



Federal Budget Submission 2013–14

From Recognition to Action

December 2012



Carers Australia is the national peak body representing the diversity of Australians who provide unpaid care and support to family members and friends with a:

- disability
- chronic condition
- mental illness or disorder
- drug or alcohol problem
- terminal illness
- or who are frail aged.

Carers Australia believes all carers, regardless of their cultural and linguistic differences, age, disability, religion, socioeconomic status, gender identification and geographical location should have the same rights, choices and opportunities as other Australians.

They should be able to enjoy optimum health, social and economic wellbeing and participate in family, social and community life, employment and education.

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Executive Summary

Carers Australia is grateful that the Australian Government has taken a number of steps in recent years to fully acknowledge the contribution that Australia's 2.6 million unpaid carers (including over half a million primary carers) make to both those they care for and the effectiveness and sustainability of the disability, aged and palliative care support systems. These Government initiatives include:

- The *Carer Recognition Act* (2010)
- Various initiatives under the National Carer Strategy Action Plan 2011-14
- The Better Start for Children with Disability initiative
- The National Disability Insurance Scheme (NDIS) which, although particularly directed at people with a disability, will also impact on their carers
- The Living Longer Living Better initiatives in aged care which will also be important to carers.

While carers are recognised under these various initiatives, there are still many gaps in actually delivering supports to carers. Since some of these initiatives have long timeframes, we would expect the commitments to their delivery will come into play over the coming years.

However, there are a number of more urgent concerns which need to be addressed in the short term and which are not currently identified in carer-directed policy and programs.

We are conscious that the government continues to operate in a climate of fiscal constraint. Against that background, the recommendations in this submission are focussed on:

- making existing commitments more cost effective;
- addressing regulatory constraints which undermine the intent and implementation of policy objectives relating to carers; and
- relatively minimal additional funding which will result in long term savings to the Federal Budget through assisting carers to participate in training, education and employment both in conjunction with caring and after their caring role has come to an end.

Recommendations

Recommendation 1:

In order to both recognise and support the needs of carers and to avoid unnecessary review of participants' plans by the National Disability Insurance Agency, incorporate formal consultation with carers (preferably a formal, separate assessment) under the Rules accompanying the *National Disability Insurance Scheme Act* to ensure that carers' capacities, aspirations, needs and the sustainability of the care they provide is properly taken into account when developing plans for people with disability.

Recommendation 2:

Carer-specific employment training and support arrangements to be introduced for former carers. These arrangements should apply when the person they care for has died or is being provided with care by another individual or organisation. They include:

- Appropriate counselling to assist the carer to deal with grief and adjustment issues in preparation for re-entering the workforce.
- Newstart participation requirements to be graduated over time to allow for readjustment and take into account any ongoing caring responsibilities (such as where the person cared for has moved to residential care).
- Access to appropriate education and training, and other measures, to support carers capable of re-entering the workforce to develop or refresh appropriate skills and experience.

Recommendation 3:

In the interests of fairness, good business practice and keeping carers in paid employment for as long as is feasible, amend the *Fair Work Act* (2009) to modify flexible work provisions and carer leave provisions including the following:

- Implement the recommendation of the Fair Work Act Review to extend the right to request flexible work provisions to carers looking after a person who is over 18 and has a serious long-term illness or disability or is frail aged. We further recommend that employers be required to document their response to a request for flexible work.
- Incorporate a more comprehensive definition of ‘carer’ to reflect the Government’s own definition in the *Carer Recognition Act* (2010).
- Remove the general requirement that access to flexible work arrangements is only available to those with 12 months continuous employment with the particular employer (which disadvantages carers moving into new employment).
- Extend the conditions under which carers’ leave can be used to incorporate accompanying care recipients to medical and other essential appointments.

Recommendation 4:

Review the application of FAHCSIA’s “25 hour rule” (under Australian Government (2011) ‘Guide to the *Social Security Act 1991* 3.6.4.70 Changes to Carer Situation – Effect on Carer Payment Qualifications) to remove ambiguity and perceived constraints on the capacity of Carer Payment recipients to participate in the workforce or in educational, training and volunteer work while they are in a caring role.

Recommendation 5:

- Continue to extend the eligibility requirements under the Better Start for Children with Disability initiative for children with disabilities who would benefit from early intervention. This includes most especially children diagnosed with a condition or conditions very similar, but differently named, to those already covered under the initiative and who would benefit from the same kind of intervention.

- In 2013, FAHCSIA to review take-up problems with the Better Start for Children with Disability initiative in rural and remote communities and recommend actions to address these problems. (Issues to be covered in such a review are identified on pages 14 and 15 of this submission.)

This submission has been informed by:

- *The Carer Recognition Act* (2010)
- Commitments under the National Carer Strategy (2011-2014)
- Evidence taken and recommendations of the Senate Committee of Inquiry into *The adequacy of the allowance payment system for jobseekers and others, the appropriateness of the allowance payment system as a support into work and the impact of the changing nature of the labour market* (2009)
- Evidence taken and recommendations of the House of Representatives Standing Committee on Family, Community, Housing and Youth report: *Who Cares ...?* (2009)
- Department of Education, Employment and Workplace Relations, *Towards more productive and equitable workplaces: An evaluation of the Fair Work legislation* (2012)
- Productivity Commission Inquiry reports into *Caring for Older Australians* (2011) and *Disability Care and Support* (2011)
- *A stronger, Fairer Australia: National Statement on Social Inclusion* (2010)
- *The Living Longer, Living Better* aged care reform package (2012)
- Feedback from carers and input from the state and territory carers associations across Australia.

Background: Australia's Carers

Unpaid care is essential to the continued operation of the health (including mental health), aged care, palliative care and disability support systems.

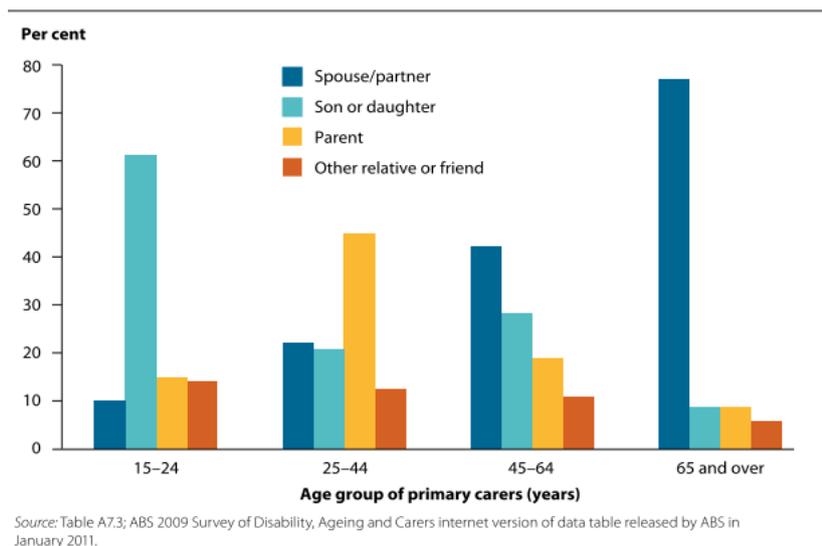
How many unpaid carers are there?

- An estimated 2.6 million or more people provide unpaid care to Australians.¹
- It is estimated that 290,000 people over 15 years of age are primary carers for one or more people under the age of 65 who have limitations in one of the core activity areas of self care, communications or mobility.²
- Over 250,000 people are primary carers for people aged 65 and over.³
- Access Economics (2010) estimated the replacement cost of informal care at \$40.9 billion.⁴
- The sustainability of both the disability and aged care systems depends heavily on these carers.

Who do they care for?

Unpaid care across all carer age groups is provided to family members as well as friends and neighbours. As would be expected, younger carers (under the age of 24) tend to care for their parents. Between the ages of 25 and 44 they are most likely to be caring for a child. Over the age of 45 they are most likely to be caring for a spouse or partner.

Figure1: Relationship of primary carer to care recipient, by age group of primary carer, 2009 (per cent)



Source: Australian Bureau of Statistics, Disability, Ageing and Carers, Australia, 2009

¹Australian Bureau of Statistics. (201. 4430.0 - Disability, Ageing and Carers

² Ibid

³ Ibid

⁴Access Economics, *The Economic Value of Informal Care 2010* (2010)

What do they do?

Every caring situation is unique and caring responsibilities can vary greatly. Caring tasks can include feeding, bathing, toileting, dressing wounds, administering medication, managing incontinence, continual supervision and assisting with communication and mobility. Carers may also care for those who are more independent, but who require some assistance in accessing education, employment, finances and transport. Emotional support and companionship is also an important element of caring. It should be noted that providing this support is often not the sole responsibility of carers. They also often have other family, paid employment and education responsibilities.

Table 1: People with severe or profound core activity limitation living in households who received informal assistance, by activity in which assistance was needed, 2009 (per cent)

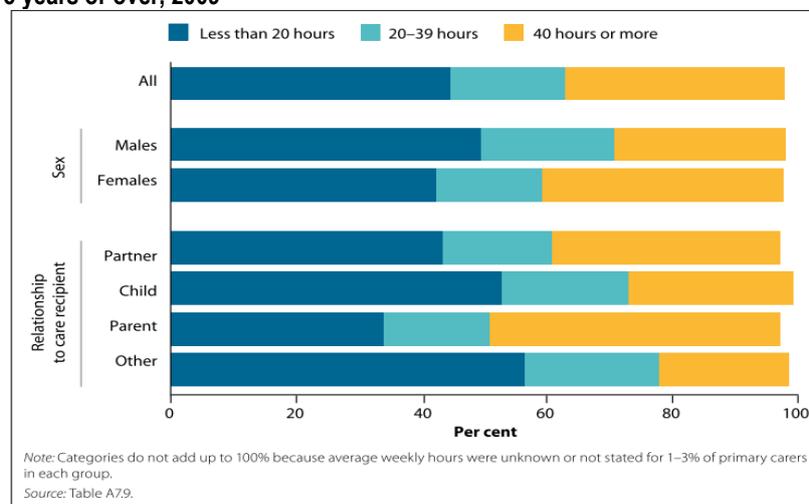
	Informal assistance only	Formal and informal assistance	Total receiving informal assistance
Core activities			
Self-care	71.1	6.9	78.0
Mobility	74.2	12.7	86.9
Communication	50.1	36.6	86.7
Total	67.6	18.3	85.9
Non-core activities			
Meal preparation	80.4	7.0	87.4
Reading or writing	84.5	*2.7	87.2
Private transport	76.6	8.8	85.4
Cognitive or emotional tasks	47.0	38.1	85.1
Household chores	63.0	17.5	80.5
Property maintenance	60.9	14.5	75.4
Health care	42.8	20.4	63.2
Total	39.3	50.0	89.3
Any of these activities	38.1	54.2	92.3

* estimate has a relative standard error of 25% to 50% and should be used with caution.

Source: Australian Institute of Health and Welfare, *Australia's Welfare* (2011)

How much time do they devote to care?

Figure 2: Average weekly hours spent providing care by primary carers aged 15 years or over, 2009



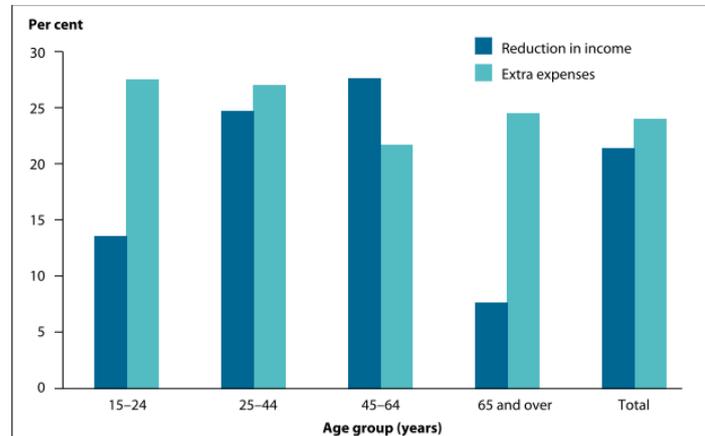
Source: Australian Institute of Health and Welfare, *Australia's Welfare* (2011)

Other characteristics of carers

Carers tend to be economically disadvantaged. Fifty percent of carers are on low incomes. Primary carers are the most disadvantaged of all carers with 62% in the two lowest income quintiles. Carers 15 years and over were more likely (49%) than non-carers (37%) to be living in a dwelling where household income was in the two lowest income quintiles.⁵

Sixty per cent of young carers (15-25 years) are unemployed or out of the workforce compared with 38% of non-carers of the same age. They are also less likely to be employed or studying (75%) than non-carers of the same age (82%).⁶

Figure 3: Main effect of caring on the income of carers aged 15 years and over



Source: Australian Institute of Health and Welfare, *Australia's Welfare* (2011)

Carers have lower general wellbeing than others. Research clearly indicates that many carers experience social, emotional and economic disadvantage. Carers have been identified as a group at risk of long-term social exclusion and disadvantage under the six priority areas of the federal government's Social Inclusion Agenda.⁷ Carers are:

- often socially isolated and disconnected from their peers as a result of a lack of alternative care;
- more likely to experience poor health;
- inclined to suffer from increased financial and emotional stress.⁸

A 2007 report on the *Wellbeing of Australians: Carer Health and Wellbeing* revealed that, among the 83% of carers who live with the person they are looking after, the level of wellbeing was the lowest ever measured for any group in 17 wellbeing surveys undertaken for the Australian Unity Wellbeing Index since 2001⁹.

⁵ABS 2009, 4436.0: *Caring in the Community*, SDAC

⁶ABS 2009, 4436.0: *Caring in the Community*, SDAC.

⁷ Social Inclusion Unit: Department of the Prime Minister and Cabinet

2009 *A stronger, Fairer Australia*: National Statement on Social Inclusion, Chapter 7, p. 42. www.socialinclusion.gov.au

⁸ Ibid

⁹Cummins, Robert et al. 2007, *Wellbeing of Australians: carer health and wellbeing*, Deakin University, Geelong, Vic..

Discussion of issues and recommendations

The following five issues in need of resolution and the resultant recommendations address in different ways the key priorities of the Australian Government's National Carer Strategy; namely:

- Priority 1 – Recognition and respect
- Priority 2 – Information and access
- Priority 3 – Economic Security
- Priority 4 – Services for carers
- Priority 5 – Education and training
- Priority 6 – Health and wellbeing

Issue 1: National Disability Insurance Scheme (NDIS) – the need to consult with carers in the formulation of participant plans

Carers Australia is very positive about the proposed National Disability Insurance Scheme and believes it has the potential to markedly improve the lives of many people with disabilities and their carers by providing them with the support and security they so urgently need.

However, the packages offered under the NDIS will inevitably be built around the amount of unpaid care already provided to many of those covered by the Scheme. We are concerned that assessors will assume that the current levels of care are sustainable without taking into account carers' ongoing capacity, aspirations and support needs.

In this context we note that in a recent National Statement to the *United Nations Fifth Conference of States Parties to the Convention on the Rights of Persons with Disabilities*, it was announced that:

“Australia's National Disability Insurance Scheme will ensure people with disability, their families and carers get the care and support they need to participate, as much as possible, in education, work and community life.”¹⁰

The importance of the role of carers is also acknowledged under Part 2, Section 5(12) of the *National Disability Insurance Scheme Bill 2012*:

“The role of families, carers and other significant persons in the lives of people with disability is to be acknowledged and respected.”¹¹

There is also some acknowledgement in the Bill of the desirability of taking into account the role of “families, carers and other persons who are significant in the life of the participant” in the preparation, review and replacement of a

¹⁰ UN Fifth Conference of States Parties to the Convention in the Rights of Persons with Disabilities, 12 September 2012, http://www.unny.mission.gov.au/unny/120912_CPRD.html

¹¹ *National Disability Insurance Bill 2012*, Chapter 1, Part 2, Section 5 (12), page 4

participant's plan. However, this is a very vague and somewhat half-hearted formulation of the need to consult; being couched in terms of "as far as reasonably practicable" and "where relevant".¹²

If the NDIS is to honour the role of carers in fact as well as in sentiment, and if individual plans are to be cost effective and sustainable, there must be some opportunity for carers to be consulted about their capacity and willingness to continue providing the assumed underlying level of support.

Some of the factors which affect the sustainability of care include: increasing age, illness, the difficult economic and emotional challenges of being an unpaid carer; and, particularly in the case of young carers, the need to access educational and training opportunities to ensure their own futures.

People with a disability may not necessarily be able to convey to a planner issues concerning the sustainability of their current care arrangements. There are many reasons why the sustainability of care may not be discussed between the carer and the person they care for. These reasons can include the unwillingness of the carer to embarrass or distress the care recipient if they are finding the task of caring increasingly difficult to sustain, or a reluctance of the care recipient to consult with the carer if there is likely to be disagreement on certain aspects of the proposed plan. There are many permutations on these basic positions, but the long and short of it is that consultation and agreement between the two parties prior to an NDIS assessment cannot be assumed – a fact that was reinforced in the extensive consultation carer engagement work on the NDIS undertaken by the National Disability and Carer Alliance in 2012.

The need to consult with carers may place some additional staff and time burdens on the formulation and finalisation of participants' plans. However, without a proper consideration of the sustainability of existing care, many plans may be based on fragile foundations and this is likely to place a greater administrative burden on the National Disability Insurance Agency as the need to review agreed plans comes into play.

Best practice would be to include under the rules governing the NDIS a formal assessment of both the person with a disability and their carer to be conducted separately (to encourage openness) prior to the determination of a package. This assessment should be enshrined in the rules.

At the very least, the NDIS must incorporate some form of formal consultation with carers as part of its processes.

Carers Australia is currently developing a checklist for carers to assist them to consider their situation, express concerns and ask appropriate questions in the context of their care recipient's engagement in the planning process. This checklist might also be of use to the National Disability Insurance Agency in undertaking assessments.

¹² *National Disability Insurance Bill 2012*, Part 2, Division 1, Section 31 (c), page 30

Recommendation 1:

In order to both recognise and support the needs of carers and to avoid unnecessary review of participants' plans by the National Disability Insurance Agency, incorporate formal consultation (preferably a formal, separate assessment) with carers under the Rules accompanying the *National Disability Insurance Scheme Act* to ensure that carers' capacities, aspirations, needs and the sustainability of the care they provide is properly taken into account when developing plans for people with disability.

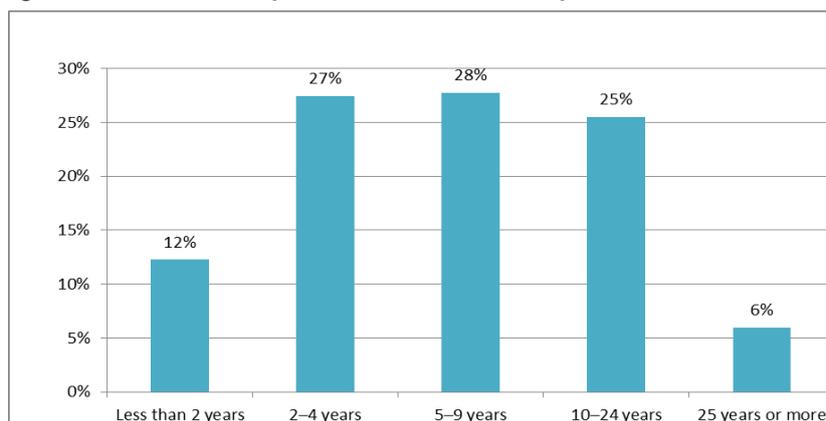
Issue 2: Transitional arrangements for former-carers

When carers cease their caring role – either because the person they are caring for has died or where alternative care arrangements are made – carers can find themselves in extraordinarily difficult circumstances. Carers receiving a Carers Payment have a 14 week period to adjust to grief and loss, a substantial reduction in income support and the daunting prospect of planning for and adjusting to a completely new way of life – often after an extended period of caring.

The fact of their previous caring role has left the carer without an employment record, referees and adequate, up-to-date skills which would enable them to re-enter the mainstream workforce.

As Figure 4 illustrates, over 59% carers surveyed by the Australian Bureau of Statistics in 2008 had been caring for between 5 and 25 years or more.

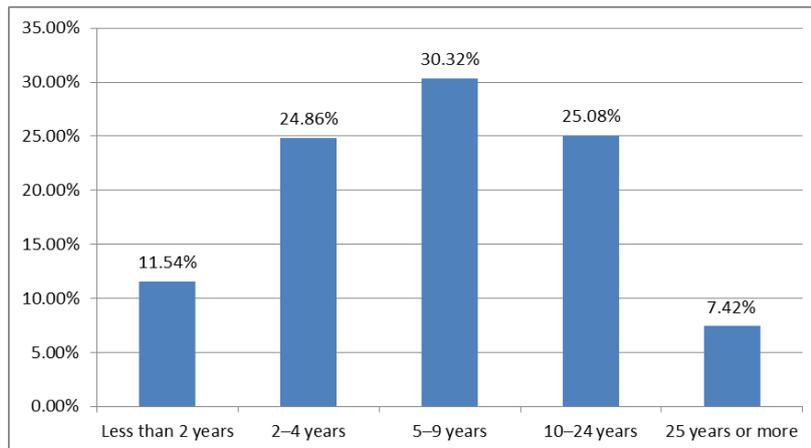
Figure 4: Years of care provided to the main recipient of care



Source Australian Bureau of Statistics, Disability, Ageing and Carers, Australia, 2009

Of the carers who provide more than 40 hours a week of care, the majority had been caring for between 5 and 9 years, although a quarter had been carers for between 10 and 24 years and 6% for 25 years or more.

Figure 5: Carers providing over 40 hours of care per week – years of care



Source: Australian Bureau of Statistics, Disability, Ageing and Carers, Australia, 2009

There are currently no specific programs in place to support people who are transitioning from a carer's role to employment.

The Senate Committee of Inquiry into *The adequacy of the allowance payment system for jobseekers and others, the appropriateness of the allowance payment system as a support into work and the impact of the changing nature of the labour market* recognised the particular problems confronted by carers and recommended that:

“the government develop targeted and tailored programs for former carers as they move to Newstart Allowance or another payment once their caring responsibilities end” (Recommendation 4.68).

Carers Australia also recommends that elements of these targeted and tailored programs include supports for former carers to enter the workforce, including: grief and adjustment counselling; access to training and education; and transitional arrangements over a period of 12 months from carer payments to Newstart allowances.

Recommendation 2:

Carer-specific employment training and support arrangements to be introduced for former carers. These arrangements should apply when the person they care for has died or is being provided with care by another individual or organisation. They include:

- **Appropriate counselling to assist the carer to deal with grief and adjustment issues in preparation for re-entering the workforce.**
- **Newstart participation requirements to be graduated over time to allow for readjustment and take into account any ongoing caring responsibilities (such as where the person cared for has moved to residential care).**
- **Access to appropriate education and training, and other measures, to support carers capable of re-entering the workforce to develop or refresh appropriate skills and experience.**

Issue 3: Employment flexibility under the Fair Work Act (2009)

It is in the interests of:

- carers,
- people they care for
- containment of the growth in social security payments, and
- the economy more generally

that carers retain an attachment to the workforce and remain in productive employment for as long as they feel it is possible.

The 2012 Fair Work Act Review recommended that the scope of the carer leave be extended:

Recommendation 5: *The Panel recommends that s. 65 be amended to extend the right to request flexible working arrangements to a wider range of caring and other circumstances, and to require that the employee and the employer hold a meeting to discuss the request, unless the employer has agreed to the request.*¹³

The Government has yet to respond to the recommendations of the Review Panel.

Other recommendations for changes to the *Fair Work Act*, which we strongly believe would not only assist carers already in the paid workforce but also carers and former carers wishing to re-join the paid workforce, are as follows:

- A definition of a carer be included in s12 of the *Fair Work Act (2009)*. We strongly urge that the definition of a carer provided in the *Carer Recognition Act 2010* be adopted. This would be in keeping with principles 6, 9 and 10 of the Statement for Australia's Carers.¹⁴
- The current provisions of the *Fair Work Act (2009)* generally restrict the capacity to request flexible working arrangements to individuals who have been working continuously for the employer for at least 12 months; or who are long-term casual employees who have a reasonable expectation of continuing to work on a regular and systematic basis for the employer. This requirement means a carer who is applying for new employment does not have a formal right to request flexible working arrangements to take account of their caring responsibilities. An approach similar to that in the *Victorian Equal Opportunity Act (2010)* which caters for new (s17) as well as existing employees (s19) would be of much more practical use to carers.¹⁵
- It would also help carers in the workforce if the paid and unpaid carer leave provisions of the *Fair Work Act (2009)* were reconsidered. The current provisions (sections 96, 97 and 102) specify that the carer can only access personal/carer leave where a person requiring care has a personal illness or injury or an unexpected emergency. The provisions relating to paid and unpaid carer leave should be extended to also cover chronic illness or disability related appointments which carers need to attend with the person for whom they are providing care. This would be consistent with the Government's commitment to the 'partners in care' concept as demonstrated in 1.5 and 1.6 of the National Carer Strategy.

¹³ Department of Education, Employment and Workplace Relations, *Towards more productive and equitable workplaces: An evaluation of the Fair Work legislation (2012)*

¹⁴ *Carer Recognition Act (2010)*

¹⁵ *Victorian Equal Opportunity Act (2010)*, No. 16 of 2010, sections 17 and 19, pages 27 and 30

Taken together, these changes would:

- give fuller effect to the intention of the *Fair Work Act*;
- assist in meeting the Government's commitment to improving the lives of carers;
- provide tangible evidence of the Government's intention to give effect to the Statement for Australia's Carers in the *Carer Recognition Act (2010)*, and
- enable more carers to participate in the paid workforce.

Recommendation 3:

In the interests of fairness, good business practice and keeping carers in paid employment for as long as is feasible, amend the *Fair Work Act (2009)* to modify flexible work provisions and carer leave provisions including the following:

- **Implement the recommendation of the Fair Work Act Review to extend the right to request flexible work provisions to carers looking after a person who is over 18 and has a serious long-term illness or disability or is frail aged. We further recommend that employers be required to document their response to a request for flexible work.**
- **Incorporate a more comprehensive definition of 'carer' to reflect the Government's own definition in the *Carer Recognition Act (2010)*.**
- **Remove the general requirement that access to flexible work arrangements is only available to those with 12 months continuous employment with the particular employer (which disadvantages carers moving into new employment).**
- **Extend the conditions under which carers' leave can be used to incorporate accompanying care recipients to medical and other essential appointments.**

Issue 4:- Review of the administration of the '25 hour rule' relating to the review of entitlements for Carer Payments

The administration of the Guidelines pertaining to Carer Payments under the *Social Security Act (1991)* have what Carers Australia believes to be an unintended impact on the capacity of carers to access educational and training opportunities while continuing to provide the equivalent of full time care. The source of the problem appears to lie in inconsistencies between different sections of the Guidelines in relation to what constitutes full time care.

To qualify for Carer Payment under the *Social Security Act (1991)* a person must be providing another person (or persons) with 'constant care'. This term is not defined in the Act, but there are administrative guidelines as to what is considered to be 'constant care'.

Part of the guidelines refer to 'constant care' being provided if the carer:

"Personally provides care on a daily basis for a 'significant period' during each day. The care may be active, supervisory or monitoring. To provide care on a daily basis for a significant period, a carer should reasonably be expected to provide at least the equivalent of a normal working day in personal care, as *the policy intent of providing Carer Payment is to recognise that the carer is not able to undertake substantial employment because of their caring responsibilities*. This includes circumstances where the carer or care receiver are absent from the care situation for part of the day, but the intensity of the care provided during the remainder of any 24 hour period is such that it roughly equates to a normal working day."¹⁶ (italics added)

However, there is also the '25 hour' policy rule which triggers a review of entitlement to payment. Under the FaHCSIA guidelines, the Carer Payment recipient will have their qualification reviewed if they 'cease to care' for more than 25 hours a week.¹⁷ Reasons for "ceasing to care" include participation in education, training, paid employment (unless that employment is home based and consistent with the care receiver's need for frequent personal care or supervision) or voluntary work for more than 25 hours per week.¹⁸ While this rule is merely intended to trigger a review of entitlement to payments, it tends to be presented as the sole determining factor in eligibility,¹⁹ resulting in considerable uncertainty among the Carer Payment recipient population, as well as presumably assessors in the Department of Human Services.

The practice of presenting the 25 hour rule as the one decisive factor in determining whether a person is providing constant care and attention not only undermines the more practical and subtle approach of it simply being a trigger for a review of entitlement (taking into account the *actual* level of care being provided over a week), but also causes considerable difficulties for certain groups of carers – including young carers trying to complete their education. The application of the 25 hour rule not only actively discourages Carer Payment recipients from participating in training and education which could assist them over the longer term (particularly once they cease their caring role), but it also acts to reduce the opportunities for these carers to participate in supportive social environments. Nor is it consistent with the policy exemption for carers who work at home. With the opportunities that technology currently offers, why should this option be denied to carers who wish to undertake online studies to achieve or improve their qualifications? Provided the overall level of care provided is sufficient, it should be largely irrelevant whether a carer participates in the workforce, undertakes study or training or engages in numerous other activities.

It is strongly suggested that FaHCSIA revisit the application of the 25 hour policy rule or at the very least provide additional information to reassure carers that the rule simply means that the totality of their caring role will be taken into account in assessing their entitlement to Carer Payment.

¹⁶ Australian Government (2011) 'Guide to the *Social Security Act 1999* 1.1.C.310 Constant Care (CP)' available at http://www.facs.gov.au/guides_acts/ssg/ssguide-1/ssguide-1.1/ssguide-1.1.c/ssguide-1.1.c.310.html.

¹⁷ Australian Government (2011) 'Guide to the *Social Security Act 1991* 3.6.4.70 Changes to Carer Situation – Effect on CP Qualifications' available at http://www.facs.gov.au/guides_acts/ssg/ssguide-3/ssguide-3.6/ssguide-3.6.4/ssguide-3.6.4.70.html.

¹⁸ Ibid

¹⁹ Commonwealth of Australia (2009) 'Government Response to the House of Representatives Standing Committee on Family, Community, Housing and Youth report: *Who Cares ...?* Report on the inquiry into better support for carers' <http://www.aph.gov.au/house/committee/fchy/Carers/report/GRwhocares.pdf>.

Recommendation 4:

Review the application of FAHCSIA's "25 hour rule" (under Australian Government (2011) 'Guide to the *Social Security Act 1991* 3.6.4.70 Changes to Carer Situation – Effect on Carer Payment Qualifications) to remove ambiguity and perceived constraints on the capacity of Carer Payment recipients to participate in educational and training while they are in a caring role.

Issue 5: Review of access to early intervention services

Currently the Better Start for Children with Disability initiative provides certain parents with much needed financial assistance for early intervention services and resources for their child with a disability. While we understand that the Government has chosen to take an incremental approach to eligibility for the initiative based on rigorous research into the benefits of early intervention for specific conditions, we are of the view that the current range of eligible conditions is far too restrictive. This is especially the case in relation to children with similar genetic conditions to those currently covered by the program and who require identical early intervention measures. We urge the Government to continue to support research into the benefits of early intervention for a broader range of conditions affecting children with a developmental disability.

That being said, there are concerns that children residing in some rural and in remote areas are finding it difficult to access the benefits of early intervention under the existing initiative. Problems arise from difficulties with access to specialist services, inadequate flexibility in the funding of support, and funding which is not tailored to the additional expenses which are incurred by virtue of different degrees of remoteness.

Carers Australia recommends that in 2013 the Government review take-up problems in rural and remote communities and recommend actions to address these problems. Some initiatives which Carers Australia believes should be given serious consideration in such a review include:

- Review of the impact and effectiveness of early intervention services, with particular attention to equity in uptake between remote, rural and metropolitan areas.
- As is the case under the Helping Children with Autism (HCWA) package²⁰, establish Aboriginal and Torres Strait Islander Liaison Officers under the Better Start for Children with Disability initiative to liaise with partner agencies, facilitate communication and problem solving with relevant Aboriginal and Torres Strait Islander organisations and communities, and facilitate sharing of effective strategies and products for increasing the knowledge of Aboriginal and Torres Strait Islander families and communities.
- Fund and implement innovative and flexible solutions to enable access to team based medical and allied health services for children living with pervasive developmental disorders or disability appropriate for a lifetime condition, and in areas where there is limited access to required services. This may include establishing options for specialist, medical and allied health care delivered to children under these programs via teleconference and videoconference. This would link to the Connecting Health Services with the Future initiative and associated Medicare items. A pilot project could be undertaken to better enable Aboriginal and Torres Strait Islander families accessing Aboriginal Community Controlled Health Services

²⁰ National Carer Strategy Action Plan (2011-14), page 15

to receive diagnosis and interventions via tele-health technologies. This could be in conjunction with the National Aboriginal Community Controlled Health Organisation's Telehealth Support project and Carers Australia's Better Start for Children with Disability Registration and Information Service.

- Create greater flexibility within the current funding arrangements, where resources can be applied to cover the travel costs of approved providers, to enable a fly-in-fly-out service to be provided where no suitable local private or public service is available.
- Change the Better Start for Children with Disability initiative's service provision allowance from a capped funding allowance in a lifetime to a set provision allowance per year for children up to 16 years of age. Alternatively bring the allowance in line with the recommendations for Chronic Disease Management which is 12 sessions per year for children after 6 years of age;
- Increase the outer-regional, rural and remote payment under the Better Start for Children with Disability program, and grade payments according to remoteness.
- Provide further funding to the National Carer Counselling Program to ensure this adequately services carers and families of children with disability.
- Ensure that the 'Better Start for Children with Disability' Early Days workshops have the capacity to provide education and training to carers and families on their rights as health consumers, how to communicate with medical and health professionals, and navigate the system in rural and remote areas.

Recommendation 5:

- **Continue to extend the eligibility requirements under the Better Start for Children with Disability initiative for children with disabilities who would benefit from early intervention. This includes most especially children diagnosed with a condition or conditions very similar, but differently named, to those already covered under the initiative and who would benefit from the same kind of intervention.**
- **In 2013, FAHCSIA to review take-up problems with the Better Start for Children with Disability initiative in rural and remote communities and recommend actions to address these problems. (Issues to be covered in such a review are identified on pages 14 and 15 of this submission.)**