

Comparative systems of assessment of illness or disability for the purposes of adult social welfare payments

Second Report

(Carers)

23 February 2016

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Introduction

Purpose of the report

This is the second report of the study of comparative systems of assessment of illness or disability for the purposes of adult social welfare payments. This report considers assessment systems for carer payments in relation to disability status of an adult cared-for person.

The purpose of the research, as set out in the RFT, is to examine systems for medical/disability assessment and review used in other comparable jurisdictions and to draw key learning for the Irish system.

Methodology

The research looks at assessment systems for adult carers payments in a number of OECD countries, using

- a review of relevant literature (including review of various online academic databases and legal databases)
- access to on-line information from social security authorities and others
- review of detailed evaluations of assessment systems (where these are available)
- contacts with key informants in the chosen countries.

The researchers first carried out a rapid review of assessment systems in a range of OECD countries (see Initial Review). On the basis of this study it was agreed to focus the research on Australia, Netherlands, New Zealand, Nova Scotia (Canada) and the United Kingdom (UK).¹

Structure of the report

In chapter 2, we provide a short overview of issues concerning support for carers drawing on the available literature. Chapter 3 provides an overview of the assessment systems in the five jurisdictions. Finally chapter 4 discusses the relevance of the findings to the Irish system. The detailed country reports are set out in the Annexes.

¹ Strictly speaking we focus here on the system in Great Britain as the Northern Irish system is legally separate and is not covered in most GB studies.

Support for carers – an overview.

Introduction

The importance of support for carers has increasingly been recognised in a range of EU and OECD countries.² Give the increased ageing of the population in developed countries and other socio-economic changes, there is an increased need for care in many countries. Many countries have recognised the advantages (both financial and otherwise) of supporting informal care (see OECD, 2011). As discussed in the OECD study (chapter 4), countries have introduced a wide range of supports for such care including policies such as care leave, respite care, counselling and training. Payments for care – whether to the carer or the care recipient – also form an important part of these policies, although the range of policies is not always well co-ordinated at a national or local level.

The broader policy issues about support for informal care fall outside the scope of this study which focusses on the assessment systems for adult carers payments and their relevance to Ireland

Overview of supports

In contrast to the vast literature on sickness and disability related issues, there is a much more limited literature of support for carers. However, a number of recent studies do discuss the approaches which have been taken to supporting carers (Courtin et al., 2014; Hoffmann and Rodrigues, 2010; OECD, 2011; Riedel and Kraus, 2011).

The OECD (2011) report of supports for care states that less than half of OECD countries have a payment to carers and this includes payments in the Nordic countries where carers are ‘employed’ by municipalities. Other countries have payments directly to the person needing care to assist in the cost of care needs although the OECD reports that about 20% of countries do not have any specific care payment (and some of those which do, do not have national payments).

Based on the above studies, there appear to be three main types of payments to support caring of relevance to this study:

- Income support payments to carers similar to the Irish carer’s payments (mainly Anglophone countries)
- Payments to care recipient which include costs of informal care (continental Europe).
- Payments to carer as part of a care agreement (Nordic countries).

Income support

The countries with income support payments for carers similar to the Irish carer’s allowance and benefit are mainly Anglophone, i.e. Australia, New Zealand and the UK. Canada does not have a national payment but one province does (Nova Scotia). These are non-

² For recent studies of informal caring and supports for carers in a range of developed countries see Courtin et al., 2014; Hoffmann and Rodrigues, 2010; OECD, 2011; Riedel and Kraus, 2011.

contributory benefits which are generally subject to a means-test or income test in some form (see country reports for details). The OECD study (2011, 133-134) highlighted the fact that these type of payments generally create disincentives to work for the carer.³

Payments to meet care needs

In contrast to the first approach, this involves payments (normally to the care recipient) to meet assessed care needs which can also allow the use of the payment to support family carers or even to hire family members formally. A number of Continental European countries – including Germany, the Netherlands and Flanders (Belgium) – have introduced care insurance schemes which include these type of cash payments as part of overall support for care needs. The Netherlands care payment has been reformed as part of a recent change in the legislation concerning care (Wet langdurige zorg) which came into effect on 1 January 2015.⁴ This is very different to the Anglophone countries and forms part of an overall care insurance system. Originally, this was paid to the care recipient but, as part of the reforms, the payments for caring is now paid to the carer by the social insurance authorities (see Netherlands country report below).

Payments to carer as part of a care agreement

The Nordic countries do have payments to carers but these are administered at municipal level and involve a form of ‘employment’ of the carer by the municipality as part of broader supports to carers. This involves a ‘care agreement’ between the carer and the municipality. For example, in Finland, the care receiver’s municipality of residence is responsible for arranging support for informal care.⁵ The issues related to support for informal care are managed by a home care supervisor or a social worker responsible for elderly or disability services. When an application is made, the person who is responsible for support for informal care will make a home visit to assess the need for care and services.

Under section 3 of the Act on Support for Informal Care, a municipality can grant support for informal care if

- a person needs care or other assistance at home because of reduced functional capacity, illness, disability or some other comparable reason
- a family member or another person close to the care receiver is ready to take responsibility for nurture and care with the help of necessary services
- the carer’s health and functional capacity meet the requirements for providing informal care
- informal care is, jointly with other necessary social and health care services, sufficient regarding the care receiver’s well-being, health and safety
- the care receiver’s home is suitable for care in terms of health and other circumstances

³ For a study of issues concerning carers and workforce participation in Australia see Ganley (2009) and for the UK see Vickerstaff et al. (2009) and Fry et al. (2011).

⁴ Because of its recent introduction, very limited information is available in English.

⁵ See <http://www.omaishoitajat.fi/support-informal-care-situations>

- it is estimated that the support benefits the interests of the person receiving care

The carer must be a family member or another person close to the care receiver. There are no age limits to support for informal care, and the law applies equally to parents of children with disabilities and children caring for their elderly parents. Approximately half of the persons receiving care are spouses with an illness or disability.

The services required by the care receiver, care allowance and leave for the carer, and services that support informal care are defined in a 'care and service plan'. The carer's need for social services to support informal care is also assessed when making the care and service plan. The care and service plan is made in collaboration with care receiver and carer.

Municipalities decide the number of payment categories and criteria for support for informal care within the limits of the law. Family income and wealth do not affect the amount of payment. Care allowance is taxable income. The amount of care allowance has different categories depending on the level of commitment and intensity of care. In 2015, the minimum care allowance for informal care was €385 per month. It is possible to apply for support for informal care during a burdensome transition period in care. The amount of this support must be at least €769 per month. For instance, an end-of-life care situation or care receiver's recovery from a serious surgery constitutes such a transition period.

Studies of care assessment

As discussed in the First Report on incapacity benefits, there are a significant number of studies both comparative and at a national level of the assessment of sickness and long-term disability payments. In contrast we did not find any comparative studies of assessment of care payments. Indeed, even at a national level there have been very few detailed studies of care assessment in the countries examined here. National reports (where they exist) are discussed in the country reports.

Carers assessment in five jurisdictions

This section addresses the key questions identified by NDA in the RFT (see Annex 1) in relation to the five jurisdictions, i.e. Australia, Netherlands, New Zealand, Nova Scotia and the UK.

Overview of supports for care

On the basis of the Initial Review it was agreed that the following five jurisdictions would be selected for detailed study:

Table 1: Benefit studied

Country	Scheme	Description
Australia	Care allowance/payment	Allowances for carers who provide (i) additional daily care and attention or (ii) constant care for a person with a disability or medical condition, or who is frail aged. Care allowance is non-contributory and non-means tested ⁶ but care payment is means-tested
New Zealand	Supported living payment	An income-tested assistance for people who are caring for someone with a health condition, injury or disability.
Nova Scotia	Caregiver benefit	A non-contributory payment to a carer of low income adults who have a high level of disability or impairment. The benefit is subject to an income test on the care receiver
Netherlands	Wet langdurige zorg (WLZ)	A system of care insurance which includes payments in respect of care
UK	Carer's allowance	An income-tested benefit to a persons who provides significant care to someone with a serious long-term health condition or disability

As set out in Table 2, there is considerable variation between the different countries in terms of the number of adult carers who are supported per 100,000 population.⁷ Although this is a somewhat rough indicator, it does show the very large variation in levels of support for carers. However, there are also significant variations in the rate of payment as set out below.

⁶ Similar to Irish Domiciliary Care Allowance.

⁷ The New Zealand data do not distinguish between adult and child care recipients.

Table 2: Level of support for carers

Country	Population (M)	No of carers in receipt of benefit	Funded carers/1,000 population	Maximum weekly payment ⁸ (€)
Australia	23.1	221,954 (CP) & 430,738 (CA) ⁹	9.6 (CP) & 18.7 (CA)	254 (CP) & 40 (CA)
<i>Ireland</i>	<i>4.6</i>	<i>61,149</i>	<i>13.3</i>	<i>204</i>
Netherlands	16.8	n/a	-	n/a
New Zealand	4.5	8,684	1.9	180
Nova Scotia	1	1,800	1.8	60
UK (Great Britain)	62.3	738,000	11.9	83

In terms of numbers in receipt of benefits, this ranges up to a high of at least 19 per 1,000 in Australia.¹⁰ However, this relates to the carer's allowance which is payable at a lower weekly rate than the other payments considered here. In terms of the higher rates of payments, the range is from about 10-12 per 1,000 in Australia and the UK to a low of less than 2 carers per 1,000 in New Zealand and Nova Scotia. It should be noted that the Nova Scotian payment was only introduced in 2009 and the numbers in receipt of benefit have been rising rapidly. Ireland falls at the top of the range.

⁸ Rate is for a single person.

⁹ There is an overlap in that many claimants of CP also receive CA but the precise numbers are not published by the DSS.

¹⁰ As some proportion of those on carer payment do not receive carer allowance, the total is somewhat higher than 19.

Nature of care criteria

The care criteria vary somewhat from one system to another as set out in tables 3 (care recipient) and 4 (nature of care).¹¹

Table 3: Care criteria for care recipient

Country	Payment	Criteria
Australia	Carer payment	An adult with a physical, intellectual or psychiatric disability assessed as needing constant care
Australia	Carer allowance	An adult with a disability or medical condition who requires permanent care
Netherlands	Personal care budget (PGB)	A person must need the type, extent and contents of the care, and s/he must also have to rely on this from the point of view of effective care, since because of medical or psychogeriatric restrictions or psychic or physic disability s/he permanently needs: <ul style="list-style-type: none"> a) Supervision in order to prevent escalation or serious harm for the insured, or b) 24 hours a day care in his or her neighbourhood since (1) s/he is not able to call help at relevant moments and because of physical impairments needs permanent attendance, nursing or relief of caring for himself or (2) because of serious problems of controlling the situation s/he needs permanent attendance and taking over of his or her tasks
New Zealand	Support Living Payment (Care)	A person who would otherwise have to receive care that is, or is equivalent to, hospital care, rest home care, or residential disability care
Nova Scotia	Caregiver Benefit	A person who has a MDS-HC (InterRai) assessment ¹² completed by a continuing care coordinator and demonstrates a very high level of functional impairment
UK	Carer's Allowance	Person must be in receipt of a qualifying benefit: Personal Independence Payment (PIP) daily living component (or predecessor payments)

In New Zealand the carer *cannot* be the carer's husband, wife or partner but this is the only jurisdiction where such a restriction now applies.

In general, the care recipient must be in need of a certain level of care. In the UK, the person must be in receipt of a payment which itself involves an assessment of the level of care need. The level of care required is defined to a greater or lesser extent by the national laws, regulations and guidelines:

¹¹ The tables provide summary details only and the full care criteria are set out in the country reports. We do not include here other qualification requirements such as residence or means/income.

¹² The Minimum Data Set-Home Care (MDS-HC) assessment is a structured system of assessment of care needs and is described in more detail in the Nova Scotia country report.

- In Australia, the care recipient must be assessed as needing a certain level of care under the Adult Disability Assessment Tool (ADAT) which has been developed specifically to assess care needs for the purposes of carer's payments.
- In the UK, the person must be in receipt of a disability payment (currently the Personal Independence Payment) which itself involves an assessment of the degree of disability and need in line with the PIP assessment tool
- In the Netherlands the person must need the care and, due to disability, must need supervision in order to prevent escalation or serious harm, or must need 24 hours a day care in his or her neighbourhood as s/he needs permanent attendance
- In Nova Scotia, the care recipient must be assessed as having a 'very high level of functional impairment' in line with a general tool used for assessing and prioritising care needs (MDS-HC). Nova Scotia currently utilises the InterRAI Home Care Assessment System. This is the same tool that has been selected as the single assessment tool by the HSE for its care needs assessments for older people, and is now being rolled out in Ireland in a number of trial settings.
- In New Zealand, a rather different approach is taken whereby the care recipient must be otherwise in need of institutional care.

There is less variation in the care criteria for the carer. In general, the carer is required to provide full-time or constant care to the care recipient. In some countries the number of hours is specified (20 hours of assistance with ADLs and/or IADLs in Nova Scotia or 35 hours in the UK). In other cases, e.g. New Zealand, there is no specific definition of 'full-time'.

Table 4: Care criteria for carer

Country	Payment	Criteria
Australia	Carer payment	Personally providing constant care, i.e. for a 'significant period' each day which is taken to be the equivalent of a normal working day
Australia	Carer allowance	Personally provide daily care and attention (no minimum hours specified)
Netherlands	WLZ	To provide care as required by the care recipient (no minimum hours specified)
New Zealand	Support Living Payment (Care)	Caring full-time for someone at home (no specific definition)
Nova Scotia	Caregiver Benefit	Providing 20 or more hours of assistance with ADLs ¹³ and/or IADLs ¹⁴ per week to a qualified care recipient
UK	Carer's Allowance	Be regularly and substantially engaged in caring for a 'severely disabled' person for at least 35 hours per week

¹³ Activities of Daily Living which are defined as 'Everyday tasks necessary for individuals to live independently, including hygiene, toileting, bathing, dressing, feeding and mobility'.

¹⁴ Instrumental Activities of Daily Living defined as 'Tasks that, in addition to activities of daily living, one must be able to perform in order to live independently. They differ from ADLs in that direct contact with the individual receiving the assistance is not required to perform the act. Examples include shopping, meal preparation, laundry and light housekeeping, banking and assistance with the management of medications'.

In general, the person providing care does not have to live in the same house as the person being cared for.¹⁵

System of assessment of care

There is considerable variation in the approach to the assessment of care (table 5).

Table 5: Assessment of care

Country	Payment	Decision maker	Assessment tool
Australia	Carer payment & allowance	Social security official	Adult Disability Assessment Tool implemented by health professional
Netherlands	PGB	CIZ	Assessment in line with 'care profiles' by multi-disciplinary CIZ
New Zealand	Support Living Payment (Care)	Social security official	Medical report by GP with possible further examination by health care professional ¹⁶
Nova Scotia	Caregiver Benefit	Continuing care co-ordinator	Minimum Data Set-Home Care (MDS-HC) assessment tool
UK	Carer's allowance	Social security official	Assessment by health professional using PIP assessment tool

In the case of Australia and the UK, assessment is on the basis of a specific assessment tool developed for the purposes of the benefit (or, in the UK, for the Personal Independence Payment). In Australia, to determine eligibility the care needs of people receiving care are assessed using a common methodology: the Adult Disability Assessment Tool (ADAT).¹⁷ The introduction of a single methodology for both benefits followed a recommendation to review the assessment process for Carer Payment and Carer Allowance to overcome the perceived subjectivity and inconsistency of the previous process.

The ADAT comprises two questionnaires, a *claimant questionnaire* and a *professional questionnaire* (or medical report), both of which are designed to assess the '... disability, emotional state, behaviour and special care needs of an adult.' In summary:

The ADAT measures care needs in terms of how much assistance an adult requires with basic activities such as eating, bathing and behaviour management. In doing so it takes account of the adult's physical, cognitive and/or behavioural disabilities. The ADAT is effective regardless of the type of disability or medical condition the adult

¹⁵ There are several Australian cases about whether a person who is not co-resident still satisfies the criteria. See, for example, *Adams v Secretary, Department of Families, Housing, Community Services and Indigenous Affairs*, [2012] AATA 507.

¹⁶ However, in practice, it appears that the NZ authorities usually require a needs assessment under the health systems (see country report).

¹⁷ See the Adult Disability Assessment Determination 1999.

may have. The ADAT does not assess higher activities of daily living such as managing finances, housework, cooking, shopping, laundry or gardening.¹⁸

A carer completes the claimant questionnaire and must then arrange for a treating health professional¹⁹ to complete the professional questionnaire. The treating health professional can be the cared-for person's treating doctor. Both questionnaires are of a 'tick box' design with multiple responses to each question. This is described in more detail in the country report. The Adult Disability Assessment Determination 1999 then specifies a five step procedure for scoring the questionnaires. Each questionnaire results in a score and to qualify for the benefits an adult must obtain a minimum score on the professional component as well as a minimum combined or overall score. The minimum scores required to qualify for Carer Payment and Carer Allowance differ.

In the UK, the PIP assessment is based on how a person's condition affects them, rather than the condition itself. To qualify for PIP, unless they are terminally ill, a person must have needed help with extra costs caused by a health condition or disability for three months or more and be reasonably likely to need help for the next nine months

Claimants initiate a claim by phone and are sent a form to complete. When submitting the form claimants are advised to submit any supporting evidence they already hold and are asked to provide details of the health professional who they consider to be best placed to provide evidence about their condition. Claim for PIP are assessed by an independent healthcare professional from Atos Healthcare or Capita Health and Wellbeing. A health professional may contact the claimant's doctor for factual information about their patient's condition. This additional evidence will be crucial in deciding whether someone needs a face-to-face consultation. Patients give consent for this to happen as part of their claim.

The PIP assessment looks at an individual's ability to carry out a series of key everyday activities.²⁰ These include *daily living* (i.e. preparing food, taking nutrition, managing therapy or monitoring a health condition, washing and bathing, managing toilet needs or incontinence, dressing and undressing, communicating verbally, reading and understanding signs, symbols and words, engaging with other people face to face, making budgeting decisions) and *mobility* (i.e. planning and following journeys and moving around). Each activity contains a series of descriptors which define increasing levels of difficulty carrying out the activity. A numeric score is allocated to each descriptor. For example, the descriptors (and associated points) in relation to the activity of 'washing and bathing' are can wash and bathe unaided (0), needs to use an aid or appliance to be able to wash or bathe (2), needs supervision or prompting to be able to wash or bathe (2), needs assistance to be able to wash either their hair, or body below the waist (2), needs assistance to be able to get in or out of a bath or shower (3), needs assistance to be able to wash their body

¹⁸ Australian Government, 2015, section 1.1.A.78.

¹⁹ These are a legally qualified medical practitioner, a registered nurse, a physiotherapist, an occupational therapist, a member of an Aged Carer Assessment Team or an Aboriginal Health Worker (in a geographically remote area).

²⁰ See https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/449043/pip-assessment-guide.pdf

between the shoulders and waist (4), cannot wash and bathe at all and needs another person to wash their entire body (8).

Once the PIP Assessment has been completed the report and supporting evidence is sent to a DWP Decision Maker who makes a decision on eligibility. A PIP claimant is extremely likely to have to attend a face-to-face medical assessment, unless they have a terminal illness. According to the DWP, at March 2014 around 98 per cent of PIP claimants were being asked to attend a face-to-face assessment. A DWP evaluation found that the assessment report was 'the principal determinant' of decisions (Sainsbury and Corden, 2014). The medical consists of several parts. First, the assessor will read or will have read any documents relating to the case. The assessor will also draw opinions from what the claimant says and does on the day and will ask the claimant a series of questions about their condition and about their day to day and, during the assessment, they may also be asked to carry out physical tasks. As with ESA, the PIP assessment uses drop down lists, multiple choice answers and text boxes to record information on a computer. They may carry out a brief physical examination, checking functions relevant to the condition, for example, eyesight, blood pressure and movement in limbs. While this is taking place the assessor will be making informal observations about the way the claimant looks and behaves. Finally, after they have gone, they will list which descriptors they consider apply. A written decision is issued to the claimant.

In Nova Scotia, the authorities use the InterRai Minimum Data Set-Home Care (MDS-HC) assessment tool. This is a widely-used tool which involves completion of a detailed form concerning the person's patterns concerning cognitive, communication/hearing, vision, mood and behaviour, social functioning, physical functioning, disease diagnosis, health status, etc. It also includes an environmental assessment (e.g. living arrangements) and an assessment of the informal supports available and services used. Studies have found that, where carried out by trained staff using recommended protocols, the MDS-HC assessment provides 'a valid measure of function and cognitive status in frail home care patients' (Landi et al, 2000). These findings point out the overall validity of the functional and clinical data contained in the MDS-HC assessment.

In the Netherlands, assessment is carried out by a special independent agency, the Central Body for Classification of Care (Centraal Indicatieorgaan Zorg - CIZ). The CIZ decides, on request of the insured person, whether the care conditions are satisfied. This is set out in a classification decision. This decision sets out whether a person needs care, and if so what form of care and to which extent. In order to make the decision, the situation has to be investigated, not only the medical situation, but also the living situation and the social circumstances. In making the decision, the CIZ assesses in which so-called 'care profile' the claimant fits. The care profiles are set out in an annex to the Regulation on long term care and indicate the level of care needed by a person in a particular situation. This decision is made by the employees of this office on the basis of the information given in the application form plus additional information of the general practitioner or specialist. If necessary the employee can ask for further information from the medical doctors. By making the profiles the Ministry of Health has introduced a system that brings a considerable extent of harmonisation of the level of care that fits with a particular situation. Thus the procedure is a form of desk review and not an examination of the person at the application stage. The

medical doctors are not involved in the decision making nor do they give an advice, but they can be asked to give information.

In case of autism or mental health problems of young persons the same procedure is followed. Thus if medical assessment shows that the young person needs specific help due to a psychiatric or behavioural problem, parents can obtain a budget for support. For this purpose a care profile, as mentioned above, is used. In that case the young person (if s/he is over age) or the parent seeks the care provider, makes an agreement and decides the payment. For these young persons the budget can be used for support of activities at home or outside the house, support to deal with problems and short respite stay (which may be beneficial for both parents and the young person).

Finally, in New Zealand, assessment is, in theory, on the basis of a short medical report submitted by the person's GP as part of the claim form with possible recourse to further medical examination. However, in practice the New Zealand authorities often request an assessment of need which is carried out as part of the health and social care system and which is not strictly required by law. This would suggest that this is felt to provide a better assessment of care needs.

Reviews

All countries provide for reviews which may be on a desk basis or involve a full review depending on the circumstances. A number of countries have specific rules to ensure that groups who are unlikely to have improved are not reviewed (Australia) or to provide that people whose circumstances have improved *as a result of* care are not penalised (Nova Scotia). In Australia, an ADAT assessment remains current for two years, and then a full review is conducted. However, if the cared-for person's condition is permanent and non-improving (with a high ADAT score) a full review is not required and a 'circumstances' review will be carried out, typically by telephone, to ensure that the carer still provides constant care to the person. In Nova Scotia, eligibility is to be confirmed on an annual basis by the CCC. However, if, on reassessment of the care recipient after acceptance into the Caregiver Benefit Program, the Care Coordinator determines that the care recipients' score improves as a result of being part of the Caregiver Benefit Program, the care recipient may still be considered eligible for the Program, unless he/she also fails to meet one of the other eligibility criteria.

Appeals

In all the jurisdictions, except Nova Scotia, there is a right of appeal to an independent court or tribunal following an internal review of the decision. In general, these courts and tribunals form part of the overall court system: for example, the First Tier Tribunal in the UK, the district court in the Netherlands and the Administrative Appeals Tribunal in Australia. Generally the judges are legally qualified persons (or persons with other relevant qualifications). In the UK, for appeals involving assessments for PIP, the tribunal will comprise a Tribunal Judge, a Tribunal Member who is a registered medical practitioner, and a Tribunal Member who has a disability qualification.

The impact of these courts and tribunals on assessment appears to vary from country to country. In the UK, decisions as to the interpretation of the law by the specialist Upper Tribunal (formerly the Social Security Commissioners) are included in the DWP Guidelines

for Decision Makers (DMGs).²¹ The DMGs are a detailed summary of the law in relation to specific benefits (legislation and case law) to assist in decision making.

Overall assessment

There are relatively few in-depth evaluations of the assessment process for carers payments. In the case of the UK the (PIP) assessment is very new while in New Zealand relatively few people receive the payment. As in the case of the incapacity report, there is no one perfect system.

The Australian Government commenced a review of the ADAT assessment process for Carer Payment and Carer Allowance in July 2015. The intention is that new assessment process will be implemented from 1st January 2018 (DSS, 2015e). This review is being undertaken because:

Stakeholders, including carers and health professionals, have raised concerns about the accuracy, relevancy and currency of the present assessment process.

The current assessment process may not be targeting payments appropriately, as it does not effectively measure both the care required by the care receiver and the care provided.

In addition, a range of differences between qualification criteria for Carer Payment and Carer Allowance, and between the adult and child care receiver streams of the payments, require examination to determine if they remain appropriate. (DSS, 2015e)

In the past, cared-for claimants have reported problems persuading treating health professionals to complete properly the professional questionnaire (National Welfare Rights Network, 2000:2). Questionnaires completed without the cared-for person present may contain contradictory responses and some people are wary of asking doctors to complete the questionnaire because they know the professional will complain about Centrelink's paperwork requirements (National Welfare Rights Network, 2000:2; Orima Research, 2008:23-4). Some claimants can also be unhappy about the cost and effort involved in obtaining appointments with health professionals, especially if only 'a small amount' of Carer Allowance was at stake (Orima Research, 2008:17).

In the case of the UK, the official evaluations have been reasonably positive about the new PIP assessment process (Sainsbury and Corden, 2014) but, as discussed in the country report, there has been considerable public criticism of the new system and the Independent Review identified a number of process issues in addition to initial backlogs and delays. It is, however, probably too early to come to any clear conclusions about the advantages and disadvantages of the system (Gray, 2014). In the UK, much of the criticism concerns the contracting-out of services and related issues and it should be recalled that this is not central to the type of approach adopted which could also be implemented by in-house staff (as in Nova Scotia).

²¹ The DMGs are a detailed summary of the law in relation to specific benefits (both legislation and case law) to assist in decision making. They are publically available on the DWP website: <https://www.gov.uk/government/collections/decision-makers-guide-staff-guide>

The tool used in Nova Scotia (MDS-HC) is well-established and has been assessed as providing a generally accurate assessment of need. However, there has not been an evaluation of its use specifically in relation to Caregiver Benefit in Nova Scotia. In contrast to the approach adopted in the UK and Australia, the Nova Scotia approach also has the advantage that it is integrated with other social care services for carers.

Finally, the Netherlands has a well-established and detailed system for assessing care needs (CIZ). However, this approach is very different to the approach adopted in Ireland and would probably need to be considered in the context of a broader review of the Irish approach to supporting care which falls outside the scope of this study.

Relevance of the findings to Ireland

Overview

As discussed in the previous section, our examination of the carer assessment systems in five jurisdictions does not indicate any one system which could be readily adopted in Ireland. However, it is noticeable that all systems (except New Zealand) have put in place a much more structured approach to the assessment of care needs and the assessments often involves a much more specific scoring system. In the Netherlands, the CIZ assesses need against a system of 'care profiles'. Australia and the UK use the Adult Disability Assessment Tool and the PIP Assessment Tool respectively, while Nova Scotia relies on a general assessment tool (MDS-HC) for the evaluation of care needs.

The scope of our study did not extend to examining the Irish assessment system nor to identifying weaknesses (if any) in the system. There does not appear to have been any recent published review of the assessment of carers' payments in Ireland. However, in 2014 appeals concerning carer's allowance made up 11% of all appeals to the Social Welfare Appeals Office (SWAO).²² This contrasts with the fact that claims for carer's allowance made up less than one percent (0.76%) of all social welfare claims received by DSP in 2014.²³

Over 55% of carer's allowance appeals decided were successful in whole or in part (allowed (36.3%); partially allowed (5.2%); revised by deciding officer (13.7%).²⁴ This is in line with the overall average for the SWAO but is much higher than the rate of success for some areas such as old age pensions or child benefit. The relatively high number of appeals and the rate of overturned decisions does not necessarily indicate problems with the initial decisions and may simply be a function of the complexity of the qualification conditions.

However, if DSP has identified any issues with the current assessment system, one lesson from this study would be that there are a number of models which involve a more detailed and structured assessment which could be adapted to Ireland.

In Nova Scotia, the Caregiver Benefit uses the same assessment tool used for social care and nursing home support. There is merit in Ireland developing a common assessment framework, where assessments for different purposes could build on a single core assessment. It is noted, however, that fewer than 2 per 1,000 population qualify for carer payments in Nova Scotia, in contrast to over 13 per 1,000 in Ireland, although the fact that their payment is so recently introduced (2009) may explain the lower claimant numbers somewhat.

Legal robustness

Despite the varying systems adopted, there is nothing to suggest that the different systems which we have studied have faced any major legal issues. In the case of the European countries, the rules in relation to a fair hearing of appeals under the European Convention on Human Rights apply and this has led to a number of cases concerning access to medical

²² Social Welfare Appeals Office, *Annual Report 2014*, table 1.

²³ DSP, *Statistical Information on Social Welfare Services 2014*, table J1.

²⁴ Social Welfare Appeals Office, *Annual Report 2014*, table 3.

reports and the right to a public hearing. As in the case of incapacity payments, we have not found that the concept of desk reviews (as opposed to face-to-face assessments) has been subject to legal challenge.

There is considerable UK case law on the role of the medical assessor (or equivalent) and how their findings should be taken into account. The UK courts²⁵ have accepted that the examining medical practitioner acting on behalf of the DWP is 'independent'.²⁶ However, the courts have also held that

there is no general rule that where there is a difference between the evidence of a medical professional producing reports for the use of the Department of Work and Pensions in making decisions as to social security benefits and the evidence of a claimant, the evidence of the medical professional should be preferred. It may be a legitimate conclusion in a particular case that a medical professional's view is to be preferred because it is more objective and independent, but that is a conclusion only to be reached after a consideration of the particular evidence ...²⁷

In terms of balancing the evidence of the person's doctor and an examining practitioner, the UK courts have stated that both the examining medical practitioner and the general practitioner should be assumed to be giving professional and independent evidence.²⁸ The medical evidence provided by both (and any other relevant evidence including the claimant's own evidence) should be evaluated and weighed on the issues in the case. For example, in a Disability Living Allowance case (the benefit which preceded PIP), the Upper Tribunal stated that

the reports provided by GPs are [often] limited in the relevant information that they provide. That is not a criticism of GPs. It is simply a fact of life, even for diligent GPs, that they either do not have the information required or they have it but do not realise its relevance. Nevertheless, reports such as the ones provided in this case are often the only sort of evidence that is available or attainable from a claimant's medical advisers. In that respect, they do not compare favourably with the reports of examining medical practitioners. That does not mean that they are valueless. Claimants are at a disadvantage compared to the Secretary of State when it comes to obtaining evidence in the form that will be of most value to the tribunal. Nevertheless, they have a statutory right of appeal and that right must be made effective. All too often, judges present the tribunal's reasons as if the tribunal had a choice between accepting the evidence of the GP or of the examining medical practitioner. There may be cases where that is so, but in many cases the reports each have their strengths and each their limitations as an assessment of the claimant's disablement. In those cases, what a proper analysis usually requires is for the tribunal to show a balance between the value that can be distilled from each report and its limitations.

²⁵ The specialist Upper Tribunal is equivalent to the High Court in its status in the judicial hierarchy.

²⁶ See, for example, CIB 2308 2001.

²⁷ *CW v Secretary of State for Work and Pensions* [2011] UKUT 386 at [24] citing CIB/16401/1996.

²⁸ CIB 2308 2001. The case involved Employment Support Allowance rather than PIP but the legal issues are the same.

The courts have accepted that where if the examining practitioner does not have medical expertise in relation to the person's disability (e.g. mental health) any medical opinion in relation to the disability is 'of little or no value'. However, the examining practitioner may still be able to prove relevant evidence as to the impact of the disability.²⁹ In the case of *PF v Secretary of State for Work and Pensions*,³⁰ the First Tier Tribunal had preferred the evidence of the medical assessor (who was a physiotherapist) to that of the claimant's psychiatrist without explanation. The Upper Tribunal held that 'Where evidence of opinion is put forward, key to the evidential value of that opinion is the source of it. The level and extent of the expertise must be of central relevance in relation to the evaluation of opinion evidence.'³¹

In contrast, in Australia, the courts have ruled that – given the terms of the Australian law - only the designated health professional can assess the level of disability (using the ADAT) and that the decision-maker and/or appeal tribunal do not have the power to substitute its own assessment. Thus, even in a case where three separate assessments had arrived at different scores (albeit none reaching the necessary level of severity), the tribunal did not have the power to substitute its own view.³² The decision-maker or tribunal can only direct that a further health professional questionnaire be completed by another treating health professional if it is satisfied that the most recent treating health professional questionnaires are incorrect or inadequate and a further questionnaire is required.³³ It is not clear that this approach would be consistent with Article 6 of the European Convention on Human Rights (ECHR) in the case of appeals.³⁴

In Ireland, an issue has been raised in relation to the role of the deciding officers who make decisions on entitlement to care payments 'rubber-stamping' the opinion of a Departmental medical assessor. In *B. v Minister for Social Protection*,³⁵ a case involving domiciliary care allowance (DCA), the deciding officer, in rejecting B's application, had relied on the negative opinion of the medical assessor. It emerged that in over 3,800 applications for DCA the same deciding officer had – in every case – relied on the medical assessor's decisions and the Department conceded that it would be 'highly unusual' for a deciding officer to decide against a medical assessor's opinion.

The High Court ruled that

The policy whereby deciding officers generally defer to the opinions of department medical assessors ... has yielded a situation in the instant case in which there has been an abdication of statutory duty by the deciding officer Indeed the manner

²⁹ See [2010] UKUT 340 and [2013] UKUT 469.

³⁰ [2013] UKUT 0634.

³¹ At [13].

³² *Maude and Secretary, Department of Families, Housing, Community Services and Indigenous Affairs* [2008] AATA 803. This was also the case where the tribunal took the view that the application of the ADAT to the specific disability was 'less than appropriate': *Deveson and Secretary, Department of Families, Community Services and Indigenous Affairs* [2007] AATA 1849.

³³ *Kolhoffer and Secretary, Department of Families, Housing, Community Services and Indigenous Affairs* [2011] AATA 561.

³⁴ See *Feldbrugge v Netherlands*, 8562/79, (1986) 8 EHRR 425.

³⁵ [2014] 2 ILRM 290.

of implementation of such policy ... is such that the court finds it has vitiated the decision-making process employed in relation to that application; this is because the deference manifested by this particular deciding officer to the opinion of medical assessors has been proven to be so great that the court concludes that the medical assessor's opinion ... was in fact determinative of that application, thus resulting in a contravention of s.300 of the Social Welfare Consolidation Act, 2005, thereby tainting the decision-making process.

This case involved DCA rather than carer's allowance or benefit but it seems likely that similar issues could arise in relation to these payments.³⁶ Without further amendment to the law, it is clear that deciding officers must make the decisions and must have regard to all relevant evidence. This would still be likely to lead to decisions consistent with the medical assessor's opinion in most (but not all) cases. This is the approach which is taken, for example, in the UK where the decision maker (DM) has regard to the opinion of the medical assessor but does not in all cases follow that opinion.

One alternative would be to change the law to make the medical assessor the deciding officer in 'disability' cases. Of course, if this was to be done, the medical assessor would have to have regard to all the evidence in coming to a decision and to comply with general rules of fair procedures which apply to decision-makers.

A second alternative would be to make the opinion of a medical assessor as to the level of care need binding on the deciding officer (as in Australia). This would, however, require a change in the current legal position of the deciding officers who, the Supreme Court has ruled, 'are, and are required to be, free and unrestricted in discharging their functions under the Act.'³⁷ As noted above, it is questionable whether such an approach would be compatible with the ECHR as concerns appeals.

³⁶ The Social Welfare (Miscellaneous Provisions) Act 2015 inserts a new section 300A re the opinion of the medical assessor which provides, inter alia, that 'a deciding officer shall have regard to [the medical assessor's] opinion in deciding the question in respect of which the opinion was sought.

³⁷ *McLoughlin v. Minister for Social Welfare* [1958] IR 1.

Annex I: Research questions

- Who conducts care assessments? Detail where it is the person's own doctor, one from the public health service or the social security body; if a generalist(GP) or specialist medical opinion is required; whether other health professionals are involved and which e.g. occupational therapists; whether non-health professionals are involved, and which e.g. vocational guidance specialists
- Is there desk review or actual medical examination at application stage
- Does the medical or other specialist assessor make a decision or give an opinion
- Is a medical etc opinion binding or is it advisory on the decision taker
- If the medical or other specialist assessor makes a decision what if any is the appeals process.
- What is the nature of the medical criteria or fitness to work criteria
- What system is in place for review of medical or fitness for work assessments
- What is the composition of the review panel (doctors, OTs etc)
- What system is in place to ensure uniformity of decisions
- Strengths or weaknesses of the systems
- Robustness of the systems from a legal perspective
- If possible, an assessment of the potential robustness of such systems in the Irish legal context.

Acronyms

AAT – Administrative Appeals Tribunal
ADAT – Adult Disability Assessment Tool
ADL – Activity of Daily Living
AWB – *Algemene wet bestuursrecht* [General Act on Administrative Law]
AWBZ - *Algemene Wet Bijzondere Ziektekosten* [General Act on Exceptional Care Costs]
CA – Care allowance (Australia)
CCG – Current Care Guidelines
CES – Commonwealth Employment Service
CIZ – Central Body for Classification of Care (Netherlands)
CP – Care Payment (Australia)
DCA – Domiciliary Care Allowance
DLA – Disability Living Allowance (UK)
DM – Decision Maker
DMA – Disability Medical Assessment
DMGs – Decision Maker Guidelines
DSO – Disability Support Officers
DSP – Department of Social Protection
DSP – Disability Support Pension
DSS – Department of Social Services
DWP – Department of Work and Pensions
EBM – Evidence Based Medicine
ECHP – European Community Household Panel
ECHR - European Convention on Human Rights
ECtHR – European Court of Human Rights
EEA – European Economic Area
ESA – Employment and Support Allowance
GP – General Practitioner
HCP – Health Care Professional
HSE – Health Services Executive (Ireland)
IADL - Instrumental activities of daily living
ICF - International Classification of Functioning Disability and Health
MDS-HC – Minimum Data Set-Home Care
NASC - Needs Assessment Service Centre
NDA – National Disability Authority
OECD – Organisation of Economic Co-operation and Development
PA – Personal Adviser
PGB – Personal care budget (Netherlands)
PIP – Personal Independence Payment (UK)
RFT – Request for Tender
SLP – Supported Living Payment
WLZ - *Wet Langdurige Zorg*
WMO – *Wet Maatschappelijke Ondersteuning* [The Act on Social Support]
ZVW - *Zorgverzekeringswet* [Health Care Act]

Annexes of country reports

Australia

1. Overview of supports for care

There are about 2.7m carers of adults and children in Australia (Department of Social Services, 2015a). The Commonwealth of Australia provides a range of financial support to people providing daily care to individuals with a disability or medical condition, or to someone who is frail aged. The principle payments available to carers are listed in Table AUS1. They are a mix of regular payments, paid fortnightly, and annual lump sums paid to assist with the extra costs of caring for someone with a disability or who is frail elderly. The carer benefits listed in Table AUS1 are not taxable. The Commonwealth Government has expressed concerns about the rising costs of carers' payments. In October 2015, the Minister of Social Services stated that expenditure on income support for carers was unsustainable due to growth in numbers and an aging population (Carers Australia, 2015).

Carer benefits are delivered by Centrelink, which administers other Commonwealth benefits, and is part of the Department of Human Services. There are a few links to support services on Centrelink's carers webpage³⁸, for example, to Carers Australia, National Disability Insurance Scheme and My Aged Care. However, the focus is on the payment of income support to carers – there is no integrated service for benefits and support services. The Government announced in its 2015/26 Budget an *Integrated Plan for Carer Support Services*, which is under development, and

will reflect Australian Government priorities for carers. The purpose of the Plan will be to outline practical actions to recognise, support and sustain the vital work of unpaid carers. A key priority of the Plan will be to streamline and better coordinate carer support services, which are currently fragmented and difficult to navigate. (Department of Social Services, 2015b)

Funding for existing caring services has been extended to June 2017 whilst the Plan is being developed. The Plan includes the establishment of a National Carer Gateway from December 2015; the Budget allocated AUS\$33.7m over the next four years for this initiative (Department of Social Services, 2015c). The National Carer Gateway will be an online service and national telephone number for all carers to access information, support and referrals to services. The aim is to make accessing information for carers less fragmented and confusing. How the National Carer Gateway interacts with existing service provision is under consideration, but it will be designed to link with My Aged Care, the new Commonwealth Home Support Programme and National Disability Insurance Agency. The Commonwealth Home Support Programme commenced in July 2015 and consolidates and replaces a number of programmes for older people and their carers (Department of Social Services, 2015d).

³⁸ <http://www.humanservices.gov.au/customer/subjects/caring-for-someone-with-an-illness-or-disability>

Table AUS1: Main carers' benefits

Benefit	Characteristics
Carer Allowance	<p><i>Purpose:</i> An income supplement for carers providing additional daily care and attention to an adult with disability or a medical condition, or to someone who is frail aged</p> <p><i>Payment:</i> Fortnightly</p> <p><i>Means-tested:</i> No – can be paid in addition to wages and any other income supplement (including Carer Payment)</p> <p><i>Taxable:</i> No</p>
Carer Payment	<p><i>Purpose:</i> Financial support to carers unable to work in substantial paid employment because they provide full-time daily care to someone with severe disability or medical condition, or to someone who is frail aged</p> <p><i>Payment:</i> Carer Payment is paid fortnightly</p> <p><i>Means-tested:</i> Yes – covers both carer and the cared-for person</p> <p><i>Taxable:</i> No, if both carer and cared-for person are under Age Pension age</p>
Carer Supplement	<p><i>Purpose:</i> Paid to help with the costs of caring for a person with disability or a medical condition for those in receipt of Carer Payment, Carer Allowance, Department of Veterans' Affairs Partner Service Pension with Carer Allowance, or Department of Veterans' Affairs Carer Service Pension - introduced in 2009</p> <p><i>Payment:</i> Annual lump sum of AUS\$600 (not indexed) – paid automatically (about €390)</p> <p><i>Means-tested:</i> No</p> <p><i>Taxable:</i> No</p>

2. Description of main payments

The remainder of this report focuses on the two largest benefits – Carer Payment with 221,954 recipients and Carer Allowance with 563,079 recipients (75 per cent adults only) in June 2013 (DSS, 2014a, Tables 18 and 21).³⁹ Carer Payment is an income-tested pension, whilst Carer Allowance is a non-means-tested supplementary payment. The two benefits are described in turn below.⁴⁰

Carer Payment

Carer Payment replaced Carer Pension in July 1997. Carer Payment is paid to carers who because of the demands of their caring role their participation in the labour market is inhibited. That is, Carer Payment is not awarded because a person has a caring role per se, but because that role significantly limits their capacity for employment (Harmer, 2009:2). Carer Payment is, following the recommendation of the Pension Review, paid at the same rate as other Commonwealth pensions to older people and those with a disability (Harmer, 2009:49). As such the payment is meant to provide a ‘safety-net’, a:

... comprehensive, conditional, basic income support to those who are most at risk of falling below an acceptable standard of living at a point in time. (Commonwealth of Australia, 2009:20)

It is not an income replacement or compensation payment for carers – the amount of the Carer Payment does not reflect the level of care provided or assessed as required as part of the application process (Harmer, 2009:48; Commonwealth of Australia, 2009:20).

As a means-tested benefit the maximum sums payable are given in Table AUS2. Carer Payment recipients may also qualify for other supplementary financial assistance, such as Pension Supplement. The maximum sums awarded are similar to rates for Disability Support Pension (DSP) and the income and asset tests for the carer, withdrawal rate and indexation arrangements applied are the same as those outlined in the DSP case study report.

³⁹ Both Carer Payment and Allowance include support for carers of children. However, given the focus of this report, we focus here on the adult payments only.

⁴⁰ The history of Carer Payment and Carer Allowance is summarised in Edwards et al. (2008:5-8)

Table AUS2: Carer Payment - Maximum payment (AUS\$ rates per fortnight)⁴¹

Component	Single	Couple each	Couple combined	Couple each, separated due to ill health
Maximum basic rate	\$788.40	\$594.30	\$1,188.60	\$788.40
Maximum Pension Supplement	\$64.50	\$48.60	\$97.20	\$64.50
Energy Supplement	\$14.10	\$10.60	\$21.20	\$14.10
Total	\$867.00	\$653.50	\$1,307.00	\$867.00

Source: Department of Human Service, nd

Note: Figures apply from 20th September 2015 to 19th March 2016.

In addition, the cared-for person must be receiving a social security or Department of Veterans' Affairs benefit or pension, or meet the special income and assets test for cared-for people. Excluding any pension or benefits the income and assets of the cared-for person should not exceed the limits in Table AUS3. However, where the person's care needs are high (the cared-for adult has a 'higher ADAT score' – this is discussed below) and is receiving a social security or service pension or benefit, then the income and assets tests for the cared-for person do not apply (see Australian Government, 2015, section 4.2.5)

Table AUS3: Carer Payment - Income and assets tests limits for people receiving care

Test source	Limit
Income	\$107,219
Assets	\$661,250
Liquid-assets	\$6,000 single \$10,000 couples

Source: Department of Human Service, nd

Carer Allowance

Carer Allowance is a non-taxable, non-means-tested income supplement payable to people providing daily care for adults or children with a disability or a severe medical condition, or who are frail aged. It was introduced in July 1999. Carers received Carer Allowance for each eligible person in their care, which can be up to two cared-for adults and/or any number of dependent children with a disability or a severe medical

⁴¹ AUS\$1 = €0.65 so \$788.40 equals about €511.

condition. For Carer Allowance (adult) the carer receives AUS\$121.70 per fortnight. It can be paid in addition to a person's wages and other income support payments, such as Carer Payment and Age Pension. Although Carer Allowance is not means-tested, the introduction of a means-test has been proposed (see National Commission of Audit, 2014:310-11). Over half of Carer Allowance recipients also received an income support payment such as Carer Payment, Age Pension, Parenting Payment or Disability Support Pension.

Recipients of Carer Payment and Carer Allowance are eligible for the annual lump sum Carer Supplement (see Table AUS1). Under both benefits, the provision of care can temporarily cease for up to 63 day per year without cancellation of the Carer Payment or Carer Allowance. Such periods are used, for instance, to allow for respite care.

3. Nature of qualification criteria

There are differences in the eligibility criteria for Carer Payment and Carer Allowance and these are discussed below.

Carer Payment

Eligibility criteria apply to both the carer and the cared-for person (SSA 1991, Section 197).

Carer

The carer must:

- be personally providing constant care in the home (or in a hospital) of someone with a disability or medical condition, or who is frail aged, and
- meets the income and assets tests (see above), and
- be in Australia at the time the care is given, and
- be a permanent resident of Australia.

For the care to be 'constant' it must be provided for a 'significant period' each day (that is, the equivalent of a normal working day) (Australian Government, 2015, Section 1.1.C.310). The care may take different forms: active, supervisory and/or monitoring.

Cared-for person

The criteria for the cared-for person, known as the 'care receiver' in the legislation, are relatively complex, as they can vary by the level of care needed determined in the assessment process (see below).⁴² In summary, the cared-for person must be an adult with a physical, intellectual or psychiatric disability and be assessed as needing care under the ADAT (see below).

In addition, the cared-for person must:

⁴² Further details about the eligibility criteria are given in Annex A.

- be needing constant care, and
- requires the care permanently or for an extended period of at least six months unless the condition is terminal, and
- meets the income and assets tests (see above), and
- be an Australian resident, and
 - be an income support recipient, or would be but for residence requirements, AND
 - not be receiving a social security pension or benefit, or Department of Veterans' Affairs pension or income supplement.

Carer Payment recipients can undertake work, volunteering and/or study up to 25 hours per week.

Carer Allowance

As with Carer Payment, there are separate eligibility criteria for the carer and the cared-for person (SSA 1991, section 954).

Carer

The carer must:

- personally provide daily care and attention to an adult with a disability or medical condition, or to an adult who is frail aged, and
- provide the care and attention in a private home, and
- be an Australian resident and in Australia when the claim is made.

The need for the 'care and attention' arises because of the person's disability or severe medical condition (Australian Government, 2015, Section 1.1.C.10). This care and attention cannot be delegated to others, unless it is a temporary cession of care, involves hospitalisation. Under Carer Allowance regulations it is possible for someone to be recognised as having a disability, but not receive care and attention on a daily basis.

Regulations allow for the carer to be both resident in the cared-for person's home, or non-resident if the care is for an adult and relates to their bodily functions or sustaining life and is provided daily for at least 20 hours per week. However, this means that the eligibility threshold for carers living separately from the cared-for is higher than for those co-residing (Carers Victoria, 2013:10).

Cared-for person

The cared-for person must:

- be disabled or have a medical condition, and
- care is required permanently or for a minimum of 12 months unless the condition is terminal, and

- be an Australian resident.

Additionally, for Carer Allowance (adult) the cared-for adult must:

- be a family member or a person approved to receive the care, and
- receive care and attention from the carer or their partner, and
- receive care in their home, their carer's home or a hospital, and
- be assessed as needing care using the ADAT.

4. What is the basic system of assessment of carers?

To determine eligibility for Carer Payment and Carer Allowance the care needs of people receiving care are assessed using a common methodology. Adult care needs are assessed using the Adult Disability Assessment Tool (ADAT). How these assessments are to be conducted and which health professionals are allowed to undertake the assessments are outlined in legislation – the Adult Disability Assessment Determination 1999.

The introduction of a single methodology for both benefits followed a recommendation to review the assessment process for Carer Payment and Carer Allowance by the Inquiry into Better Support for Carers and accepted by the Government (House of Representatives Standing Committee on Family, Community, Housing and Youth, 2009:20; Commonwealth of Australia, 2009:22). A new assessment process was required to overcome the perceived subjectivity and inconsistency of the previous process. Notwithstanding this recent review, the Government commenced a further review of the assessment process for Carer Payment and Carer Allowance in July 2015. The intention is that new assessment process will be implemented from 1st January 2018 (DSS, 2015e). This review is being undertaken because:

Stakeholders, including carers and health professionals, have raised concerns about the accuracy, relevancy and currency of the present assessment process. The current assessment process may not be targeting payments appropriately, as it does not effectively measure both the care required by the care receiver and the care provided. (DSS, 2015e)

Adult Disability Assessment Tool

The ADAT comprises two questionnaires, a *claimant questionnaire* and a *professional questionnaire* (or medical report), both of which are designed to assess the '... disability, emotional state, behaviour and special care needs of an adult.' (Adult Disability Assessment Determination 1999, section 2.1). In summary:

The ADAT measures care needs in terms of how much assistance an adult requires with basic activities such as eating, bathing and behaviour management. In doing so it takes account of the adult's physical, cognitive and/or behavioural disabilities. The ADAT is effective regardless of the type of disability or medical condition the adult may have. The ADAT does not assess

higher activities of daily living such as managing finances, housework, cooking, shopping, laundry or gardening. (Australian Government, 2015, section 1.1.A.78)

A carer completes the claimant questionnaire and must then arrange for a treating health professional to complete the professional questionnaire.

Table AUS4: List of ADAT recognised treating health professionals

a legally qualified medical practitioner
a registered nurse
a physiotherapist
an occupational therapist
a member of an Aged Carer Assessment Team
an Aboriginal Health Worker (in a geographically remote area).
Source: Social Security (Treating Health Professionals) Determination 2009.

The professional question must be completed by a recognised 'treating health professional' – see Table AUS4. Legislation, *Social Security (Treating Health Professionals) Determination 2009*, specifies which allied health professionals are allowed to act as treating health professional for ADAT. The treating health professional can be the cared-for person's treating doctor.

In the past, cared-for claimants have reported problems persuading treating health professionals to complete properly the professional questionnaire (National Welfare Rights Network, 2000:2). Questionnaires completed without the cared-for person present may contain contradictory responses and some people are wary of asking doctors to complete the questionnaire because they know the professional will complain about Centrelink's paperwork requirements (National Welfare Rights Network, 2000:2; Orima Research, 2008:23-4). Some claimants can also be unhappy about the cost and effort involved in obtaining appointments with health professionals, especially if only 'a small amount' of Carer Allowance was at stake (Orima Research, 2008:17).

The questionnaires

Both questionnaires are of a 'tick box' design with multiple responses to each question. The carer and health professional when completing the questionnaires must base their responses on the cared-for person using any aids, appliances or other special equipment and/or prescribed medication.

The claimant questionnaire comprises 29 questions. Example questions about the cared-for person are:

Move around the house (may use walking stick, frame, wheelchair etc)?
Without help

With help of one person
 With help of two people
 Is confined to bed

Understand what you, the carer, say?

Always
 Usually
 Sometimes
 Never

Wander away or 'run away' from home?

Never
 Sometimes
 Often

The health professional questionnaire comprises up to 13 questions, including:

Bladder - Assess preceding week. Occasional = less than once a day. A catheterised person who can completely manage the catheter alone is registered as 'continent'.

Incontinent or catheterised and unable to manage

Occasional accident (once a week)

Continent

Cognitive Function

This is an assessment of cognitive function. Ask the person receiving care for the following information. Tick box (☐) to indicate if the person's answers were right or wrong.

Time (to nearest hour)

Memory Phrase: Repeat this phrase after me and remember it for later - *42 West Street*

Name of institution or suburb where the person lives

Recognition of 2 persons in the room (doctor, nurse, carer etc)

Date of birth (day, month and year)

Name of present Prime Minister of Australia

Count backwards from 20 to 1

Repeat the memory phrase

Right	Wrong

Show signs of depression?

Never
 Sometimes
 Most of the time

The health professional is not expected to undertake a full investigation for each of the areas covered. They are asked to draw upon their own clinical assessment, and they may use information from the carer, and/or another (health) professional. However, there are concerns that some health professionals make erroneous assumptions about a cared-for person, and that the expertise and knowledge of the cared-for person, carer and wider family are ignored (Carers Australia, 2007:7).

Rating procedure

The *Adult Disability Assessment Determination 1999* (Schedule 2) specifies a five step procedure for scoring the questionnaires:

Step 1: 'If a medical practitioner has certified that the care receiver is in the terminal phase of a terminal illness and is not expected to live for more than 3 months, the total final score is 30 (no further steps relevant).'

Step 2: Calculate the claimant questionnaire score. Each possible response is assigned a numerical value and the total score is the sum of the questions' scores. The numerical values across the responses can range from 0 to 9 and include some responses with fractional scores. The same scoring scale is not used for each question; a response of, for instance, 'often' to one question can score 0 but 6 to another question. In other words, the responses to each question are not weighted equally.

Step 3: Calculate the professional questionnaire score. The scoring arrangements are similar to those for the claimant questionnaire.

Step 4: Sum the two questionnaires scores to calculate the overall total score.

Step 5: Outlines the minimum scores required professional questionnaire to qualify for benefit and these are described in the next section.

Minimum scores required

Each questionnaire results in a score and to qualify for the benefits an adult must obtain a minimum score on the professional component as well as a minimum combined or overall score. The minimum scores required to qualify for Carer Payment and Carer Allowance differ.

For Carer Payment the two minimum scores required vary depending upon the caring situation (SSA 1991, section 198). The cared-for adult must have a physical, intellectual or psychiatric disability AND:

- for where there is a disabled adult and a dependent child of the adult a 'lower ADAT score', that is, a professional questionnaire score of 8 or higher and an overall score of 20 or higher, OR
- for where the carer is the only person providing care a 'higher ADAT score', that is, a professional questionnaire score of 10 or higher and an overall score of 25 or higher, OR

- for where there are two carers providing care to the same person, a higher ADAT score with a professional questionnaire score of 32 or higher and an overall score of 80 or higher.

In addition and as mentioned above, the person must be likely to suffer from the disability permanently or for an extended period. For Carer Allowance (adult), the cared-for person requires a professional questionnaire score of 12 or higher and an overall score of 30 or higher. (And similarly to Carer Payment must be likely to suffer from the disability permanently or for an extended period.)

If the cared-for person does not achieve a qualifying ADAT score, then they may submit a new claim at any time they believe that their care needs have increased.

5. Review and appeals

There are three forms of review to ensure continuing eligibility for Carer Payment and Carer Allowance:

- a full review, which involves a new ADAT and confirmation of the care situation
- a circumstances review to determine that care is still required by the cared-for person and continues to being provided by the carer
- *for Carer Payment only*, an income and assets review for the carer and cared-for person.

An assessment against the ADAT remains current for two years, and then a full review is conducted (Australian Government, 2015, section 3.6.9). However, if the cared-for person's condition is permanent and non-improving and an ADAT score of 40 or more was obtained then a full review is not required. Yet a circumstances review will be conducted every two years typically by telephone to ensure that the carer still provides constant care to the same person in their home. Additionally, the income and assets test is reviewed annually where a Carer Payment award entailed the cared-for person meeting the special income and assets test. Where someone receives both Carer Payment and Carer Allowance, both are reviewed at the same time.

The internal review, tribunal and court appeal arrangements for Carer Payment and Carer Allowance are the same as those discussed in the Disability Support Pension report.

6. Overall assessment

The availability of Carer Payment and Carer Allowance can be seen by carers as a recognition of the importance of the caring role in society (irrespective of whether they are benefit recipients) (Carers Victoria, 2013:8). However, Carer Payment in particular is seen by Government as poorly targeted (National Commission of Audit, 2014:309). Eligibility for both benefits is relatively complex and this may lead to low take-up. For example, some carers who do not reside with the cared-for person report that some health professionals or other carers had told them that they were

not eligible for Carer Allowance, even though regulations do allow for such claims (Carers Victoria, 2013:10). More generally, carers can be unaware of the existence of the two benefits and, if they have heard of them, of their differing purposes and eligibility criteria (Carers Victoria, 2013:14-15; Orima Research, 2008:11). Carers believe that Centrelink could be more active in promoting both benefits, as well as the weightings used in the questionnaire.

Accessing Carer Payment and Carer Allowance, especially for those caring for someone with a mental health condition, can be difficult (Carers Victoria, 2013:8). The process of applying can be seen as 'intimidating' (Carers Australia, 2007:5). The process is seen as complex and involves too much jargon, and this can lead some carers to distrust the system. Some carers can find completing the claimant questionnaire straightforward (yet too 'long'), but for others it is difficult (Orima Research, 2008:22-3). Centrelink staff can be perceived as being unhelpful, even rude (Carers Victoria, 2013:9, 15). Those caring for people with complex, rare or undiagnosed conditions can worry that the questionnaire does not adequately capture the person's caring needs (Orima Research, 2008:23). Carers can 'normalise' caring and so find it difficult to estimate accurately the time spent caring unless prompted – thus the demands of caring may be under-estimated in the assessment (Carers Victoria, 2013:9, 14).

Carer organisations report their perceptions of certain difficulties with the application process. These organisations also perceive there are difficulties in how certain conditions such as mental health or episodic conditions are assessed as eligible or otherwise for carer support. We report these here as being the views of these organisations. Carers Australia (2007:3) observe:

The application forms for Carer Allowance and Carer Payment can be complex and difficult for Australian families. They are particularly difficult for Aboriginal and Islander families, as well as families with culturally and linguistically diverse (CALD) backgrounds. Many of whom may not identify with the construct of carer and, or, may be language disadvantaged. In addition, different cultural attitudes (e.g. towards disability and mental illness) may also present additional barriers for people from CALD backgrounds, especially in the use of deficit based assessment approaches.

Moreover

Application forms may also be complex and difficult for people of different ages and educational background. Young carers who may have limited experience with completing forms may have difficulty. This may also apply to older carers that may have limited use of support services, and so have had little experience of the system and completing application forms.

In addition, the ADAT is also seen to disadvantage young carers (see Carers Australia, 2007:5). For example it does not recognise that the dependent child might be the carer.

The ADAT has been criticised for not adequately assessing the care needs of some groups of people. Those believed to be disadvantaged are people with (Carers Australia, 2007:3 -4):

- episodic conditions – the ADAT does not cover the frequency of episodes nor the “...care load that may fall on family carers as a result of the need for constant vigilance, encouragement, observation, advice, emotional support, monitoring medication compliance and ‘trouble shooting’”
- mental health, cognitive, behavioural and motivational issues – the functional assessments by both carers and health professionals lack consistency. Care receivers with a mental health condition can be denied a ‘voice’ in the professional assessments on grounds of confidentiality (that is, the cared-for person may refuse to consent to information being disclosed to the health professional (see Carers Victoria, 2013:14)).⁴³ Carers can underestimate their care load in order to ‘... present the person with a mental illness as positively as possible, and to protect the person’s self concept’ (Carers Victoria, 2013:4). Where the cared-for person has challenging behaviour the outcome of the assessment can depend upon how well the carer articulates the need for care.

There is a concern that ADAT is skewed towards those with a physical disability (Carers Victoria, 2013:10); ‘...rules, questionnaires and language used in the application process are not a good fit for ...’ for where the cared-for person has a mental health condition. The questionnaires do not refer to the ‘... distress or symptoms of psychosis, whether active (hallucinations, delusions, thought disorder) or negative (flattened affect, reduced motivation).’ (Carers Victoria, 2013:13). Carers Victoria (2013:13), based on research with carers, are critical of the scoring system used, arguing it does not adequately weight the care needs of someone with a mental health condition.

The ADAT is also criticised for not adequately covering some caring activities, such as advocacy, liaison with health professionals, and providing transport to health appointments (Carers Victoria, 2013:9). That the ADAT does not cover all caring activities is recognised in official guidance:

The ADAT measures care needs in terms of how much assistance an adult requires with basic activities such as eating, bathing and behaviour management. In doing so it takes account of the adult's physical, cognitive and/or behavioural disabilities. The ADAT is effective regardless of the type of disability or medical condition the adult may have. The ADAT does not assess higher activities of daily living such as managing finances, housework, cooking, shopping, laundry or gardening. (Australian Government, 2015, section 1.1.A.78)

⁴³ The law and practice around consent, confidentiality and assessments in Australia are complex and, Carers Victoria (2013:14) has called for clarity.

That is, the ADAT is focused on Activities of Daily Living, and attaches insufficient weight to Instrumental Activities of Daily Living, yet the latter activities can form a significant part of the carer's workload.

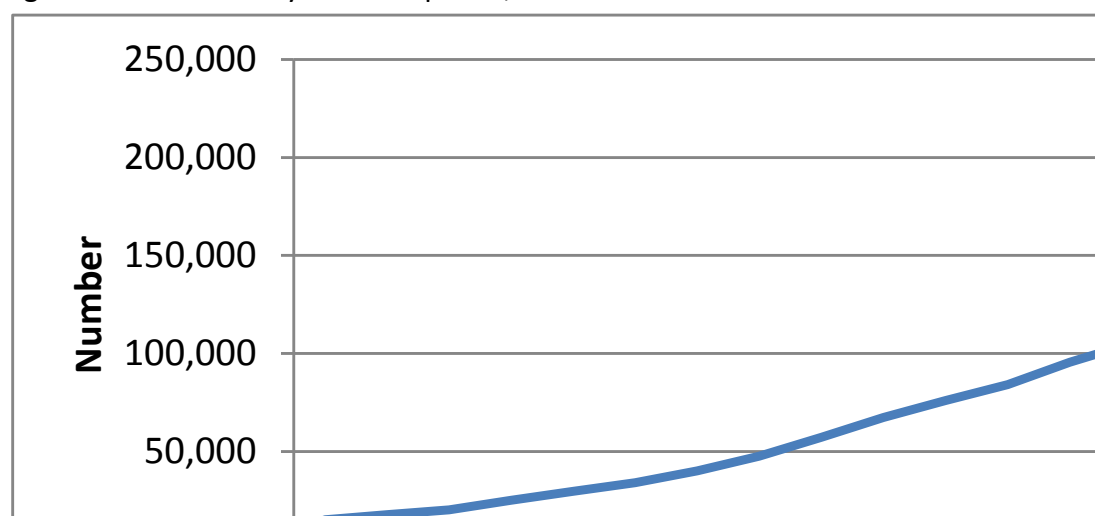
That the professional questionnaire can be completed by a range of health professionals gives carers the opportunity to get their cared-for person's questionnaire completed by someone with specialist knowledge (Carers Australia, 2007:2).

Some claimants believe that their applications have been unfairly rejected (Carers Australia (2007:5). Some report not being given a reason for their claim being rejected (Carers Victoria, 2013:9, 15). Yet they can be reluctant to request a review or appeal (Carers Australia (2007:5). Moreover, claimants' awareness of the benefit review procedures can be low, especially of the two-yearly review cycle, and this can generate a worry that benefit entitlement has been unintentionally terminated because the carer had missed a review (Orima Research, 2008:15-18). Conducting reviews by telephone is generally popular '... because they were fast, efficient and any concerns / questions could be addressed immediately.' (Orima Research, 2008:20). There was also a lack of knowledge about the appeals process – but this was seen as a less of a concern as it was believed the necessary information could be obtained in the event that an appeal would be instigated (Orima Research, 2008:18).

7. Data

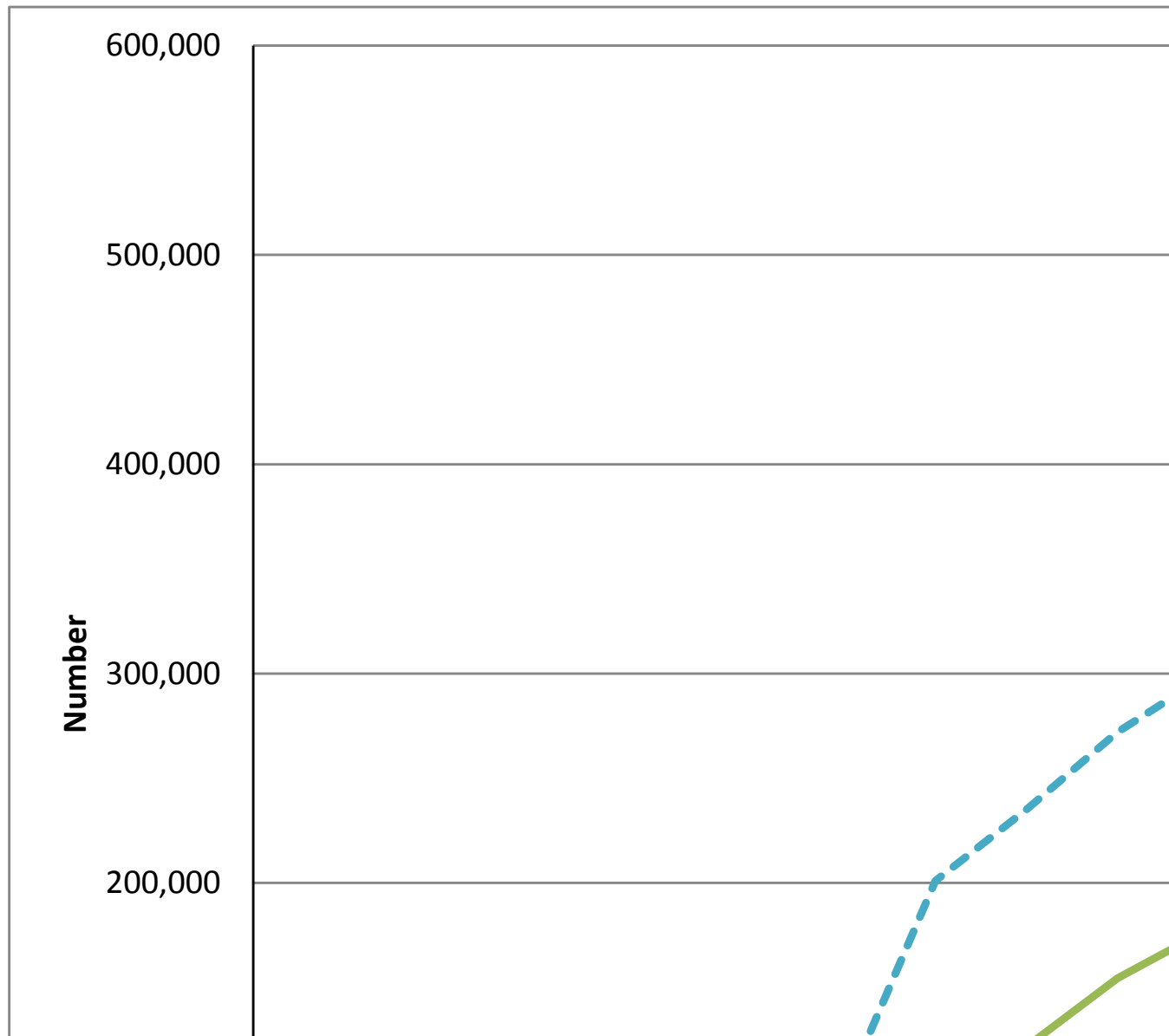
The number of Carer Payment and Carer Allowance (adult) recipients has increased rapidly in recent years (See Figures 1 and 2); and is anticipated to increase over the medium term (National Commission of Audit, 2014:308). Whilst an aging population is one of the explanatory factors for this increase, there '... is no clear reason why numbers of recipients are growing at such a strong rate.' (National Commission of Audit, 2014:308).

Figure AUS1: Carer Payment recipients, June 1993 to June 2013



Source: DSS (2014a) Table 18.

Figure AUS2: Carer Allowance recipients by carer type, June 1993 to June 2013



Source: DSS (2014a) Table 21. NB Carer Allowance was introduced in 1999.

Table AUS5: Carer Payment recipients, characteristics by sex, June 2013

Characteristics	Male— No.	Male— %	Female— No.	Female— %	Total— No.	Total— %
Total	68,203	30.7	153,751	69.3	221,954	100
Age (years)						
<20	839	1.2	1,290	0.8	2,129	1.0
20–29	5,946	8.7	9,960	6.5	15,906	7.2
30–39	8,189	12.0	21,075	13.7	29,264	13.2
40–49	13,757	20.2	35,614	23.2	49,371	22.2
50–59	17,010	24.9	43,624	28.4	60,634	27.3
60–64	10,390	15.2	24,321	15.8	34,711	15.6
≥65	12,072	17.7	17,867	11.6	29,939	13.5
Marital status						
Married/de facto	39,720	58.2	92,010	59.8	131,730	59.4
Single/separated/divorced / widowed	28,483	41.8	61,741	40.2	90,224	40.6
Country of birth (top five countries)						
Australia	43,885	64.3	98,183	63.9	142,068	64.0
United Kingdom	3,737	5.5	6,439	4.2	10,176	4.6
Iraq	3,213	4.7	4,299	2.8	7,512	3.4
Lebanon	1,789	2.6	5,522	3.6	7,311	3.3
Vietnam	1,510	2.2	4,769	3.1	6,279	2.8
Other ^(a)	14,069	20.6	34,539	23.8	48,608	21.9
Home ownership						
Home owner	25,973	38.1	72,442	47.1	98,415	44.3
Non-home owner	42,230	61.9	81,309	52.9	123,539	55.7
Rate ^(b)						
Full rate	–	–	–	–	166,178	74.9
Part rate	–	–	–	–	55,776	25.1
Paid under income test						

Characteristics	Male— No.	Male— %	Female— No.	Female— %	Total— No.	Total— %
Single	27,937	41.0	60,767	39.5	88,704	40.0
Partnered	37,521	55.0	86,186	56.1	123,707	55.7
Home owner paid under assets test						
Single	269	0.4	740	0.5	1,009	0.5
Partnered	1,936	2.8	4,888	3.2	6,824	3.1
Non-home owner paid under assets test						
	376	0.6	600	0.4	976	0.4
Income/assets test not coded ^(c)	164	0.2	570	0.4	734	0.3
Duration ^(d)						
<1 year	14,054	20.6	30,807	20.0	44,861	20.2
1 to <2 years	11,602	17.0	24,386	15.9	35,988	16.2
2 to <3 years	8,713	12.8	19,630	12.8	28,343	12.8
3 to <4 years	6,911	10.1	16,317	10.6	23,228	10.5
4 to <5 years	5,521	8.1	13,196	8.6	18,717	8.4
5 to <10 years	13,604	19.9	34,338	22.3	47,942	21.6
≥10 years	7,798	11.4	15,077	9.8	22,875	10.3
Mean (weeks)	256.3		249.1		251.3	
Median (weeks)	182.0		190.7		186.3	

Source: DSS (2014a) Table 19.

Table AUS6: Carer Allowance recipients, characteristics by sex, June 2013

Characteristics	Male— No.	Male—%	Female —No.	Female —%	Total—No.	Total—%
Total	148,552	26.4	414,527	73.6	563,079	100
Age (years)						
<20	1,156	0.8	1,785	0.4	2,941	0.5
20–29	7,196	4.8	19,650	4.7	26,846	4.8
30–39	12,346	8.3	69,520	16.8	81,866	14.5
40–49	22,769	15.3	102,163	24.6	124,932	22.2
50–59	27,798	18.7	84,958	20.5	112,756	20.0
60–69	32,844	22.1	81,344	19.6	114,188	20.3
70–79	27,931	18.8	41,125	9.9	69,056	12.3
≥80	16,512	11.1	13,982	3.4	30,494	5.4
Marital status						
Married/de facto	103,368	69.6	285,658	68.9	389,026	69.1
Single/separated/ divorced/widowed	45,184	30.4	128,869	31.1	174,053	30.9
Country of birth (top five countries)						
Australia	93,264	62.8	288,557	69.6	381,821	67.8
United Kingdom	10,298	6.9	20,590	5.0	30,888	5.5
Italy	5,172	3.5	8,475	2.0	13,647	2.4
Greece	4,261	2.9	6,550	1.6	10,811	1.9
Lebanon	2,480	1.7	7,984	1.9	10,464	1.9
Other	33,077	22.3	82,371	19.9	115,448	20.5
Duration ^(a)						
<1 year	21,458	14.4	44,883	10.8	66,341	11.8
1 to <2 years	23,245	15.6	53,222	12.8	76,467	13.6
2 to <3 years	18,635	12.5	45,306	10.9	63,941	11.4
3 to <4 years	15,566	10.5	41,954	10.1	57,520	10.2
4 to <5 years	14,180	9.5	38,972	9.4	53,152	9.4

Characteristics	Male— No.	Male—%	Female —No.	Female —%	Total—No.	Total—%
5 to <10 years	37,811	25.5	116,499	28.1	154,310	27.4
≥10 years	17,657	11.9	73,691	17.8	91,348	16.2
Mean (weeks)	241.6		287.2		275.2	
Median (weeks)	186.3		234.0		216.7	

Source: DSS (2014a) Table 22.

In 2013/14 expenditure of carer benefits was nearly AUS\$7bn, and this was forecast to increase by seven per cent per annum up to 2023/24 (National Commission of Audit, 2014:306). In 2013/14 the breakdown of this expenditure by benefit was (National Commission of Audit, 2014:307):

- 61 per cent Carer Payment
- 21 per cent Carer Allowance (adult)
- 8 per cent Carer Allowance (child)
- 8 per cent Carer Supplement
- 2 per cent other.

Annex A: Carer Payment - Eligibility criteria for the cared-for person

This Annex provides further information on the eligibility for cared-for people where the carer receives Carer Payment. The regulations identify six types of care receivers and their associated eligibility criteria are given in Table A.1. Adults are assessed using the Adult Disability Assessment Tool (ADAT) and eligibility criteria vary depending upon the caring situation and whether the cared-for person has a higher ADAT score or a lower ADAT score.

Table A.1: Eligibility criteria for Carer Payment for the cared-for person

Type of care receiver	Criteria for the relevant cared-for person
Adult with a higher ADAT score	<p>requires constant care, AND (if only one person is caring for them) is assessed and rated using the ADAT and given a score of at least 25, being a score calculated on the basis of a total professional questionnaire score of at least 10, OR (if more than one person is caring for them) is assessed and rated using the ADAT and given a score of at least 80, being a score calculated on the basis of a total professional questionnaire score of at least 32, AND is aged 16 years or more, AND is an Australian resident, AND is an income support recipient, or would be but for residence requirements, OR is not receiving a social security pension or benefit or Department of Veterans' Affairs pension or income supplement, AND passes the care receiver income and assets test (or has an exemption from the assets test).</p>
Adult with a lower ADAT score	<p>requires constant care, AND is assessed and rated using the ADAT and given a score of at least 20, being a score calculated on the basis of a total professional questionnaire score of at least 8, AND is aged 16 years of age or more, AND is an Australian resident, AND is an income support recipient, or would be but for residence requirements, AND is not receiving a social security pension or benefit or Department of Veterans' Affairs pension or income supplement, AND passes the care receiver income and assets test (or has an exemption from the assets test).</p>

Dependent child of lower ADAT adult	under 6 years of age, OR if aged 6 or more but under 16 years of age, is a Carer Allowance (child), AND the carer supervises the care of the child.
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Source: Australian Government, 2015, Section 1.1.C.20.

New Zealand

1. Overview of supports for care

New Zealand has a *Carers Strategy* adopted in 2008 with an initial four year Action Plan to 2012. This has now been replaced by a new Action Plan 2014-18 (Ministry of Social Development, 2014). The Action Plan states that over 400,000 (or almost one in ten) New Zealanders are carers. The Action Plan's four guiding principles are to recognise diversity; be proactive; enable carers; and be inclusive. However, the Action Plan makes no reference at all to the Supported Living Payment (or indeed to any form of cash support for carers).

Like Ireland, and a number of other countries, the main income support payment for carers (Supported Living Payment) is the responsibility of the social protection department (Ministry of Social Development) while many aspects of care policy lie with the Ministry of Health. The latter Ministry provides funding for some disabled people to pay a family member to provide personal care and household management and also administers Carer Support (see below).

There appears to have been limited academic study of supports for care and caring in New Zealand. However, one recent study looked at the connection between informal and formal care by way of focus groups and individual interviews with informal carers, formal care service providers and representatives from carer advocacy groups (McPherson et al., 2014). One of the key findings was that 'the needs of the carer and the person being supported were intrinsically linked'. The study also found that '[a]n important message from informal carers (and indeed formal carers) was that whilst the rhetoric was frequently positive, in their experience, the actions did not often match' (McPherson et al., 2014, 425-6).

As in other countries, the study found that 'The majority of informal carer participants referred to a "constant struggle" with regards to engaging with formal services, understanding processes, what they were entitled to, which services were responsible for what, "navigating the pathway" through a "web" of services' (Ibid, 426). Again, however, the study does not specifically refer to SLP, cash or income issues.

2. Description of main payment(s)

The main cash payment which provides support to carers is the Supported Living Payment (Caring). This replaced the Domestic Purposes Benefit (Care) in 2013 and forms part of the overall Supported Living Payment which is mainly paid to persons who are permanently and severely restricted in their ability to work because of a health condition, injury or disability (similar to the Irish disability allowance).

SLP is an income tested payment. To get Supported Living Payment one must be a New Zealand citizen or permanent resident who has lived there for at least two years at one time since becoming a citizen or permanent resident, and who normally lives

there. SLP is administered by Work and Income which is an executive agency under the Ministry of Social Development

The Ministry of Health administers Carer Support which is a subsidy towards the daily cost of a carer's respite breaks. Carer Support is assessed by NASC (see below) and appears to operate completely separately to SLP.

3. Nature of qualification criteria

In order to qualify for the Supported Living Payment a person must be caring full time for someone at home. However, that person must *not* be the carer's husband, wife or partner.

As set out in the relevant legislation, the carer must be

- (i) required to give full-time care and attention
- (ii) at home
- (iii) to some other person (other than the person's spouse or partner)
- (iv) who would otherwise have to receive care that is, or is equivalent (in the case of adults) to hospital care, rest home care, or residential disability care, within the meaning of the Health and Disability Services (Safety) Act 2001.⁴⁴

Every application for a supported living payment (caring) must be supported by the certificate of a medical practitioner certifying that the person requires the applicant's full-time care and attention; and that, but for that care and attention, the patient would have to receive institutional care (as specified above). Work and Income may require that the patient be examined by a medical practitioner nominated by them.

In line with the general New Zealand approach to conditionality (Stephens, 2013), some carers may be required to undergo compulsory work-related activities (e.g. work assessment, work experience, etc.).⁴⁵ Similarly, carers with children must take all reasonable steps to ensure that every dependent child is enrolled in and attends school and is enrolled with a primary health care provider and is up to date with core health checks.

4. What is the basic system of assessment of carers?

Applications for SLP (a 48 page form) include a 4 page medical certificate for the person being cared for which must be completed by a registered Medical Practitioner. This will normally be the person's own doctor. The form is then submitted to Work and Income and the information is considered by Work and Income staff (desk review). Although not required by law, the form asks the doctor

⁴⁴ Section 40D of the Social Security Act 1964. Like the Australian payments, SLP may also be paid in respect of children but we focus here on payments to adults.

⁴⁵ Section 60Q(3).

whether an NASC assessment has been completed for the person and encourages the doctor to make reference to it. Work and Income may request a further medical examination if appropriate and it appears that, in practice, a NASC assessment is often sought (personal communication).

All decisions about granting benefits are ultimately made by Work and Income staff who are not health professionals but depending on the particular benefit in question are guided by information from health professionals. Generally speaking this advice is about the impact of a disability, injury or health condition on a person - either on their capacity to consider suitable work or in the case of a carers payment on the level of need for care (see above). Often the level of care is established by a NASC (a Needs Assessment Service Centre) who are contracted by the Ministry of Health to do all support service assessments.

A needs assessment is required to get most health and disability support services funded by the Ministry of Health or a District Health Board (DHB) including residential care.⁴⁶ NASCs are organisations contracted by the Ministry of Health to work with disabled people and their family or carers, to identify their strengths and support needs; outline what disability support services are available; and determine their eligibility for Ministry-funded support services. NASCs allocate Ministry-funded disability support services and help with accessing other supports. These services are then delivered by their respective service providers. NASCs are contracted by the Ministry of Health's Disability Support Services unit.

5. Review and appeals

If a person disagrees with a decision made by Work and Income on the basis of medical information then a review is possible through the Medical Appeal Board process. This is a panel of three Health Professionals (who have had no previous involvement with the case) who meet with the appellant and the Work and Income case manager to hear both sides from a fresh perspective. The panels are typically a couple of GPs and another health professional who has rehabilitation interests. However, there have very few appeals about SLP (Carer) because Work and Income usually insist on an independent assessment (NASC) being done before making a decision.

6. Overall assessment

There do not appear to any official evaluations of the SLP (Caring) or its predecessor payment. Nor have we located any academic assessments of the benefit. It appears to play a quite limited role given the relatively small number of carers who qualify for the payment. This is partially explained by the fact that spouses and partners are not entitled to the payment.

⁴⁶ New Zealand has been piloting and then rolling out the MDS-HC assessment tool for use by the NASCs. This tool is described in more detail in the Nova Scotia section of this report.

Despite the fact that SLP is a new payment (introduced in 2013), there appears to be a difference between how the assessment works in theory and in practice. In theory, decisions are made by a non-medical person on the basis of an application form with a short medical report from the person's own doctor with the possibility of guidance from health professionals. However, it appears that, in practice, Work and Income encourage the submission of more detailed assessments carried out by NASC which are required for access to social services provided by the Ministry of Health. It is not clear whether these different processes are well-aligned.

While the broader issues of support for carers fall outside the scope of this report, it is not clear that there is a high level of co-ordination between the cash and in-kind supports provided by the Ministry of Health and the cash supports provided by the Ministry of Social Development.

There do not appear to have been any legal challenges to the robustness of the assessment systems to date.

7. Data

Statistics published by the Department of show that relatively few persons receive SLP (Caring).

	Sep-2010	Sep-2014	Sep-2015	Annual change	
Supported Living Payment - Caring	6,744	8,636	8,684	48	0.6%

Three quarters (75%) of carers are women (Table NZ1). The largest age group is between 40-54 (47%) while those aged 55-64 make up 25% and those aged 25-39% constitute 22%. Maori make up the largest ethnic group (35%) while Pacific Islanders make up a further 16%, with 30% with a European background. A large percentage of carers are unspecified or have not returned their ethnicity. The vast majority (85%) of claimants have been in receipt of the payment for more than one year.

Table NZ1: Recipients of Supported Living Payment (Caring) by gender, age and ethnicity, September 2015

	Total	%
Female	6517	75.0
Male	2167	25.0
Maori	3027	34.9
Pacific Islands	1389	16.0
European	2642	30.4
Others	1626	18.7
Aged 18-24	564	6.5
Aged 25-39	1925	22.2
Aged 40-54	4069	46.9
Aged 55-64	2126	24.5

Netherlands

1. Overview of support for care

The Dutch system of social security includes three schemes on the basis of which health care and social support can be provided:

- 1) The Health Care Act (*Zorgverzekeringswet – ZVW*)
- 2) The Act on Long-Term Care (*Wet Langdurige Zorg – WLZ*)
- 3) The Act on Social Support (*Wet Maatschappelijke Ondersteuning 2015 – WMO 2015*).

The Health Care Act and the Act on Long-Term Care are resident schemes: all residents and persons working in the Netherlands are covered. The Health Care Act insures basic care (including drugs, general practitioner and hospital care).

The Act on Long-Term Care, that in 2015 succeeded the *Algemene Wet Bijzondere Ziektekosten (AWBZ)* - General Act on Exceptional Care Costs, covers those parts of medical care that cannot, or only at exceptional costs, be insured under a health care insurance, for instance stay in a nursing home.

The Act on Social Support was introduced in 2015 as a result of the reform of the *Algemene Wet Bijzondere Ziektekosten*. In this reform medical care was shifted to the Act on Long-term Care and non-medical care (household costs, cleaning, helping with getting dressed, care outside hospitals, such as transport of long-term ill persons to day centres etc.) were moved to the Act on Social Support. This Act is administered by the municipalities and paid from their budget (so it is not an insurance scheme). The Act was introduced in order to control the rising costs of the AWBZ, for this reason the non-medical costs were removed from the latter Act. The objective of the Act is that everyone can participate in society. For this purpose claimants are encouraged to first attempt to make arrangements to take responsibility (by doing as much themselves as possible and also engaging neighbours, family members and other volunteers). The support by the municipality is given only if they cannot make such arrangements. Hence the maybe somewhat curious name of the Act: its purpose is to organize and promote the support of persons needing care by society.

As part of this reform some other former AWBZ benefits were shifted to the Health Care Act, including nursing outside hospitals and personal care.

This was to bring the AWBZ back to its roots. These roots were to insure severe medical risks that cannot be insured by individual health insurance. Since the inception of the Act many additional benefits were included in the Act causing costs to rise enormously and the need for reform.

The Act on Long-Term Care now covers care of persons who need care and supervision for 24 hours a day in a hospital or other institution. It is thus focused on severe forms of long-term care, including for the disabled and the elderly.

If a person needs care, the administration of the Act provides care in kind or it can compensate the costs. A person can choose between care in kind and a personal budget (PGB). The latter is relevant to this report, since it concerns the payment for personal carers.

The right to care is laid down in the three different acts discussed above. It depends on the type of care which act is applicable. Note that there are different organisations that decide on this. For the Act on the Long term care this is a national organisation; for the Act on Social Support the municipality defines its policy and there can be important differences between the municipalities. For the Health Care Act the care is defined in the conditions of the insurance. The following types of support are often provided:

- Personal care (assistance with daily activities, such as getting dressed, showering, eating, drinking, going to the toilet).
- Nursing (assistance with the use of drugs, caring for wounds, support with getting oxygen)
- Supporting company (support with activities at home and outdoors).
- Respite (for a weekend or holidays)
- Support and assistance with administration
- Support in living outside an institution.

The personal care budget (PGB) cannot be used for medical treatment or therapy.

This report will focus on the position of carers under the Long-Term Care Act and in particular those who are paid by the patient from the personal budget.

The Long Term Care Act is a national insurance scheme for which contributions have to be paid. The right to care under this Act is stronger than under the Act on Social Support, where the municipalities have a broad discretion on whether and how care is to be provided.

The support for care by a budget is one of the forms by which care can be provided, in addition to care provided in an institution or by a care organization working in the area where the claimant lives. In the light of the total package of services (i.e. support in institutions and nursing home) it is a minor instrument.

2. Description of the Main Forms of Benefit

Under the Act on Long-Term Health Care the insured can choose between care in kind and a personal budget (Article 2.31(1) Act on Long-term Care). The latter is relevant to this report, since it concerns the payment of personal carers. The conditions for the budget are laid down in Article 3.3.3 of the Act on Long-Term Care and Articles 3.6.1 – 3.6.7 of the Decree on Long-Term Care.

The maximum level of the personal budget is defined by a regulation of the Minister of Health (Regulation on Long-term Care). The insured person has to make an

agreement in writing with any care provider that s/he wants to pay from the budget (Article 3.6.4 Regulation on Long-term Care). For this purpose the body responsible for the administration of the Act, the *Sociale Verzekeringsbank*, can make a model contract.

Payments from the budget are made by the Sociale Verzekeringsbank. Until 2015 claimants made the payments themselves, but this led to abuses and mistakes. Companies claimed the budget on behalf of the insured did not always actually provide care. The introduction of the Sociale Verzekeringsbank as administrator was meant to reduce fraud; during the first months of the new system, however, there were huge problems with paying the money to the carers in time and this led to serious political problems for the government. By now the problems seem to be solved.

In a Ministerial Regulation (*Regeling langdurige zorg*), that was made in addition to the Decree, rules are laid down on the conditions to be included in the agreement between the claimant and the care provider.

The agreement between claimant and care provider/giver has to be approved by the Sociale Verzekeringsbank. Approval can be withheld only if it is contrary to the law or the interest of the administration of the personal budget.

The Ministerial Regulation lays down the maximum rates for the care to be paid from the budget. These rates distinguish between companies and persons who professionally provide care (who have to be registered in the register on medical professions) and non-professional care givers (these are often family members, acquaintances, relatives).⁴⁷

The Sociale Verzekeringsbank pays care providers only according to the decision that was made by the *Centraal Orgaan Indicatiestelling Zorg (CIZ)* on the personal budget, and according to the agreement with the care provider or care giver, and taking into account taxes and contributions that have to be deducted.

3. Nature of the Qualification Criteria

In order to be entitled to care one must be insured and have a care insurer; in addition the care has to be part of the insured benefits and the insured person has to be in need of these.

Residents of the Netherlands and those are working in the Netherlands are insured for the Act on Health Care and the Long-term Care Act. Under the Long-term Care Act all those who satisfy this criterion are automatically insured; for the Act on Health Care it is required to conclude an agreement with a private insurance

⁴⁷ Because of the seriousness of the care that is needed, as is decided by the *Centraal Orgaan Indicatiestelling Zorg* – see below, their care can no longer be given on a voluntary basis and therefore they can be paid from the budget.

company, since this Act provides that it is administered by private companies, although the main elements of the insurance are defined by the Act.

Insured persons have a legal right to care vis-à-vis the insurance company or the administration of the Act on long-term care.

The main elements of the benefits for both Acts are laid down in the Acts and in decrees based on the acts. Examples for the Act on health care are basic medical care and specialist medical care, nursing at care at home, stay in a hospital. In the insurance agreement, further conditions cannot be laid down for this care.

The Act on long-term care also provides for care and personal care, nursing and accompanying.

In order to be entitled to this care an insured person must have reasonably to rely on the nature, contents and extent of the insured forms of care (Article 2.1(3) of the Decree on the Act on Health Care and Article 3.2.1 of the Act on Long-term care). For the Act on Health Care this means that there is a need for care (Article 10 of the Act). This is decided on the basis of a medical criteria (Article 14(1) Act on Health Care).

The Act on long-term care sets out more specific criteria to decide that an insured person is reliant on care. For this purpose it is not only necessary that a person needs the type, extent and contents of the care, but s/he must also have to rely on this from the point of view of effective care, because of medical or psychogeriatric restrictions or mental or physical disabilities s/he permanently needs:

- a) Supervision in order to prevent escalation or serious harm for the insured, or
- b) 24 hours a day care in his or her neighbourhood since (1) s/he is not able to call help at relevant moments and because of physical impairments needs permanent attendance, nursing or relief of caring for himself or (2) because of serious problems of controlling the situation s/he needs permanent attendance and help with tasks (Article 3.2.1 of the Act on long term care).

A special agency, the Central Body for Classification of Care (Centraal Indicatieorgaan Zorg - CIZ) decides, on request of the insured person, whether these conditions are satisfied. This is laid down in a classification decision. This decision sets out whether a person needs care, and if so what form of care and to which extent. This decision is necessary to be able to claim the care that is mentioned in it.

In order to make the decision the medical situation, living situation and the social circumstances must be investigated. If someone near to the claimant can provide the help, this is relevant to the form and extent of the care.

In order to be allowed to have a budget it is required that

- The insured person is able, in the view of the insurance company, the tasks and obligations linked to the budget in a reliable way with or without help

- The insured person is able, in the view of the insurance company, to control with or without help the care providers chosen by him or her in such a way and to coordinate their activities that there is or will be reliable care.

4. The Basic System of Assessment of the Carers

The *Centraal Orgaan Indicatiestelling Zorg* decides, as was discussed above, the classification of the claimant. This is done by a decision as to in which so-called 'care profile' the claimant fits. The care profiles are mentioned in an annex to the Regulation on long term care and indicate the level of care a person in a particular situation needs. This decision is made by the employees of this office on the basis of the information given in the application form plus additional information of the general practitioner or specialist. If necessary the employee can ask for further information from the medical doctors.

The profiles were introduced by the Ministry of Health to harmonise the level of care for particular situations.

In case of autism or mental health problems of young persons the same procedure is followed. Thus if medical assessment shows that the young person needs specific help due to a psychiatric or behavioural problem, parents can obtain a budget for the help. For this purpose a care profile, as mentioned above, is used. In that case the young person (if s/he is over age) or the parent seeks the care provider, makes an agreement and decides the payment. For these young persons the budget can be used for support of activities at home or outside the house, support to deal with problems a short stay away from home (which may be beneficial for both parents and the young person).

Thus the procedure is a form of desk review and not an examination of the person at the application stage. The medical doctors are not involved in the decision making nor do they give advice, but they can be asked to give information.

Before 2015 care providers were given the power to prepare decisions of the CIZ, in order to reduce the administrative burdens. These decisions were supervised and checked by the CIZ but since 2015 this is no longer a possibility..

In case of a review procedure or appeal it is the decision of the *Centraal Orgaan Indicatiestelling Zorg* that is to be challenged (see below).

After the decision on the classification is made, the application for a budget is made to the insurance company (in this respect insurance companies can also cooperate) and the applicable rate for the level of need is determined. If a budget is awarded, the budget holder can choose the care providers from those contracted by the insurance company or s/he can choose non-professional care givers (who may be relatives, acquaintances etc. of the claimant).

As mentioned, a contract has to be agreed which must lay down the conditions of care. This contract also specifies the level of pay but it must meet the minimum wage.

5. Review and appeals

If a person disagrees with the decision of the Centraal *Orgaan Indicatiestelling Zorg* s/he can ask for review. The procedural rules are laid down in the General Act on administrative Law (*Algemene wet bestuursrecht – AWB*). Thus the rules on this decision are the same as in other areas of administrative law.

Asking for a review has to be done in writing within six weeks after receiving the decision with the arguments against the decision. An employee of the Centraal *Orgaan Indicatiestelling Zorg* will hear the person (a person different from the original decision maker). In general review are only successful if the person provides such medical information that it is clear that the initial decision was wrong. The employee can also ask for additional medical information, from the person concerned and, with his/her permission, also from medical doctors. So the decision-making person and the reviewer do not examine the person themselves. The reviewers are legally trained and can ask medical advisors for advice.

The results of the procedures are (2014): 15% of the request for review are non-admissible (for instance because they are too late); 43% are unfounded; 17% are withdrawn and 25% are successful (page 14 of Annual Report 2014).

Within six weeks after the review decision a person can appeal to the district court and, further appeal that decision to the Central Appeals Court (Centrale Raad van Beroep). For this purpose fees have to be paid. In order to succeed, the appellant must provide medical information that shows that the initial decision was wrong.

In 2014 there were 1100 appeal cases before the court and 97 for the Central Appeals Court. Some of the higher appeal cases were by the CIZ itself, when it disagreed with a court decision. Of the appeals 11 per cent were founded (page 15 of the Annual Report 2014).

According to the Annual report 2014 5,564 reviews were requested (from 900,000 applications).

6. Overall Assessment

The Personal Budget has increased the freedom of choice of people with disabilities and their relatives and allows them to live their own living independently. This was the main conclusion of the Secretary of State on the basis of several evaluation studies.⁴⁸

There has been some discussions on how budgets have been used: for instance if horse riding is appropriate for a young person with mental or adjustment problems. People with disabilities can have a budget for being supported to live an independent life, but how far can this go? Another issue is whether payment for

⁴⁸ Tweede Kamer (Second Chamber or House of Representatives) 2004-2005, 25 657 and 26 631, nr. 29 (2004), p. 1.

caregivers creates a tension with voluntary work: to what extent does this work have to be paid. However, it is also clear that in some situations caregivers are overburdened and have often resigned from paid work to dedicate themselves to giving care.

In 2014 it became apparent that abuses of the system by budget-administration organizations were occurring. This was corrected by giving the Sociale Verzekeringsbank the task to administer the budget. The new task, which was done on the basis of strict rules in order to avoid fraud or improper use, created very long waiting-periods before the care providers were paid and subsequent stress for care givers.

The current system allows the minister to adjust the rules if necessary to correct undesired effects.

In conclusion despite problems with the system it was maintained, as the advantages were larger than the problems.

There have not been any legal challenges at national or European level to the structure of the system. As we have seen there are relatively few legal procedures, and these consider mainly the assessment of the need for care.

The PGB is seen as a benefit in kind by the Central Appeals Court, so it has to be paid only in the Netherlands (Article 17 Regulation 883/2004). However, budget holders can buy help in another country for a maximum of 13 weeks. This seems to be consistent with EU law.⁴⁹

7. Data

According to the Central Office for Statistics the 2014 total sum for the budget was 2.7 billion euros. The sum of budget holders was 120,000, so the average amount of the budget was €22,500 a year. Unfortunately data is not yet published as to the number of payments to carers or any detail as to who the carers are.

⁴⁹ See Directive 2011/24/EU on cross border health care, in particular to Article 1(3): This Directive shall not apply to: (a) services in the field of long-term care the purpose of which is to support people in need of assistance in carrying out routine, everyday tasks.

Nova Scotia

1. Overview of supports for care

Nova Scotia (population 1 million) is a province of Canada. Canada is a federal state and although social insurance payments (pensions and employment insurance) are normally a federal responsibility, support for carers and social assistance (means-tested) payments are normally provided at the level of the province and territory. Nova Scotia is the only Canadian jurisdiction which currently has a specific payment for carers (the Caregivers Benefit). However, a number of jurisdictions provide tax supports for carers including the Manitoba Primary Caregiver Tax Credit and the Quebec Tax Credit for Caregivers (O'Hara, 2014).⁵⁰

Nova Scotia has a ten year *Continuing Care Strategy* (Nova Scotia, 2006). However, this dates from 2006 (prior to the introduction of the Caregiver Benefit in 2009) and does not specifically refer to such a payment. More recently, Nova Scotia (2015) has published a discussion document on the way forward and plans to publish a new five year strategy in 2017. The discussion document provides an assessment of the implementation of support for carers and the existing challenges. It covers both institutional and community care but only makes a passing reference to the Caregiver Benefit (2015, p. 7).

There are a number of different Home/Community based-Programs available for persons requiring long-term care in Nova Scotia. As can be seen, the Caregiver Benefit is the largest in terms of persons covered.

Home & community based program	Number of clients October 2014	Number of clients October 2013
Personal alert assistance program (expanded February 2013)	511	239
Caregiver benefit (expanded November 2012)	1766	1482
Self-managed care program (expanded February 2013)	147	147
Supportive care	222	109
Home Oxygen (ended 2013-2014)	120	0
Medicated Dispenser Program (implemented February 2013)	6	6

Source: Hallal (2015).⁵¹

⁵⁰ See <https://www.gov.mb.ca/finance/tao/caregiver.html> and http://www.revenuquebec.ca/en/citoyen/credits/hebergement_parent/

⁵¹ The Supportive Care Program supports eligible Nova Scotians with cognitive impairments (difficulty thinking, concentrating, remembering, etc.) by providing them with CAN\$500 (€330)/month for Home Support Services (personal care, respite, meal preparation and household chores).

2. Description of main payment(s)

The Caregiver Benefit is a payment to eligible carers. It is not means tested as such but is subject to an income test in the case of the care recipient. The Caregiver Benefit is intended to acknowledge carers' contributions in providing assistance to a family member or friend and to assist the caregiver in sustaining the support they provide. The level of the benefit is relatively low at CAN\$400 per month (€265). The Program is an administrative one set out in the Caregiver Benefit Program Policy (revised 2012) rather than in law. It is the responsibility of the Department of Health and Wellness rather than the Department of Community Services which is responsible for social assistance payments. It is administered by the Nova Scotia Health Authority.

3. Nature of qualification criteria

For the purposes of the Caregiver Benefit Program, a caregiver is an individual who is providing unpaid assistance with ADLs and IADLs to a family member or friend. An individual is eligible to receive the Caregiver Benefit where the person

- is a resident of Nova Scotia, with a valid Nova Scotia health card number or is in the process of establishing permanent residence in Nova Scotia and has applied for coverage under Nova Scotia's Health Insurance Plan;
- is 19 years of age or older;
- is providing 20 or more hours of assistance with ADLs⁵² and/or IADLs⁵³ per week to a qualified care recipient;
- has a care giving relationship with the qualified care recipient that is ongoing, regular and is expected to extend beyond 90 days;
- is not being paid to provide assistance to the qualified care recipient;
- is determined by the continuing care coordinator to meet the eligibility criteria for the Caregiver Benefit Program;
- is willing to sign an agreement with Continuing Care defining any terms and conditions for receiving the Caregiver Benefit.⁵⁴

A Qualified Care Recipient is a person who is receiving assistance from an eligible caregiver and who is determined, through assessment by Continuing Care, to meet the qualification requirements of the Caregiver Benefit Program. An individual is

⁵² Defined as 'Everyday tasks necessary for individuals to live independently, including hygiene, toileting, bathing, dressing, feeding and mobility'.

⁵³ Defined as 'Tasks that, in addition to activities of daily living, one must be able to perform in order to live independently. They differ from ADLs in that direct contact with the individual receiving the assistance is not required to perform the act. Examples include shopping, meal preparation, laundry and light housekeeping, banking and assistance with the management of medications'.

⁵⁴ Clients are required to sign an agreement which outlines the terms and conditions that the caregiver is required to meet to receive the funding. This three-way agreement is signed by the caregiver, the continuing care coordinator (Nova Scotia Health Authority), and the Department of Health and Wellness.

considered to be a qualified care recipient, for purposes of the Caregiver Benefit Program, when he or she

- is a resident of Nova Scotia, with a valid Nova Scotia health card number;
- is aged 19 or older;
- has a MDS-HC assessment completed by a continuing care coordinator and demonstrates a very high level of functional impairment, as indicated by a score of 5 on the MAPLe (Method for Assigning Priority Levels) decision support tool, or by a MAPLe score of 4 combined with either a Cognitive Performance Scale (CPS) score of 4 or higher and/or Activities of Daily Living (ADL) Self Performance Hierarchy Scale score of 3 or higher (discussed below)
- has a care giving relationship with an eligible caregiver that is ongoing, regular and is expected to extend beyond 90 days;
- has a net annual income of \$22,003 or less if single or a total household income of \$37,004 or less, if married or common law.

The level of care required is seen by the Department of Health and Wellness as being 'a very high level of impairment or disability, requiring significant care over time'.⁵⁵

4. What is the basic system of assessment of carers?

The continuing care coordinator (CCC) - an employee of the NS Health Authority - is responsible for the determination of eligibility for the Caregiver Benefit Program. The CCC is responsible for the Case Management (intake, assessment, service planning and implementation, and ongoing case management / coordination of care) for clients within the Continuing Care Program under the Health Authority in line with the Continuing Care policies, standards and guidelines. The CCC will have a Bachelor's Degree in Nursing, Social Work, Occupational Therapy, Physiotherapy or Nutritional Studies; be registered or licenced (or be eligible to be so registered or licensed) with the appropriate provincial professional licensing body; and have relevant work experience.

As noted above, the assessment is done on the basis of a Minimum Data Set-Home Care (MDS-HC) assessment completed by the continuing care coordinator and based on scores assigned by the MAPLe (Method for Assigning Priority Levels) decision support tool possibly combined with the Cognitive Performance Scale (CPS) score of 4 or higher and/or Activities of Daily Living (ADL) Self Performance Hierarchy Scale. Nova Scotia currently utilises the InterRAI Home Care Assessment System. This is the same tool that has been selected as the single assessment tool by the HSE for its care needs assessments for older people, and is now being rolled out in Ireland in a number of trial settings.

The Minimum Data Set-Home Care (MDS-HC) assessment involves completion of a detailed form concerning the person's patterns concerning cognitive, communication/hearing, vision, mood and behaviour, social functioning, physical

⁵⁵ <http://novascotia.ca/dhw/ccs/caregiver-benefit.asp>

functioning, disease diagnosis, health status, etc. It also includes an environmental assessment (e.g. living arrangements) and an assessment of the informal supports available and services used. An example of the form is set out in annex 1. Studies have found that, where carried out by trained staff using recommended protocols, the MDS-HC assessment provides ‘a valid measure of function and cognitive status in frail home care patients’ (Landi et al, 2000). These findings point out the overall validity of the functional and clinical data contained in the MDS-HC assessment.

The MAPLe (Method for Assigning Priority Levels) decision support tool was created to assist case managers in determining the relative priority that should be attached to a client regardless of whether he or she needs community or institutional services (Hirdes et al., 2008). Instead of attempting to match client care characteristics to specific venues or types of care, the MAPLe system prioritizes clients to identify those in most urgent need of services, irrespective of the care setting. It involves an algorithm (a procedure or formula for solving a problem) developed from a large sample of existing cases. It uses the data gathered in the MDS-HC. CCCs who have completed an MDS-HC assessment can obtain the MAPLe results automatically from software in which the algorithm is embedded. The client must meet the identified eligibility criteria, including MAPLe scores, in order to qualify for the Caregiver Benefit.

MAPLe classifies service seekers/clients into five priority levels, based on their risk of adverse outcomes. Clients in the lowest priority level have no major functional, cognitive, behavioural, or environmental problems and are considered self-reliant. The highest priority level is based on the presence of ADL impairment, cognitive impairment, wandering, behavioural problems, etc. Research has demonstrated that the five priority levels are predictive of risk: Individuals in the highest priority level are nearly nine times more likely to be admitted to a long-term care facility than are the lowest priority clients. MAPLe also predicts caregiver stress.

Hirdes et al. (2008) found that ‘MAPLe provides an empirically sound decision-support system that will allow case managers to make more systematic evaluations of the needs of clients and the urgency with which they should respond to those needs’. They also found that MAPLe was ‘a valid predictor of nursing home placements, caregiver distress and ratings that the client would be better off elsewhere, and it ha[d] been shown to perform well in a variety of international jurisdictions’.

The Cognitive Performance Scale (CPS) again draws on the MDS-HC data and can be used to evaluate the level of cognitive impairment affecting a person. Studies have found that it provides a valid assessment of cognitive performance (Morris et al., 1994). Its structure is set out below:

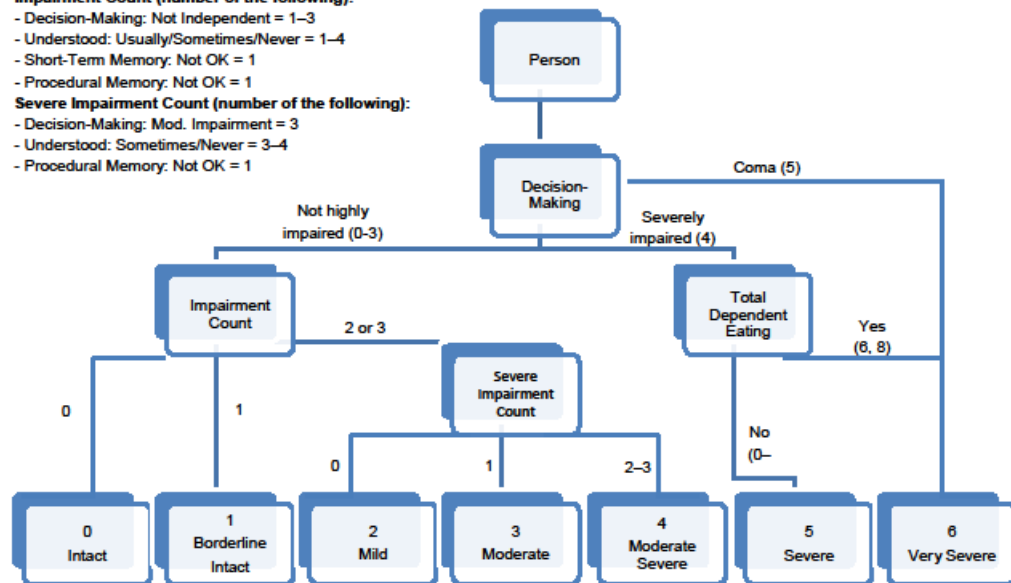
Cognitive Performance Scale

Impairment Count (number of the following):

- Decision-Making: Not Independent = 1–3
- Understood: Usually/Sometimes/Never = 1–4
- Short-Term Memory: Not OK = 1
- Procedural Memory: Not OK = 1

Severe Impairment Count (number of the following):

- Decision-Making: Mod. Impairment = 3
- Understood: Sometimes/Never = 3–4
- Procedural Memory: Not OK = 1



Source: Morris JN, Fries BE, Mehr DR, Hawes C, Philips C, Mor V, Lipsitz L. 1994. MDS Cognitive Performance Scale. *Journal of Gerontology: Medical Sciences* 49(4): M174–M182.

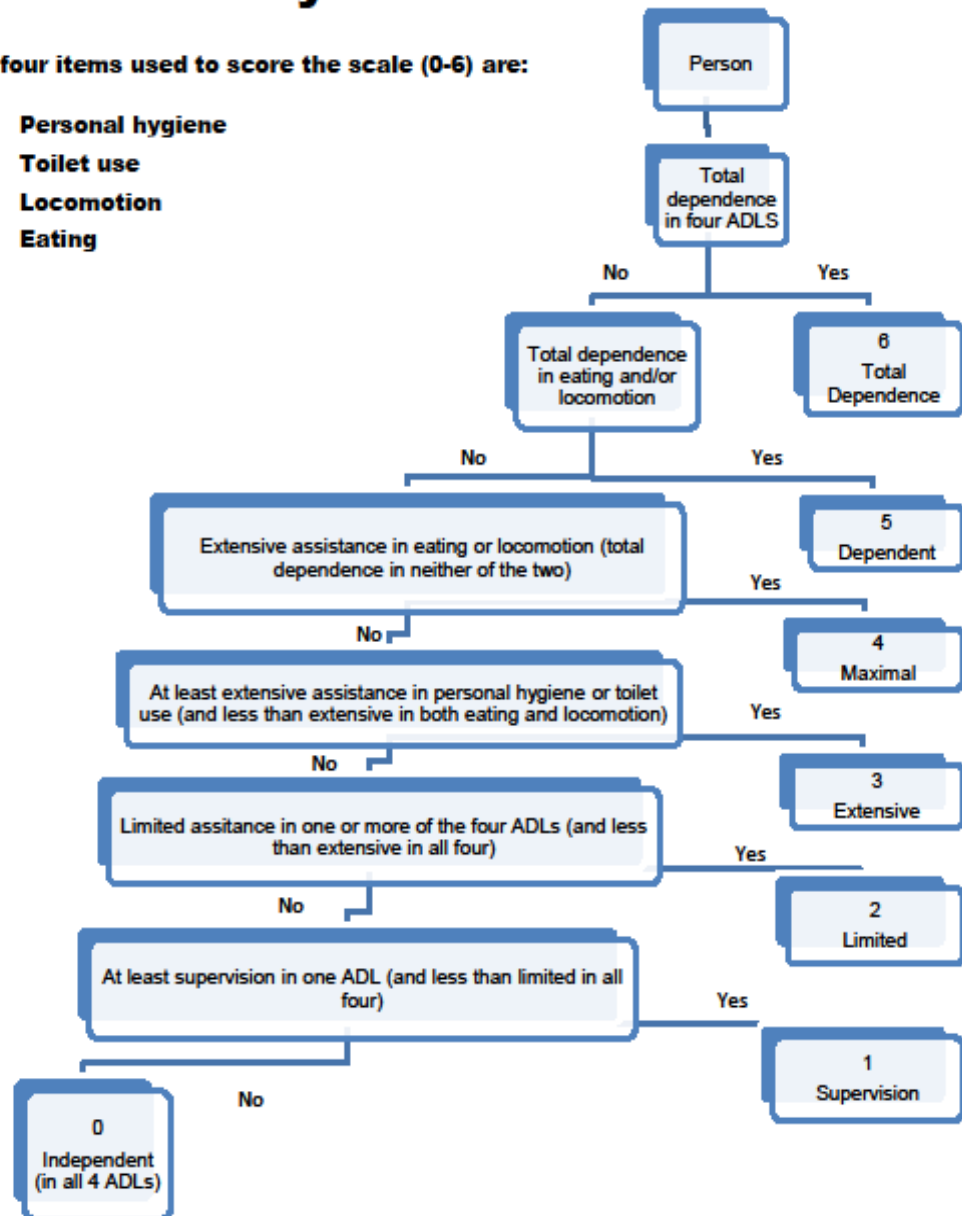
The Activities of Daily Living (ADL) Self Performance Hierarchy Scale groups activities of daily living according to the stage of the disablement process in which they occur. Early loss ADLs (for example, dressing) are assigned lower scores than late loss ADLs (for example, eating). The ADL Hierarchy ranges from 0 (no impairment) to 6 (total dependence) (Morris et al., 1999). Its structure is set out below:



ADL Hierarchy Scale

The four items used to score the scale (0-6) are:

- **Personal hygiene**
- **Toilet use**
- **Locomotion**
- **Eating**



Source: Morris JN, Fries BE, Morris SA. (1999) Scaling ADLs within the MDS. Journals of Gerontology: Medical Sciences 54(11):M546-M553.

Updated 9/2014

With respect to assessing the need for care, assessments for all Continuing Care programs are processed through SEAscape (Single Entry Access Simultaneous Client Assessment Placement Evaluation), an electronic system that automates and facilitates Continuing Care processes. The policies and business rules of the Continuing Care Branch, Nova Scotia Department of Health and Wellness, are incorporated in the SEAscape application where possible.

As noted above, Continuing Care currently utilises the InterRAI Home Care Assessment System (HC), including the foundation RAI-HC, Client Assessment Protocols (CAPS), Quality Indicators (QI's), Resource Utilization Guidelines (RUGS), and Outcome Measures.⁵⁶ The RAI-HC is used with clients to support evidence based decision making within case management and throughout Continuing Care. Nova Scotia data is submitted quarterly to the Canadian Institute for Health Information (CIHI).

5. Review and appeals

Continued program eligibility is to be confirmed on an annual basis by the CCC. Reassessments are completed annually, and include a face-to-face meeting with the care recipient and care provider. However, if, on reassessment of the care recipient after acceptance into the Caregiver Benefit Program, the Care Coordinator determines that the care recipients' MAPLe score improves as a result of being part of the Caregiver Benefit Program, the care recipient may still be considered eligible for the Program, unless he/she also fails to meet one of the other eligibility criteria.

There is an informal internal appeal system (more in the nature of a review).

6. Overall assessment

There has been no official evaluation of the Caregiver Benefit. A recent Masters thesis (O'Hara, 2014) examined the Manitoba Tax Credit and the Nova Scotia Caregiver Benefit based on a review of documentation and expert interviews. It provided a generally positive view on the impact of the Caregiver Benefit. It cited an unpublished study which found that clients who received the Caregiver Benefit were 56% less likely to be admitted to long term care.

There do not appear to have been any major legal challenges to the Caregiver Benefit in Nova Scotia. The MDS-HC (also referred to as the RAI-HC) system is widely used in assessing care needs in Canada. It has been referred to in a number of reported cases concerning appeals about entitlement to care services in other

⁵⁶ See generally <http://www.interrai.org/welcome.html>

Canadian jurisdictions but there does not appear to have been any challenge to the use of the system.⁵⁷

7. Data

The number of the number of clients in the program has increased significantly over the last few years:

31-Mar-12	31-Mar-13	31-Mar-14	31-Mar-15
1,007	1,269	1,777	1,890

The 2015-16 budget for Caregiver Benefit is CAN\$8,804,000 (€5.8 million).

O'Hara (2014) found that there were more female care recipients than male (56.7% female and 43.3% male). Since program launch, the average age of female care recipients upon enrolment has been 74 and the average age of women Caregiver Benefit clients is much higher than the average age of male clients (68 years). A high proportion of Caregiver Benefit clients (since program launch) were married (38%)⁵⁸ and a third of caregivers were spouses.

O'Hara (2014) reported that 41% of carers were children or children-in-law; 33% were spouses, 24% other relatives and only 2.5% were friends of neighbours. This had an impact on the number of hours of care. Care recipients with 'other relatives' (siblings, niece, nephew, etc.) as their care provider received the most care with an average of 68.20 hours per week. People with spousal caregivers received an average of 60.12 hours per week, those with child-or-child in law received 57.47 hours and lastly, those with a friend or neighbour caregiver received 52.11 hours per week.

⁵⁷ For example, the Ontario Health Services Appeal and Review Board has routinely upheld decisions concerning entitlement to care based on the RAI-HC, e.g. in *GM v North Simcoe Muskoka Community Care Access Centre*, 2013 CanLII 73121.

⁵⁸ 32% were widowed.

United Kingdom

1. Overview of supports for care

A National Strategy for Carers was published in 1999. This was then reviewed in 2010 after consultation. The resulting document set out the Government's priorities for carers, including:

- supporting those with caring responsibilities to identify themselves as carers at an early stage, recognising the value of their contribution and involving them from the outset both in designing local care provision and in planning individual care packages
- enabling those with caring responsibilities to fulfil their educational and employment potential
- personalised support both for carers and those they support, enabling them to have a family and community life
- supporting carers to remain mentally and physically well.

Carers strategy: the second national action plan 2014 to 2016 was published in October 2014.⁵⁹ The Department of Health is the lead department for the National Strategy for Carers. It leads the Carers Cross Government Programme Board to oversee implementation of the National Strategy. The Department for Work and Pensions has two representatives at this Board, covering their responsibilities regarding income and employment.

The legal framework for carers is provided by a raft of legislation that has been put in place in a piecemeal fashion over time with some pieces dating back more than 60 years. The law relating to carers differs across the UK and covers an extensive range of issues. The most recent legislation, the Care Act 2014 (which applies to England only), came into force on 1 April 2015. Its main provisions for carers simplify, consolidate and improve existing legislation, putting carers on an equal legal footing to those they care for and putting their needs at the centre of the legislation. The new Act significantly reforms the way social care needs are assessed, met and paid for, and how social services are provided. The Care Act is supported by regulations and guidance which provide more details on how the Act is to be implemented. The Act introduces new rights and duties including a right to an assessment of carers' needs. There are corresponding rights in the Children and Families Act 2014 which also came into force on 1 April 2015 which give carers the right to an assessment.

Under the Act, local authorities take on new functions. Local authorities now have a legal duty to assess any carer who requests one or who appears to need support – either practical or financial. These duties now include obligations relating to

⁵⁹ <https://www.gov.uk/government/publications/carers-strategy-actions-for-2014-to-2016>

information and advice, universal services, assessments and market shaping among others all applying to self-funders. It also sets out a new model of paying for care, putting in place a cap on the care costs which an individual is liable for. The assessment of carer's needs carried out by local authorities under the Care Act 2014 is separate to and independent of Carer's Allowance. The authority carrying out the assessment may draw the carer's attention to a potential entitlement to Carer's Allowance

2. Description of main payment(s)

Carer's Allowance is the only social security benefit paid specifically to carers. It is a non-contributory categorical benefit paid to a person who provides significant care to a severely disabled person for at least 35 hours a week. The 'caree' must be in receipt of one of the following benefits:

- Personal Independence Payment (PIP) daily living component
- Disability Living Allowance (DLA) at the middle or highest care rate
- Attendance Allowance
- Constant Attendance Allowance at or above the normal maximum rate with an Industrial Injuries Disablement Benefit, or basic (full day) rate with a War Disablement Pension
- Armed Forces Independence Payment (AFIP).

Carer's Allowance is currently paid at £62.10 a week into a bank or other account either weekly in advance, or every 4 or 13 weeks.

Receipt of Carer's Allowance impacts on means-tested benefits and tax credits. Carer's Allowance is not normally payable in addition to other income-maintenance benefits. The justification for this is that they are all income replacement benefits, and only one benefit can be paid for the same purpose. Where another income replacement benefit is payable at a lower rate than Carer's Allowance, a top-up of Carer's Allowance can be paid to make up the difference. From 1990, entitlement to Carer's Allowance became the passport to a new 'carer premium' included in the calculation of means-tested benefits and a person in receipt of Carer's Allowance may be eligible for a Council Tax Reduction. Receipt of Carer's Allowance may also affect benefits and Council Tax reduction of the person being cared for.

Carer's Allowance was included in the 'benefit cap' which limits the amount of benefit that most people aged 16 to 64 can receive. However, on 26 November 2015, the High Court has ruled that carers in receipt of Carer's Allowance should be exempt from the benefit cap, following a judicial review challenge to the policy.⁶⁰

⁶⁰ *Hurley v Secretary of State for Work and Pensions* [2015] EWHC 3382. This ruling will almost certainly be appealed.

Carer's Credit - a National Insurance credit to build entitlement to the basic State Pension and additional State Pension is payable to people who spend at least 20 hours a week caring for someone who receives:

- Disability Living Allowance care component at the middle or highest rate; or
- Personal Independence Payment daily living component at either rate; or
- Attendance Allowance / Constant Attendance Allowance; or
- Armed Forces Independence Payment.

It may, however, be possible for someone who spends over 20 hours a week caring for someone who does not claim one of these benefits to receive Carer's Credit.

3. Nature of qualification criteria

The eligibility criteria for receipt of Carer's Allowance are:

Carer

To be eligible for Carer's Allowance the carer must satisfy all of the following:

- be aged 16 years of age or over
- spend at least 35 hours a week caring for someone
- have been in England, Scotland or Wales for at least 2 of the last 3 years and normally live in England, Scotland or Wales, or live abroad as a member of the armed forces
- not be in full-time education or studying for 21 hours a week or more
- earn no more than £110 a week (after taxes and some other deductions). Pension is not counted as income

Different rules apply in Northern Ireland. Exceptions apply for people living in another EEA country or subject to immigration control.

As described above, receipt of an income replacement benefit may make someone ineligible to receive Carer's Allowance or reduce their carer's allowance pound for pound

The person cared for must be in receipt of specific benefits (see above).

A person can only receive Carer's Allowance to care for one disabled person, even if they are in fact caring for more than one person. If more than one person is caring for a disabled person, then only one of them can claim a Carer's Allowance. If the qualifying criteria are met the relationship of the carer to the cared for person is immaterial, the cared for person can be a partner, relative, friend or neighbour, who lives in the same or separate accommodation.

4. What is the basic system of assessment of carers?

Claims for Carer's Allowance can be made online at the gov.uk website or by a paper claim form. On the online claim form the person being cared for no longer has to sign their consent. Instead, there is a disclaimer section where the applicant for Carer's Allowance declares that they have made or will make the caree aware of the potential consequences to their benefits. A DWP Decision Maker makes the decision about a claim for Carer's Allowance based on the claim for and any supporting evidence submitted. A notification will still be sent to the caree informing them that a claim has been made and the impact this may have on their benefits. According to the Marie Curie Trust the "assessment process is very straightforward as there are only a few rules you need to satisfy." A recipient of Carer's Allowance may be offered the option of attending a voluntary work focussed interview to discuss work prospects.

As described in section 2 above, receipt of Carer's Allowance is conditional on the caree receiving a specific benefits including the Personal Independence Payment (PIP) daily living component. The next part of this section describes the conditions of entitlement and claims process for Personal Independence Payment. PIP is gradually replacing Disability Living Allowance for people aged 16 to 64. PIP helps with the extra costs arising from a long term health condition or disability that is expected to last 12 months or longer.

The PIP assessment and entitlement is based on how a person's condition affects them, rather than the condition itself. To qualify for PIP, unless they are terminally ill, someone must have needed help with extra costs caused by a health condition or disability for three months or more and be reasonably likely to need help for the next nine months

Claimants initiate a claim by phone and are sent a form to complete. When submitting the form claimants are advised to submit any supporting evidence they already hold and are asked to provide details of the health professional who they consider to be best placed to provide evidence about their condition, so that when the Assessment Provider is completing the Assessment they can request additional evidence if required.

Claim for PIP are assessed by an independent healthcare professional. DWP has appointed two Assessment Providers on a regional basis: Atos Healthcare and Capita Health and Wellbeing. The assessment involves a PIP Assessment Tool which (like the ESA process) uses descriptors. A health professional from Atos Healthcare or Capita Health and Wellbeing may contact the claimant's doctor for factual information about their patient's condition. This additional evidence will be crucial in deciding whether someone needs a face-to-face consultation. Patients give consent for this to happen as part of their claim.

Once the PIP Assessment has been completed the report and supporting evidence is sent to a DWP Decision Maker who makes a decision on eligibility. A PIP claimant is extremely likely to have to attend a face-to-face medical assessment, unless they have a terminal illness. According to the DWP, at March 2014 around 98 per cent of PIP claimants were being asked to attend a face-to-face assessment. This, according to Benefits and Work, is much higher than the 75 per cent that the DWP had anticipated, mainly because neither Atos nor Capita are succeeding in getting enough medical evidence from claimants' nominated health professionals to make decisions based solely on paper evidence.

The medical consists of several parts. First, the assessor will read or will have read any documents relating to the case. The assessor will also draw opinions from what the claimant says and does on the day and will ask the claimant a series of questions about their condition and about their day to day and, during the assessment, they may also be asked to carry out physical tasks. As with ESA, the PI assessment uses drop down lists, multiple choice answers and text boxes to record information on a computer. They may carry out a brief physical examination, checking functions relevant to the condition, for example, eyesight, blood pressure and movement in limbs. While this is taking place the assessor will be making informal observations about the way the claimant looks and behaves. Finally, after they have gone, they will list which descriptors they consider apply. A written decision is issued to the claimant.

There are several layers of quality control which include internal checks of decisions, feedback from internal mandatory reviews and from the independent appeals system, and issues identified by National Audit Office Value For Money reviews.

An early process evaluation of PIP assessment was generally positive (Sainsbury and Corden, 2014). It found that assessments were 'largely unproblematic' although some groups, including people with mental health problems, did experience problems.⁶¹ A recent study by the National Audit Office (2016) found that the contracted-out assessment providers were failing to meet overall quality targets but had performed well in relation to the target of the proportion of assessments returned to providers as not fit for purpose. However, there has been public criticism of the assessments including delays of up to 6 months to get a medical appointment. It has also been argued that 'The majority of health professionals carrying out PIP medicals are physiotherapists with very little knowledge of mental health issues, learning difficulties or more complex physical conditions. There are also some occupational therapists, nurses and, very occasionally, doctors doing assessments. All health professionals receive around a week's training in how to carry out

⁶¹ See also a study of people with sensory impairments by Ellis et al. (2015)

assessments, but much of this is about how to use the computer software and how the points system for PIP works.”⁶²

The Government has established an independent assessment of PIP assessment and the first report was published in 2014 (Gray, 2014). Gray found that the current assessment process provided a ‘disjointed experience’ for claimants and recommended a number of process improvements (including better communications). He also recommended that the way in which further evidence is gathered be improved. He concluded that it was too early to draw definitive conclusions about the overall effectiveness of the PIP assessment. He made various recommendations which have generally been accepted by Government (with the notable exception of a recommendations to put in place a rigorous evaluation strategy of the effectiveness of assessment)

5. Review and appeals

As described in the First (Incapacity) Report there are two stages to the process to appeal a Department for Work and Pensions’ benefit decision which includes Carer’s Allowance and PIP. Before making an appeal a claimant who disagrees with a decision must within one month of the date of a decision request a ‘mandatory reconsideration’. However, there is no time limit for the completion of mandatory reconsideration of decisions. Mandatory reconsideration involves, in the case of Carer’s Allowance, a Carer’s Allowance Unit Decision Maker reviewing the decision and any new evidence provided to support the reconsideration. To request a mandatory reconsideration a claimant must write to the Carer’s Allowance Unit at the Department for Work and Pensions stating the reasons they want the decision reconsidered including why they believe that the decision is wrong and including any supporting evidence. Following reconsideration a ‘mandatory reconsideration notice’ is issued to the claimant.

If a claimant does not agree with the outcome of the mandatory reconsideration they can appeal to the independent Social Security and Child Support Tribunal within a month of the date of the mandatory reconsideration decision. Late appeals up to 13 months after the date of the original decision, may be accepted if someone was ill or in hospital or coping with bereavement. The tribunal is comprised of a judge and an independent doctor.

An appellant may choose to be present at the tribunal hearing or have the appeal decided on the basis of their application form and supporting documents. An appellant may have a representative for example, a friend, lawyer or other advocate, at the hearing and request necessary arrangements for mobility or other health issues. Reasonable expenses are payable for loss of earnings, transport, subsistence etc. The tribunal’s decision may either be reported at the hearing or by post.

⁶² <https://www.benefitsandwork.co.uk/personal-independence-payment-pip/pip-medical-assessments>

A decision can be further appealed to the Upper Tribunal (Administrative Appeals Chamber) on the grounds of legal error. Decisions of the Upper Tribunal are appealable on points of law up through the hierarchy of courts to the Supreme Court.

6. Overall assessment

A Value For Money study of Carer's Allowance by the National Audit Office found that:

- The Department of Work and Pensions does not have an estimate for the take-up of the Allowance.
- The Department does not have specific employment support programmes for carers as a group, since carers are not required by law to be available for work.

The NAO VFM study recommendation to help the Department improve its services to carers included the following:

- The Department does not know the take-up rate of Carer's Allowance. The Department should estimate the take-up rate of Carer's Allowance, in order to understand the reasons for lack of take-up, where it exists, and identify what action would most cost-effectively encourage those carers who are eligible to receive benefits to do so.
- Carers need clarity about what benefits are available and to whom. The Pension, Disability and Carers Service should draw up a plan and timetable for improving communications with customers and their carer networks about the application process, eligibility criteria and interaction with other benefits.
- Jobcentre Plus should make it clearer to staff and customers what support it does and does not provide to carers. About 70 per cent of carers and a third of Jobcentre Plus Personal Advisers the NAO surveyed believe services are not as well-suited to carers' circumstances as they could be so the Department should make it easier for carers to benefit from services more suited to their needs.
- The Department and Jobcentre Plus should reinforce their communication about part-time work being a valuable and valued outcome and incorporate this message into objectives for Personal Advisers.⁶³

In response to the NAO's finding that the Department for Work and Pensions did not know the take up rate for Carer's Allowance DWP commissioned an independent feasibility study (Berthoud, 2010).

⁶³ NAO (2009) Department for Work and Pensions Supporting Carers to Care. The Stationery Office <https://www.nao.org.uk/wp-content/uploads/2009/02/0809130es.pdf>

In terms of the assessment of carer's allowance, the main issue is the assessment of the qualifying payment (currently PIP). As set out above, there has been considerable initial criticism of the approach to assessment. However, this is at a very early stage and it is probably too early to come to any definite conclusions on this issue (Gray, 2014).

7. Data

At May 2015, there were 738,000 people receiving Carer's Allowance (not including underlying entitlement cases). This represents a 62,000 increase since May 2014. Twenty-eight per cent of claimants were male, and 72 per cent were female. At May 2015, there were a further 413 thousand people entitled to Carer's Allowance but not receiving any payment due to overlapping benefit provisions (i.e. underlying entitlement cases).

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