addresses the questions raised in the *Guide to Written Submissions: Improved Assessment Process for Carer Payment and Carer Allowance*, issued by the Department of Social Services.

LACs advise and assist clients with respect to social security matters, including eligibility for Carer Payment and Carer Allowance. This case work experience informs our submission.

NLA understands that the review is only into the assessment process for CP and CA, but notes that reforming individual payments, without consideration of how they fit within the overall income support scheme, can be problematic. In light of this, where appropriate, we have noted issues with other payments that impact on CP and CA qualification issues.

## **1. Level and types of care**

**1. How could an assessment process measure care needed?**

**2. How could an assessment process measure care provided?**

### **Evidence from treating doctors and carers**

NLA submits that the CP and CA assessment process should continue to assess care needed and provided with evidence from both the carer and the care receiver's treating doctor.

In terms of care need the treating doctor is able to provide important information about diagnosis, functional ability and restrictions. However in many cases a person's treating doctor will not have a sophisticated understanding of the at-home care needs of the care receiver. They may be unable to comment on how the person's functional limitations or behavioural difficulties translate in terms of care provided. NLA submits that carers are best placed to advise on the care needs within the home.

For example, a doctor can comment on a person's restrictions in lifting their leg, but the carer's evidence is needed to detail what this means in practice. The carer's experience may be that the person cannot get into bed unassisted, lift their leg to get into a shower or bath, or walk up stairs which are in the home.

NLA does not support any move towards relying on diagnostic testing, as has occurred with new claims for Disability Support Pension (DSP). Two people can have the same disability but have different care needs. Diagnostic testing is inadequate for assessing care needs for CP and CA claims. For CP and CA the focus should be on measuring care needs, not level of disability.

### **Assessment tool questions**

In our experience the *Adult Disability Assessment Determination 1999 (ADAT)*, which is currently used to assess the care needs of an adult and determines eligibility for CP and CA, does not wholly capture the care required of care recipients. The *Disability*

*Care Load Assessment (Child) Determination 2010 (DCLA)* which assesses care needs for children provides a better assessment method.

NLA submits that consideration should be given to adopting a similar questionnaire for assessment of adults as that used to determine care needs of children.

In particular NLA notes the following favourable features of the DCLA assessment:

- ***Guidance on how to answer questions***

In each question the *DCLA Assessment of care load questionnaire* provides examples of what is meant by 'no help', 'a little help', 'a lot of help' and 'completely dependent', whereas the ADAT is silent on what is meant by 'always', 'often', 'sometimes' and 'never'. The guidance given by the examples for each behaviour or functional ability in the DCLA leads to more consistency in assessment of care needs. For example, depending on the care need being assessed, 'sometimes' may mean hourly, daily or weekly. It is especially important to provide this guidance for people from culturally and linguistically diverse backgrounds where English is not their first language.

- ***Assessing medical appointments and treatment***

The DCLA measures care needs such as attending health care appointments related to the child's disability multiple times per month and assisting with exercises prescribed by a treating health professional. NLA considers assessment of an adult's care needs should include those supports and treatments contained in questions 47, 51, 52 and 54 of the *DCLA Assessment of care load questionnaire*.

Currently a person caring for an adult does not have their contribution to treatment of a person with a disability considered as part of the assessment of care. An assessment of care provided must include taking into account activities such as taking people to medical appointments, helping with medical treatment and helping with medical testing (such as regular blood or urine testing). Many of these activities are time-intensive and go directly to why carers are unable to support themselves through employment.

- ***Impacts on a carer's ability to undertake non-caring activities***

The assessment process in the DCLA includes inviting the carer to provide additional information about care provided and importantly "any other effects that the child's disability or medical condition has on you (e.g. any other effects on your daily routine, ability to take up paid employment, your health, social activities or emotional effects.)" The ability to describe the care provided and the impact of caring on the carer's capacity to undertake other activities recognises that a simple "tick a box" approach does not always capture an individual person's circumstances. NLA acknowledges that the introduction of the ADAT was to move away from a solely subjective assessment of care, however, restricting assessment to answers

from pre-formed statements does not allow for a comprehensive assessment of the multi-faceted needs of a care receiver.

### **Assessment of care needs of a person with a severe mental illness**

Any assessment tool needs to ensure sufficient weighting or scoring is given to the care needed by people with severe mental illnesses who need supervision, monitoring and management of behavioural difficulties. The current ADAT does not ask enough questions to assess this type of care needed and provided.

A person with a severe mental illness may be able to undertake an activity themselves, such as dressing or bathing. However they may not do the activity if not constantly prompted or supervised to do it. NLA acknowledges that the instructions in Division A of the ADAT *Claimant questionnaire* and the *Professional questionnaire* state that “help” for a person with activities of daily living means “any physical assistance, guidance or supervision”. However we submit that the drafting of many of the individual questions do not provide sufficient prompting to a carer to disclose the amount of supervision/prompting required to get the care receiver to undertake the activity.

For example, question 11 in the ADAT *Claimant questionnaire* asks: does the person “Shower or bathe himself or herself?” The answer choices are: ‘without help’, ‘with some help’, ‘with a lot of help’ and ‘cannot do this’. The form of the question and answers does not adequately address the situation of a carer of a person with a mental illness. It does not elicit details about the amount of prompting or supervision the carer must give to get the person to have a shower or bath. Similar issues arise with questions 10, 12, 13 and 14 which relate to dressing, eating, grooming and taking medication.

Further, any assessment tool needs to contain questions that seek information about the care needed and provided where a person with, for example, severe depression, requires constant supervision because of the risk of self-harm. NLA notes questions 17 and 19 in the DCLA *Assessment of care load questionnaire* allows assessment of care needed related to suicidal behavior and high risk behaviour. This type of care should also be assessed when someone is caring for an adult with a disability. The current ADAT only assesses deliberate self harm (at question 7 of Division C in the ADAT *Claimant questionnaire*) but not high risk behavior. NLA proposes that a new assessment tool measure the care needs covered by questions 1 - 8 of the ADAT *Claimant questionnaire*, as well as questions 17 and 19 of the DCLA *Assessment of care load questionnaire*.

### **Assessment of care needs of a person with an intellectual or cognitive impairments**

It is also important for any assessment tool to ensure appropriate questions are asked to assess the care needs of a person with an intellectual or cognitive

impairment. If the right questions are not asked this may result in an underassessment of care needs of people with intellectual or cognitive impairments.

### **Structure of assessment tools**

NLA submits that the structure of an assessment tool/questionnaire is equally important to accurately establish care needs and care provided.

NLA cautions against the use of 'yes' or 'no' questions which may direct a carer or treating doctor away from answering a whole series of questions about particular care needs. For example, the *DCLA Assessment of care load questionnaire*, question 10 asks "Does the child have severe behaviour difficulties?" If the person answers 'no' they are directed away from considering questions 10 to 21. We understand these type of directing questions are designed to reduce the amount of time a person must take to complete a form. However, they can be problematic as they may result in an underassessment of care needs.

Case study: Tran is the parent and carer of a child whose main disability involves progressive muscle wasting causing loss of mobility and loss of control/strength in their limbs. He assumes questions 10 to 21 of the *DCLA Assessment of care load questionnaire* do not apply to his child because he is focused on his child's physical functional limitations. However his child, due to frustrations with his physical conditions and a degree of cognitive impairment which developed from the physical symptoms, also needs supervisory care because he becomes aggressive towards others, including kicking, hitting and screaming. The 'yes' and 'no' options in question 10 of the *DCLA Assessment of care load questionnaire* may direct Tran away from answering question 13 (which covers behaviour that harms others).

### **Reduction in care provided**

NLA notes that in some situations the care provided by a carer may decrease over time as the carer themselves becomes disabled or frail. Following amendments to the eligibility criteria for DSP in 2011, there is a disincentive for an older carer, who is not yet Age Pension (AP) age, to declare this reduction in care provided if they are themselves disabled and unable to work.

Since the September 2011 changes to DSP, a carer may be very disabled but will not qualify for DSP as they are unlikely to meet the 'program of support' requirements. Most people only meet the program of support requirements once they have attended a job network provider or disability employment services provider for 18 months in the three years prior to their DSP claim. A carer faced with this qualification criteria for DSP may struggle to retain qualification for CP until AP age because they know they will not cope with Newstart Allowance activity testing and the lower rate of payment.

NLA proposes that amendments should be made to the DSP qualification criteria for people claiming DSP straight from receiving CP. If a person has been on CP for at least the previous three years, and they otherwise meet qualification for DSP, (i.e. awarded a total of 20 impairment points or more and have a continuing inability to work), the program of support requirements should not apply. An alternative to this proposal is to allow the carer to remain on CP while undertaking the 18 month program of support pre-requisite for DSP.

### **3. How can an assessment process recognise the varying frequencies of care activities and intensity of care?**

#### **Constant care**

NLA submits that the legislative requirement that the care be 'constant' be abolished. 'Constant care' is not defined in the legislation. The Department of Social Services' *Guide to Social Security Law* policy is that the care must be provided on a 'daily basis' for a 'significant period' each day.

In our experience it is the Department's definition of 'constant care' that has restricted a decision-maker's capacity to consider varying frequencies and intensity of care. Restricting CP to people who provide care for a 'significant period' each day fails to recognise the different caring needs of people with a disability. Some people with a disability need frequent care over a few days a week but less care on other days.

Case example: Jane provides care to her mother in their home. The mother suffers from seizures (as a result of brain damage), lupus, severe spinal condition, vision impairments and depression. Jane's claim for CP was rejected as she attends school three days a week (21 hours). However, she provides substantial care before and after school including toileting, feeding and showering her mother, and all cooking and cleaning. On the days she is not at school Jane has to do extra cleaning of the house (due to the mother's compromised immune system), take her mother to appointments and manage the household finances. Throughout the week she provides important care in respect of her mother's depression by providing targeted social interaction and monitoring her mother's behaviour.

NLA acknowledges that the policy intent of providing CP is to recognise that the carer is not able to undertake substantial employment because of their caring responsibilities. However the narrow interpretation of 'constant care' has precluded payment to carers who undertake more caring than someone in full-time employment. A person who provides 5 days care per week should be entitled to have a weekend (or equivalent two days) off from caring.

The Department's interpretation of 'constant care' also excludes some separated parents who care for a disabled child, both young children and adult children, as

shared care of children is often worked out across a fortnight not a week. In our experience a shared care arrangement where a child lives with one parent for 9-10 days a fortnight and the other parent 4-5 days a fortnight precludes either parent from receiving CP. This is notwithstanding that the parent with primary care of the child may be fully engaged in intensive caring of their child during the 9-10 days the child is in their care, and use the time where the child is out of their care to catch up on grocery shopping, cleaning and sleep before the child returns to their care.

One way of addressing these concerns is assessing care needs over a fortnightly, rather than weekly period. Another option is the legislation providing for a minimum amount of hours of care that must be provided over that fortnight.

Case example: Jemima is the primary carer of two children with severe behavioural disabilities. Following Family Court proceedings the children spend nine days a fortnight in her care and five days a fortnight with their other parent. As a result of the new orders Centrelink cancelled her CP.

Jane's caring responsibilities do not suddenly stop when the children are with their other parent. Jane is still the parent who is called up to the school when there are problems with the children's behaviour, which happens frequently. She takes the children to all medical and psychologist appointments, even on the days the children are in the other parent's care. She does all her shopping and cleaning while the children are absent, as she cannot do those activities when they are in her care.

### **Assessment to include schedule of care being provided**

NLA proposes that as part of the assessment process a carer should be invited to note any particular time-intensive caring activities. For example, if the carer needs to attend to the care receiver numerous times throughout a night, this information should be able to be taken into account. This allows consideration to be given where 'extra' care is needed and provided, rather than just taking into account information captured through a tool that simply measures if 'the care receiver required attention throughout the night'. This will lead to a more accurate assessment of the care needs of the care receiver and the nature and level of care being provided.

One option is to include a schedule with a CP claim form where a carer can include a snapshot of the care they provide across a set time period, such as a week or fortnight. This would allow the carer to articulate on a running basis how much care is given across the day for particular tasks, and how often care is provided of a supervisory or personal nature.

### **Mental health conditions**

Any assessment tool needs to provide sufficient scoring or weighting to ensure recognition of the caring needs of people with a severe mental illness whose intensity may fluctuate.

### **Caring for a person in a nursing home or hospital**

Under current eligibility rules, a person can qualify for CP if caring for a person in their home, which includes a situation where the care receiver is in a nursing home. However, the current rules do not contemplate the long-term payment of CP in a situation of a carer who provides (or continues to provide) care to someone in a hospital in addition to the care provided by nurses/doctors. Currently, the carer would continue to qualify for the first 63 days the care receiver is in hospital under the respite rules, but after that is not qualified.

NLA submits that there should be an assessment of the care provided by the carer in a hospital if the person being cared for remains in hospital for longer than the 63 days covered by the respite rules. If the care being provided in the hospital meets the CP conditions, the payment should be continued.

### **Abridged claim option**

NLA notes that there may be situations where a care receiver's care needs may vary in intensity over time. For example a person with a mental illness may have periods where they do not require care and at other times need constant supervision and monitoring. The process for claiming payments, especially CP, can be arduous and act as a disincentive for a carer to tell Centrelink in periods when their caring is not required.

NLA submits that guidelines should be introduced to allow carers who care for a person with care needs that may vary over time, to reclaim CP (within a prescribed period of time) without going through the full claims and assessment process. A similar abridged claims process exists for disability support pensioners who go off payment due to employment.

## **4. Are there differences between caring for adults and caring for children?**

NLA considers that it is difficult to assess adult and child care needs using the same assessment tool or process due to the intrinsic care needs of all young children. However as detailed above, NLA considers there are a number of favourable features of the DCLA that should be retained and should be applied in an assessment process for carers of adults.

NLA supports extending qualification for CP to a person who cares for two disabled adults. This would make it consistent with the way that a person can qualify for CP on the basis of combined care of two disabled children. For example, a person caring for two elderly disabled parents should be able to have their care needs assessed together.

## **2. Impact of medical conditions on functionality and requirement of care**

**5. Are there situations where one care activity is needed, and therefore it is certain that another care activity would always be required?**

NLA has no comments to make in response to this question.

**3. Impact of developments in medical diagnoses and treatments on care**

**6. What is the role of technology in reducing or increasing the caring role? How can we determine the right balance?**

As noted in the *Guide to Written Submissions*, advances in technology may have an impact on carers. Technology may increase or decrease a person's care needs. Importantly for CP assessment purposes, any improvement in treatment and therapies available to people with a disability needs to be considered. It may be that treatment that was previously only available in hospital can now be provided at home with the assistance of a carer trained in providing that treatment. It may be that treatment or therapies exist where previously there was nothing that could be done to improve the situation of the person with the disability.

It is therefore important that any assessment process or tool asks questions about treatment provided by the carer in the home, for example, as suggested in the *Guide to Written Submissions*, dialysis or daily exercises/physical therapy. We have case experience of the dialysis example. The current ADAT does not assess this type of care provided, even though it may be very time consuming.

This also provides another basis to allow carers and treating health professionals to set out the exact nature of care given in any CP or CA assessment process, not just to 'tick a box'. For example, setting out where, due to technology, care is provided at home in lieu of hospital treatment.

**4. Impact of caring on carers' capacity to do other activities**

**7. What is the reasonable time, pattern of time, and purpose to be away from caring?**

**'25 hour rule'**

NLA acknowledges that CP is paid as income support for a person who is 'working' as a carer. However NLA submits that the Department of Social Services current policy to cancel or refuse CP for a person who is absent from caring for more than 25 hours per week due to work, study or volunteering is unduly harsh and applied inflexibly. For example, LANSW is aware of carers whose CP has been cancelled because their part-time work (including travel time) absents them from caring for 26 or 27 hours, yet the person also provides well in excess of 40 hours caring per week.

The '25 hour rule' acts as a disincentive to working, studying or volunteering and therefore may lock the person out of future workforce participation if the person's caring role ends. This is particularly an issue for people caring for elderly parents or people with terminal illnesses.

Case example: Mary provides care to her elderly mother in their home. She works three days per week (21 hours) in her employment, but with travel time she is absent from the home for 27 hours. Her CP was cancelled. Aside from the 27 hours per week absence, she provides '24/7' care to her mother who cannot be left alone due to numerous physical conditions and dementia. While Mary is at work her mother either attends a day program or is cared for by one of her other adult children. Mary's employment pays very little but it give her an opportunity to leave the home, engage with other people, undertake non-caring tasks and, importantly for a carer of an elderly person, keeps her in the workforce.

Rather than limiting how many hours a carer can work, study or volunteer, NLA proposes that to qualify for CP a person must provide a minimum number of hours of care. This could be the equivalent of full time employment. We note that as an income test applies to CP, income earned by a carer reduces their need for taxpayer funded income support.

We thank you for the opportunity to make this submission. Please do not hesitate to contact us if you require any further information.

Yours sincerely,



Gabrielle Z Canny  
Chair