Submission to the Department of Social Services Review:

Improved Assessment Process for Carer Payment and Carer Allowance

November 2015
About NWRN

The National Welfare Rights Network (NWRN) is the peak community organisation in the area of social security law, policy and administration. We represent community legal centres and organisations whose role is to provide people with information, advice and representation about Australia's social security system.

NWRN member organisations operate in all states and territories of Australia. They are organisations which have community legal services and workers dedicated to social security issues. Their services are free and they are independent of Centrelink and government departments.

The NWRN also has as Associate Members the Central Australian Aboriginal Legal Aid Service (CAALAS) and the North Australian Aboriginal Justice Agency (NAAJA). The NWRN develops policy about social security, family assistance and employment assistance based on the casework experience of its members. The Network provides submissions to government, advocates in the media and lobbies for improvements to Australia's social security system and for the rights of people who use the system.

Part A Overview

The Commonwealth currently provides two payments to support carers, Carer Payment and Carer Allowance. There is also an annual one-off payment, Carer Supplement, paid to recipients of these payments and a Carer Adjustment Payment.

The rationale for these payments is that people who have caring responsibilities and, as a result, are unable to support themselves through paid employment or other means, should...
receive public income support. This reflects the value the community places on supporting those who take on a significant caring role.

In 2014-2015 the cost of Carer Payment was $4.19 billion, Carer Allowance was $1.97 billion and Carer Supplements were $6.86 billion. ¹

As the Carers Australia Federal Budget Submission 2014-2015 noted “Australia’s 2.7 million family and friend carers are an integral part of Australia’s health system and are the foundation of our aged, disability and community care systems. Access Economics estimated in 2010 that carers provided 1.32 billion hours of unpaid care each year and that it would cost $40.9 billion per annum to the Australian economy to replace their care with formal care services”.²

**Carer payment**

Carer payment is paid to people who personally provide “constant care” to one or more adults or children with a disability in their home and care is expected to be needed for at least 6 months, unless the condition is terminal. As at 30 June 2015, there were 255,542 recipients of carer payment of whom 111,406 (around 43%) were over 55 and 173,719 (around 67%) were over 45.³

The maximum rate of carer payment is the same as for the age pension and disability support pension. The carer is also subject to the same indexation and means testing arrangements as for the age and disability support pensions. However, there is also a separate additional means test for the person receiving care.

**Carer allowance**

Unlike carer payment, which is intended to provide a basic level of income support on its own, carer allowance is a supplement, currently $121.70 per fortnight or around $3,000 per year. It can be paid in addition to another income support payment, including carer payment. Care must be provided on a daily basis to a person with a disability in their home and be expected to be needed for at least 12 months. The person cared for must be a child under 16 or adult who requires substantially more care because of disability or a medical condition.

In addition, if the carer and the person cared for do not live together, there are additional eligibility criteria, which are that the care must be for at least 20 hours per week and be related to the care receiver’s bodily functions or sustaining their life.

As at 30 June 2014, there were about 601,364 people receiving carer allowance, of whom 288,433 were over 55 (around 48%), and 415,537 were over 45 (around 69%).

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¹ DSS (2015) Portfolio Budget Statements 2014-2015, Table 2.1.9, page 77
² Carers Australia Federal Budget Submission 2014-15 Unpaid Carers: the necessary investment, p 1
Most recipients of carer payment also receive carer allowance and this is automatic if the care receiver is a child.

**Carer supplement**

Carer supplement is an annual one-off payment of $600 to eligible carers for each person in their care.

**Part B Submissions**

1 **Reform should not narrow eligibility**

Although the number of recipients of carer payment is projected to grow significantly, this does not warrant any restriction in eligibility criteria or reduction in rates of payment. The number of recipients of carer payment has been growing at a significant rate. It is projected to continue to do so. However, this is of itself no basis for further restricting access to carer payment or reducing rates of payment.

Clearly, one of the main drivers of this growth in recipients is the ageing population. The 2015-2016 Budget stated that the growth is “largely as a result of growth in Carer Payment and Carer Allowance (adult) payments predominantly driven by the increasing number of frail aged Australians receiving care at home.” Another likely driver is the increase in the qualification age for Age Pension, meaning that more people who might have simply qualified for the age pension will qualify for the carer payment.

The July 2006 welfare to work changes and the January 2013 changes to parenting payment single which now means single parents with a youngest child over 8 now receive newstart allowance, and the September 2009 unlinking of parenting payment to the pension rate have meant that single parents of disabled children face a serious adequacy issue unless they can obtain a carer payment.

Similar concerns about the growth of a particular welfare cohort were used to justify the restriction of access to the disability support pension, which has seen thousands of people forced to rely on the poverty level newstart allowance. The NWRN is very concerned that a similar mistake should not occur in relation to support for carers.

As the population ages, and more and more people take on significant caring responsibilities, it is appropriate for the community to continue to provide income support at least at the current level. Linking carer payment to the age pension is appropriate, given the significant period carers may be out of the workforce.

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5 Ibid

A substantial proportion of carer payment recipients exit onto another income support payment, such as newstart allowance or age pension. The McClure Report observed that “over 63 per cent of carers who exit from Carer Payment before Age Pension age transition to another form of income support such as Newstart Allowance. Two out of three individuals receiving the Carer Payment in 2011 remained on income support three years later.”

Measures to improve the entry of carer payment recipients into paid work, once their caring responsibilities reduce are very important.

However, the NWRN remains concerned that similar issues were raised in relation to the disability support pension and resulted in unjustifiable restrictions on eligibility. As the example of the disability support pension shows, restricting eligibility has not led to improved employment outcomes for that cohort. Rather it has simply moved them onto the lower newstart allowance, not into employment.

A 2015 Melbourne Institute Working Paper found that “(t)he suggestion is that disability reforms need to do more than simply reduce the generosity and tighten the conditionality of payments – with the associated risk of exacerbating the already high levels of poverty experienced by people with disability in some countries (e.g. OECD, 2010) – if they are to substantially impact on welfare dependence among people with disability. People with disability face barriers to employment that these measures, in isolation, are unlikely to overcome.”

Our view is that any restriction to eligibility for carer payment would have the same impact, simply shifting this group onto other (lower) payments rather than addressing the real barriers to employment. This would disproportionately affect older women, as our experience is that most carer payment recipients are women over 50. We believe it likely that the main reason for poor employment outcomes for this group, when they exit carer payment, largely reflect their age and the other major barriers to employment this cohort face. We reject as offensive the unsubstantiated claim, made in the National Commission of Audit report, that “it may be that Carer Payment is being used by some people as a way of maintaining an income until they reach Age Pension age”.

2 Measuring the care needed

Clearly, public spending can only be justified on the basis that care is both needed, and that it is actually being provided.

NWRN considers that both objective medical evidence from treating health professionals and subjective carer evidence of care needed must be considered in the assessment of carer entitlement. Health professionals such as doctors can provide objective, professional

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9 Ibid
information about diagnosis, treatment and functional impact on ability and resulting care needs for a person with that disability.

It is important the carer also provide evidence as to care needs in order to obtain an accurate picture of the care required by a particular child or adult with a disability. This is because only the carer can provide information about the specific care needs arising for that person in their care environment.

We would strenuously oppose any steps down the path of administrative processes which may limit evidence gathering of care needs to “raw” medical evidence as has been recently implemented for DSP claimants with the removal of the Treating Doctors Report as a required source of medical evidence in the assessment of eligibility for DSP.

It is necessary, when looking at the hours of care being provided, to look beyond what would usually be required for a person’s condition, to what the real care needs are for that person.

When assessing hours of care, there should also be a question for whether other non-medical factors, such as remoteness, social isolation, social skills, lack of literacy or numeracy, being from another cultural background and not able to learn English, or other disadvantage may be exacerbating their care needs. Clearly, it would not be enough that those factors exist, they would need to materially impact on the day to day care needs in order for an assignment of points. We note that the DCLA for assessing children has a question like this. It asks about “any other effects on your daily routine, ability to take up paid employment, your health, social activities or emotional effects”.

Scenario 1: Jenny has to drive her sister Marcie 1.5 hours each way, 3 times a week, to access dialysis treatments at their nearest hospital. Marcie is unable to drive herself, is unable to use public transport and there are no volunteer drivers to assist with transport. Their remoteness means that her carer spends 9 hours per week driving as part of the care she provides, which leaves her less time to do other caring tasks and less time to be able to look for work.

Scenario 2: Tom and Bill are both blind.

Tom lives in Sydney and has a degree in social work, with support services to get him to work and a workplace that has installed various modifications and technologies that enable him to work 4 days a week. Tom requires care at home, which his wife provides, but his house has a number of modifications and he is able to perform many key tasks independently.

Bill lives in a remote Indigenous community. He is illiterate. He has lived with a number of relatives but struggles to adapt to new physical environments and carers. He is currently being cared for by two aunts, one whose house he goes to during the day, the other whose house he is at in the early morning, evening and night. He

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11 Scenarios we provide in our submissions are drawn from our casework experience, but are not based on any one particular client. Where an example is a summary of the experience of a particular client it is instead referred to as a “case study”.

is unable to perform many key tasks and becomes disoriented easily. He sometimes struggles with depression. He requires care during all waking hours (6am to 11pm – 17 hours per day) and sometimes at night. He requires well over 80 hours of care each week.

Clearly, while they have the same condition, Bill’s care needs are exacerbated by his illiteracy, unstable care arrangements and remoteness. His care needs are higher to the point that several carers may provide more than 40 hours each of care each week.

In some cases we see, people need 24 hour “around the clock” care from their carers.

It is reasonable to assess care needs based on supports that are actually available, but care must be taken not to move to assessment based on supports that are only theoretically available. 12

It is important that any assessment process be able to recognise the higher care needs that can arise from dual/multiple disabilities.

It is worth noting that a list of disabilities that automatically meet care needs requirements can result in administrative simplicity, but may also create an arbitrariness that can result in people who have an equal or higher caring load being assessed in a different manner.

Given the rationale for carer payment, better assessment is needed of how patterns of care impact on ability to work. The DCLA form asks a general question about the impact of caring on the person’s ability to take up work (as well as in other areas like health, social activities and emotional – all of which may bear on the person’s ability to look for or maintain work).

It should also be possible to add the scores of all the people being cared for (see our recommendations about rationalising the payments below) because a person providing the same hours of care to several carees as another person does for a single caree has the same impact on the carer’s ability to participate in the workforce and is presumably equally valuable to the community.

One of our member centres in Perth provided the following case study which illustrates this issue:

Case study: “We have a case of a sole parent with three dependents with cerebral palsy and the care needs of each individual young person (teenagers and 1 over 16) were not sufficient to qualify [the mother] for Carer Payment as all had care needs just below what was required to qualify, yet she was looking after three people with significant care needs. She was on the lower Newstart rate and given a temporary activity exemption but due to the combined care needs would be unlikely to get work.”

There is no justification for having more restrictive requirements for carer allowance in situations where the carer does not live with the care receiver. Carer allowance should

12 That is to say, the approach currently taken at xx Guide should not change.
respond to the level of care provided by the carer, regardless of whether the carer lives with
the person cared for overnight. Questions about whether carers who commute to provide
care are actually doing so is just another question of fact to be determined in the claim
process. Requiring a person to live with their care receiver is too blunt a tool to resolve that
question as it results in unfairness for people who provide equal or greater levels of care but
have to commute to do so (eg because they have other family they care for elsewhere). It
may also restrict the choice of carers for people with disability. The separate and more
restrictive requirements for carer allowance when the carer and care receiver do not live
together should be abolished.

This is both fairer and simplifies the payment and administration of carer allowance.

3 Measuring care provided

3.1 Need for both doctor reports and carer questionnaires

The doctor’s report goes to the disability/medical need, however the carer questionnaire
can provide more information about the actual care given (which may be impacted by
situational and non-medical factors). Both are important to get an accurate composite
picture of the care required, because there are aspects of care needs and care provided that
can only be provided by the health professional or the carer. In our experience, some care
receivers underestimate their care needs to their doctor, an example might be an older
person ashamed at the need for help showering, toileting, supervision etc, or a parent who
is focussed on emphasising their child’s ability rather than disability as one of our member
centres commented:

“our concern is when parents/carers fill out the ACL questionnaire they often over assess
their children’s functional abilities and under assess the level of care they as carers provide.
The ACL questionnaire does not accurately reflect the functional ability, behaviour and
special care needs of the child. This positive view allows parents to undertake and continue
to care for children living with disability. Unfortunately, this can result in carer allowance
being rejected even though the independent Dr’s report shows a high level of care is
required.”

3.2 Need to measure both active and supervisory care

The definition of care for purposes of carer payment and carer allowance should continue to
encompass both active and supervisory forms of care.

Many carers care for people suffering significant mental illness. Often this care takes the
form of supervisory or monitoring care, for example, ensuring that medication is taken and
personal hygiene is attended to.

Any restriction of “care” to purely active forms of care would unfairly discriminate against
carers of people suffering a mental illness.
The current medical questionnaire needs amendment to better accommodate mental illness. The questions are poorly worded and insufficient weight is given to care in the form of supervision and managing behaviours. The way the current form handles this issue is that at point 13, before the series of questions relating to independence/dependence in certain activities of daily living, it includes a general instruction in a box with a note that if a person needs supervision, they are not independent for the purpose of answering the question (and therefore will attract points on the questionnaire).

This is not unreasonable, but we observe cases where the person filling out the form has neglected this aspect. One option to redress this may be to add a specific box to each relevant question along the lines of “needs supervision or prompting”. At the very least, the text from the “Note” in point 13 onwards should be bolded.

Example 3. Tarek has chronic depression and anxiety. His mother has to make sure that he gets out of bed in the morning and that he showers, eats his meals, takes his medication, attends appointments, and participates in activities which help stabilise his mental health. If she did not do so, his mental health would rapidly decline. However, while he needs prompting, he is generally able to do these tasks himself. She also needs to monitor his mental state closely.

Question 10 is problematic in the sense that if you answer “improve”, you get pushed onto question 13. At the least, some clarification is needed so that instead of asking the temporally vague question of whether it will improve or not, ask something more like, “is the person’s current need for care likely to change in the next:

- less than 6 months;
- 6 months to 12 months; or
- 12 months or more.

Also absent from the medical form are questions about:

- care and supervision provided at night (question 7 only refers to care provide each “day”); and
- assistance to attend appointments and outings/activities.

It is also important to measure activities directly related to the care that may need to occur while the caree is absent (eg, time spent shopping, cleaning, catching up on lost sleep to the extent that they are directly related to the care needs of the care receiver).

The claimant questionnaire needs to include questions about broader aspects of care such as:

- assistance to attend appointments and outings/activities and the regularity of those activities;
- special dietary requirements;
- preparation of food;
• shopping; and
• cleaning.

4  Measuring frequency and intensity of care

4.1  Problems with the current definition of constant care

To be eligible for carer payment, a person must demonstrate that they are providing “constant care”. This term is not defined in the Social Security Act. According to DSS policy, it requires care for a “significant period”, equivalent to 8 hours per day, on a daily basis. This definition is too restrictive. The underlying rationale for carer payment is to provide income support to people who are unable to support themselves through paid work due to caring responsibilities. A person who spends 8 or more hours per day, 5 days per week, should not be expected to support themselves through paid work on the remaining 2 days per week. They have, in effect, a “full time job” as a carer which should be recognised as such.

DSS policy restricting carer payment to carers who care literally every day is especially harsh and unfair on separated parents caring for disabled dependent or adult children. A shared care arrangement whereby, for example, one parent cares most days but the child spends every second weekend with the other parent is sufficient to rule them out from qualifying for carer payment. Many shared care families have fortnightly carer arrangements. When assessing hours of care it would make sense to use a fortnightly period to better align overall care assessment with these care arrangements.

As a case study, we recommend reading a similar case involving shared care that one of our members ran: Halls and Secretary, Department of Social Services [2014] AATA 129. The Administrative Appeals Tribunal declined to apply DSS policy on constant care:

“Taking into account Jamie’s need for close supervision, and that he kept adult hours, we are satisfied that the intensity of care Mr Halls was providing when Jamie was at home roughly equated to a normal working day on each weekday. Realistically, to undertake substantial employment, Mr Halls would have had to work all day on Saturdays and Sundays when Jamie was with his mother. That would have amounted to roughly 15 hours a week which, combined with his caring responsibilities, would have been more onerous than most full-time jobs. We are satisfied that, at 17 August 2012, Mr Halls was unable to undertake substantial employment by reason of the high level of care he was providing to Jamie, which care was roughly equivalent to a full-time job. We are satisfied that he was providing constant care within the meaning of the Act to Jamie and so qualified for carer payment.”

Changes could be achieved by amending DSS policy, given the absence of statutory definition of constant care. The downside to this approach is that the lack of legislative definition of constant care continues to cause undue litigation. An alternative would be to
replace the phrase “constant care” with a more rigid definition such as a requirement that, for example, care be provided at least 40 hours per week, over a certain number of days.

The number of days may need to vary, depending on the nature of the care required. For example, a person providing care to an adult child with severe autism and violent behavioural issues for 16 hours per day 4 days per week may face similar barriers to obtaining or maintaining paid work as a parent of an adult child with intellectual disability but mild behavioural issues who is providing care 8 hours per day, 5 days per week.

When measuring care, it is necessary to include both active and supervisory care (see discussion on this at 3.2). It is also important to measure activities directly related to the care that may need to occur while the caree is absent (eg, time spent shopping, cleaning, catching up on lost sleep to the extent that they are directly related to the care needs of the care receiver). The case of Halls cited above is a good example of this. In that case, the carer also spent a significant part of each Saturday attending to his son’s care by way of shopping, washing and cleaning up after him.

5 Differences caring for adults and children

In the past, Carer Payment Child qualification was based on prescriptive lists of disability and denied access to the payment for people caring for seriously disabled children with extremely high care needs. Fortunately, changes in 2009 to carer payment child qualification and the introduction of the Disability Care Load Assessment tool have improved access to Carer Payment for parents caring for children with disability. While there may be some scope for improvement, this has resulted in a much fairer qualification and assessment process.

The Government’s stated policy intent of providing Carer Payment is to recognise that the carer is not able to undertake substantial employment because of their caring responsibilities. 13 It is appropriate to assess qualification for carer payment and carer allowance based on the hours and intensity of care provided.

However, the distinction for children and adults should be retained. Unlike adults, children, whether disabled or not, need assistance with a broader range of basic tasks, such as food preparation, bathing, etc. so different assessment processes are required. While there is always room for improvement, the current DCLA is a vast improvement on its predecessor. It is critical that assessments for children recognise that disability of a child increases the regular care needs of the child, and decreases work capacity. For example, a child may need a special diet or special routines and may be so difficult to feed, bathe etc that those tasks are considerably more onerous than for a child without a disability. Parents also report difficulty in meeting the needs of their other non-disabled children, eg because of constant interruptions and the higher needs of the disabled child. Assessment tools need to be able to capture the extra care (whether as preparatory, active or supervisory care) involved in what would otherwise be the ordinary care needs of children.

13 Guide to Social Security Law at 1.1.C.310
Rationalising the payments / equity and simplification

In the same way that the combined care for two disabled children can qualify a person, so too should it be possible for the combined care for two disabled adults qualify a person.

Qualification for children with a terminal illness is currently more generous than for adults with a terminal illness.

6 Reasonable time, pattern of time and purpose to be away from caring

Clearly, the current “constant care” definition needs to be discarded (see above). Someone providing 40 waking hours of care per week (whether day or night) is effectively working a full time job and should be entitled to the equivalent of a weekend (ie two days per week), on top of any respite care/temporary cessation of care requirement permitted.

NWRN will be guided by carer organisations as to how much respite care is needed. We recognise that a person who provides care 7 days per week may require more access to respite care/temporary cessation of care than someone providing, say 40 hours over 5 days.

Consideration needs to be given to extending portability rules in situations where a carer has no family support in Australia and needs to travel to family overseas for support.

Consideration also needs to be given to enabling carers to access indefinite portability if the person they are caring for is granted indefinite portability for DSP purposes and they will continue to provide the care overseas.

The limitation on the number of study/work/training a person may do while in receipt of carer payment operates as a trigger, so that if a person exceeds 25 hours per week of these activities, their eligibility may be reviewed. In practice however, it is often perceived (by clients, advocates and DHS staff) that doing 25 hours or more per week will automatically result in cancellation and therefore may work as a disincentive to study, work, volunteering or training.

The government will of course be looking at disincentives to work/study/train. The 25 hour per week rule may in theory create a disincentive to dip their toes into the employment market. However, in our experience, the reason carers do not work is because they are facing too many employment barriers, including caring responsibilities, age and so on. A quick survey of our members for the purposes of this submission revealed no cases where people consciously choose not to engage in work so as to maintain eligibility.

For carers who receive offers of short term work of over 25 hours per week (eg 4 month contract) it might be appropriate to revisit the policy around temporary cessation of care extensions for a special reason, such as where the employment is likely to positively impact on the carers ability to re-enter the workforce.
The transition from Carer Payment to other payments can be traumatic both in terms of the circumstances around the exit, and the move to lower rates of income support and different participation requirements. This is particularly so for long term carers, carers whose transition is connected to the death of a care receiver, and for aging carers who may have developed a disability of their own. These carers face extreme disadvantage in the labour market. For those who have a disability, transition to disability support pension may take several years where they do not have 20 points under one table and have not met the program of support requirements. During those years, the person is likely to receive newstart allowance and the drop in income may have negative impacts, including loss of housing etc. Encouraging voluntary participation in a program of support may be beneficial for carers who are unlikely to be caring for their caree (eg due to the care receiver’s age, terminal illness, likelihood of recovery) for greater than 2 more years. If the program of support works, the person may return to the labour market, if it doesn’t, a smoother transition to disability support pension is likely to result in greater stability and better long term wellbeing outcomes for the person.

7 Role of technology

Technology and new developments in treatment may increase the amount of treatment a person may be able to access in their own homes, or in their immediate community (eg mobile dialysis treatment). This may, for example, reduce the burden on carers to have to assist with travel to access medical appointments and treatment. Assessment tools, which should include points for time spent helping people attend appointments etc, should be flexible enough to adapt to changing technological and treatment advances now and into the future.

Core unchanging data should be prepopulated (eg, date of birth, date of citizenship, permanent disability eg Down Syndrome).

To reduce the load on doctors (and in turn on carers liaising with doctors) in situations where a new carer claims for a care receiver already in the Centrelink system, the new carer should not have to obtain fresh evidence of care needs if sufficient information is already held by Centrelink and there has not been a change in care needs. It may be necessary for a doctor to briefly certify that care needs have not changed. The new carer would of course still have to provide evidence of care provided by them.

Prepopulated data identified as potentially changing, but also identified as not likely to have changed, should be displayed asking claimants to confirm whether the data remains correct or has changed. Without such a prompt regularly clients accept that prepopulated information is accurate.

Where a person’s claim scores sufficiently on the THP, but fails based on the carer questionnaire, they should be able to lodge a new carer questionnaire and not have to submit a new THP and all the other information if they reclaim within a certain period (eg 6 months). This would reduce red tape for all parties. The same applies in reverse if the claim failed based on the THP score. Similarly, where a claim fails because a page of a form is
missing, it should be enough to provide that page (or have Centrelink call the doctor about the missing question) rather than require a whole new form to be completed.

It is important to enable both online and hardcopy forms for doctors and generally to improve the user experience for doctors. However, doctors who wish to use forms rather than online tools should be able to do so. Every possible step that can be taken not to discourage doctors from completing forms or providing information should be taken. Encouraging doctors to use online tools is fine, but channelling them to digital services against their preference could be counter productive.

8 Young carers

The government should investigate and put in place measures to support young carers. The NWRN’s clients often include young people with significant caring responsibilities for a disabled parent or grandparent. These responsibilities often exclude the young person from the ordinary social and educational opportunities young people should have. More support is needed for young people in this situation, although carer payment should continue to be paid in these circumstances. The current limitations on hours of participation can be a barrier for young people with substantial caring responsibilities.

The government should investigate and put in place measures to support young carers to transition back into the workforce, wherever possible.

9 Maintaining workforce connections

Maintaining connection with the workforce is desirable, where possible. The employment outcomes for people exiting carer payment are very low. Encouraging voluntary participation in employment services programs tailored to the needs of carers may help, but in our experience, as noted above, low employment outcomes for people exiting carer payment are generally due to labour market conditions that are not fixable by changes to social security law, including age discrimination. Limiting access to social security payments and use of the jobseeker compliance system cannot overcome the labour market forces operating against aged, long term carers exiting carer payment.

Of critical importance is the need to look at the rate and activity requirements for people on newstart allowance who have a partial capacity to work due to caring responsibilities. We note again the case study at section 2 above, of a mother caring for three children with Cerebral Palsy while receiving only newstart and with access to only a temporary exemption from the activity test.