Carers
AUSTRALIA

# Submission to the Productivity Commission Inquiry into Disability Care and Support

August 2010

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, mental illness or disorder, chronic condition, terminal illness or who are frail.

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. These rights should be mandated in legislation.

Carers Australia is grateful for the input from carers in developing this submission. Consultations with carers were very beneficial and their insights very valuable in assisting Carers Australia strengthen our understanding of their needs and the importance of a long term disability care and support scheme.

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| Title: | CA Submission to the Productivity Commission Inquiry into Disability Care and Support |
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# Executive summary

Carers Australia's submission is informed by input from consultations with carers from around the country. Expectations for the introduction of a Long-term Disability Care and Support Scheme (LDCSS) are high. If the scheme is made extensive enough, it has the potential to deliver real benefits over generations. Emphasis needs to be placed on the whole picture of care provision and on making caring a shared community responsibility.

The design of the scheme must include an understanding of the true nature of care delivery in this country, and appropriate support that reflects this reality, if a scheme with meaningful benefits is to be realised. The important contribution of carers to our societies is clear. Family carers are an integral part of Australia's disability, mental health, palliative care, aged and community care systems and provide the majority of care in our communities.

The needs of family carers are linked to the needs of the person with the disability but carers also have individual needs including accurate and timely service information, emotional and social support, counselling, practical assistance, financial security, respite, workforce participation, retirement funds and planning and services that acknowledge their expertise and include them in decision making where appropriate.

The scheme must be based on the following **principles:**

- Legislatively based
- Person and family centred
- Wide coverage
- Choice
- Self-determination
- Whole-of-life
- Portable
- Nationally consistent
- Fair, flexible and equitable
- Accessible and affordable
- Transparent
- Sustainable
- High-quality

Carers Australia believes is it essential for the scheme to adopt a family-centred approach to determine access to support. A family-centred assessment process would involve assessments that consider:

- the needs of the person with a disability
- the needs of the carer
- the needs of other members of the family, such as siblings or partners.

These assessments should then be used to inform the allocation of services as required and account for the true costs of care. When the needs of all individuals are given adequate attention, a family-centred approach will provide a perspective that recognises individual differences and whole-of-family needs, taking into account the wide variety of family and care structures in our society.

Carers Australia believes funding for a Long-term Care and Support Scheme should cover:

- nationally consistent and portable family-centred assessments
- an accurate reflection of the costs of care
- early intervention services
- essential care and support services including personal care, food services, medications, therapy, aids, equipment, home modifications, transport
- carer specific services including information, respite, counselling, advocacy skills and training
- services to support social and emotional needs
- an appeals and complaints process

# Introduction

Carers Australia welcomes the opportunity to provide input to this inquiry. A new approach and new thinking around care and support provision in Australia is urgently needed. This must include an understanding of the true nature of care delivery in this country, and appropriate support that reflects this reality, if a scheme with meaningful benefits is to be realised.

Carers Australia strongly supports the introduction of a comprehensive National Long-term Disability Care and Support Scheme (LDCSS). We believe that getting the scheme right the first time is important and this may mean substantial changes to our service systems. There is an assumption by many, including family carers, that this will be the solution to the majority of the current problems with the system, and will be expansive enough to cover the majority of services required by the majority of people experiencing disability and their families and carers. Expectations for the scheme are high. If the scheme is made extensive enough, it has the potential to deliver real benefits over generations. The introduction of such a scheme is a proactive response to the current inefficiencies and gaps in our care systems, and could address the pressure faced by family carers to deliver much of the care required nationally.

The Commission has been asked to consider the scheme in light of the "shared risk of disability across the population" and Carers Australia believes that caring must become a shared community responsibility. Currently an undue amount of the care required in our country falls to family carers, many of whom have limited resources as a result of the high costs of care, and often pay the price in terms of their health and wellbeing, workforce participation and limited or no retirement funds. The issues paper rightly notes that "Carers often find it hard to cope if they have to provide **most of the support** and are uncertain about future care arrangements." This inquiry must ensure that this imbalance of the care and support provided is addressed with a focus on the level of care provided by individuals. This scheme must not simply support carers indirectly, but must fund supports that are designed to directly benefit them and improve their health and wellbeing outcomes and life choices.

The Commission as part of the terms of reference is to consider the "contribution of, and impact on, informal care." The important contribution of carers to our societies is clear. Family carers are an integral part of Australia's disability, mental health, palliative care, and aged and community care systems. Family carers were recently recognised by the National Health and Hospitals Reform Commission as the "invisible health workforce" and provide 79 per cent of assistance required by Australians due to disability or illness. That is, they provide the majority of care to the majority of people needing care in the community.

Carers in Australia contributed an estimated 1.2 billion hours of care in 2005. This is estimated to be the annual equivalent of $30.5 billion of formal aged and disability care services. [i] However, the worth and value of caring extends way beyond financial or economic measures:

- carers support family members with disabilities or chronic illnesses to maximise their life and independence in the community
- carers provide care in a highly individual and flexible way
- people needing care can remain at home in a familiar environment with people they love and who have their interests at the centre of considerations
- family structures and relationships are preserved
- family members or friends experience a quality of care, not always possible in institutional and other care settings.

Carers Australia wants to ensure the voice of carers is heard as part of this process and has been funded to conduct several consultations with carers about the introduction of a Long-term Disability Care and Support Scheme. Three separate consultations have provided Carers Australia with input from over 40 carers from across the country, including regional and remote areas.[1] This submission is informed by this consultation process and we greatly appreciate these carers contributing their time, expertise and input to the process.

In this submission, Carers Australia puts forward key principles to ensure a well-delivered scheme and a family-centred approach to inform the assessment of need and eligibility under this scheme. We believe this approach has the greatest potential to most effectively meet the needs of people with a disability and the individuals and families providing care and support to them.

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[1] Consultations were held Canberra, 23 June; Brisbane, 4 August and Canberra, 9&10 August

## About Carers Australia

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

Carers Australia's members are the Carers Associations in each state and territory that deliver specialist information, counselling and others services to carers in the community through a network of over 60 sites that cover the length and breadth of the country. Carers Australia is informed about carer issues through its member Carers Associations (the Network of Carers Associations) and its participation in national and international forums.

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

## About Australia's carers

Australia has almost 2.6 million carers, and nearly 500,000 of these are primary carers – the people who provide the most care.[ii]

Carers are sometimes referred to as 'family carers' to distinguish their role from other caring roles in our society such as paid care providers, foster carers, grandparent carers, parents or guardians.

Many carers are termed 'sandwich carers or the sandwich generation' because they care for more than one person – a frail parent, a partner or a child with a disability or chronic condition. Anyone, anytime can become a family carer and the caring journey can last a lifetime. This can be from the birth of a child through to their own inability to continue to provide care because of age or illness.

Carers are from all walks of Australian society and come into the caring journey at various stages throughout their life. Carers are young, of working age, older, Aboriginal and Torres Strait Islanders, they live in our cities and towns and in rural and remote areas, and may have been born outside Australia.

The Carer Payment (Child) Review Taskforce in its report to the Australian Government that was released in February 2008 stated*…."The caring role is one of immense social and economic value. It cannot be overemphasised that the care provided is often the difference between life and death."*

### The statistics

Carers in Australia cross all age groups, cultural backgrounds and geographical locations:

- there are 2.6 million carers across Australia
- almost 500,00 are primary carers
- 380,000 Australians under the age of 26 provide care to a family member who has a disability, or a mental or chronic illness
- 170,000 carers are under the age of 18
- 31,600 Indigenous carers are over the age of 15
- 620,000 of Australia's carers were born outside Australia
- 366,700 of those born outside Australia were born in other than main English-speaking countries.

## Caring across Australia

The following numbers of primary and all family carers across the States and Territories are provided by the ABS *Survey of Disability, Ageing and Carers* (2004)

| | ACT | NSW | NT* | QLD | SA | TAS | VIC | WA |
|---|---|---|---|---|---|---|---|---|
| Primary | 3,800 | 149,700 | 2,500 | 111,300 | 37,300 | 14,600 | 116,600 | 38,800 |
| All carers | 34,200 | 748,000 | 9,600 | 535,800 | 222,700 | 69,500 | 690,400 | 246,800 |

*Note: Northern Territory figures are not provided with other state values in the ABS SDAC (2004) as the figures are not regarded as reliable. The figures provided here for NT have been calculated based on other state figures and number of carers nationally.

## Disability

According to the 2004 ABS Survey of Disability, Ageing and Carers (SDAC), there are 3,958,300 people in Australia with a disability. The age ranges for these people are 0-90 and over. The statistics also show that:

- 594,100 people live with a profound core-activity limitation
- 650,400 people live with a severe core-activity limitation
- 700,300 people live with a moderate core-activity limitation.

Of these, 1.07 million people with profound or severe core-activity limitations live in private households. And 79 per cent of people with a disability who live in households receive care from relatives and friends, mainly partners, parents or children.

In addition to people living with a disability, there are 4,149,000 with a long-term health condition.[iii]

According to the Australian Institute of Health and Welfare, and based on projected trends in the ageing of the Australian population, the broad National Disability Agreement target population is projected to grow substantially. For example the number of people aged 0-64 years with profound or severe core activity limitations is projected to increase to 752,100 people (an increase of 4.8%) between 2006 and 2010.[iv]

This data clearly indicates that the availability of Australia's carers, and their ability to continue their caring role, is critical to the long-term sustainability of the Australian health, disability, aged and community care systems.

## Principles

Carers Australia believes that the following key principles should form the basis of the scheme and would achieve the best outcomes for carers and those for whom they care. Our initial principles have been built upon as a result of consultations with family carers. These principles also address several key questions raised in the issues paper regarding the design of the scheme.

### Legislatively based

First and foremost the scheme must be supported by effective legislation and recognise Australia's commitment to the UN Convention on the Rights of Persons with Disabilities. Many carers have encountered situations where they believe their basic human rights were not upheld. For this reason, Carers Australia also supports the introduction of National Legislation that provides carers with the same rights as all other Australians.

### Person and family centred

> "I think the catch-cry for most carers would be "I'm tired" - Tired of lack of support; tired of battling on our own; tired of a government that doesn't care about the smaller issues, let alone the bigger issues, tired physically, emotionally, mentally; tired is a way of life."

It is important that the scheme takes a 'whole-of-family' approach that recognises that families have needs for support as do individuals within families. This also must take into account the changes to traditional family structures in our society as discussed later in this submission.

### Wide coverage

The issues paper asks whether the scheme should provide wide or narrow coverage. Carers Australia believes the scheme should provide assistance to all Australians with a disability their families and carers no matter how their disability was acquired, where they live, their cultural heritage or their financial situation. People born with a disability or who acquire a disability through accident, illness or progressive medical condition should all be eligible for assistance. The scheme should also provide support to those with a mental illness and their families and carers. The scheme should be no fault and should provide support for people who have a disability that impacts significantly on their daily life.

### Choice

> "Need affordable, accessible, disability designed housing."

Carers Australia believes the concept of choice is a fundamental to the scheme and key to any improvements in the lives of carers, people with a disability and their families more broadly. Currently many family carers feel as if they are provided with little choice in their access to services and few viable alternatives to the care they provide. There needs to be adequate and quality formal services available to assist carers in their role and the person they care for or enable them to make choices about alternative care arrangements should they need to access them.

### Self-determination

Carers and those they care for and support must be able to lead decisions regarding their access to services and support. This principle also supports the concept that there should be enough flexibility in the system to allow carers and those they support to access a range of options and be provided with real choice. To support this principle processes for engagement with carers and people with a disability at all stages of access to services under the scheme is essential.

### Whole-of-life

"My daughter was born disabled.  First help we ever got was when she was old enough to get a pension."

Services and support should be delivered at all stages of the life-course of the person with a disability and their carers and families with an awareness that needs will change over time.

### Portable

In maximising efficiency and effectiveness, the scheme should also establish national standards and ensure portability across jurisdictions. Many services are not portable across state/ territory and program boundaries. This means people with disabilities and their families can receive different services with different names, eligibility, fees and allocation if they move to other areas and interstate.[v]

### Nationally consistent

"Services don't exist in rural areas – and this scheme needs to remedy that."

A nationally consistent scheme and services will address barriers that currently exist regarding relocation and inequities in service access resulting from geographical location. This principle also further supports the principle of portability.

### Fair, flexible and equitable

"It's not fair that I get the support that I need, but others with the same disability that I talk to are getting so much less."

The system should essentially operate fairly with a view to promoting equality in service access and support. All people with a disability and their carers should be entitled to the support they require to be full and equal participants in the economy and the community. It must also be flexible enough to accommodate individual differences and to recognise that needs change over a person's lifetime and based on circumstances. People with similar disabilities may have very different needs. The scheme must be flexible enough to allow carers to make realistic choices about the care they provide. This is also supportive of the key principle of choice. There should also be capacity to allow access for carers and people with a disability to whichever system best meets their needs, for example, it may be beneficial for some people with a disability to access the support provided under other care programs rather than the disability sector.

### Accessible and affordable

"Financial burdens on a weekly basis eg for therapy, as part of a long-term plan to assist our daughter to develop more independence are a constant concern."

The scheme should be accessible and affordable for all regardless of location, cultural background, financial capacity or other situational factors.

### Transparent

"A national lifelong entitlement scheme needs for every dollar to be transparent and must account for how many dollars actually gets to the person who needs it."

Currently there is concern that it is very difficult for those accessing services and the broader public to know how funding is being spent, how services are being delivered and to whom. Greater transparency is needed in the introduction of a new scheme. There is also some concern regarding who gets paid, and what proportion of funding goes to providers or administration costs currently. Payments that go directly to families to purchase or broker services may allow families to have greater clarity regarding how much money they are being provided with and where it is directed to.

### Sustainable

The scheme must be sustainable over the long-term which factors in the lifetime approach to provision of care. Financial sustainability is one aspect, but a sustainable system must also address issues such as capacity, workforce development, infrastructure, research and innovation. It must ensure supports and services are available through a diverse range of organisations, which themselves must be viable and sustainable. Investment in carer support must also be made in ensuring the sustainability of care provided by family carers.

### High quality

“Longing for respite but I have a fear of trusting others to look after my child.”

An increase in the accessibility of services and supports will not achieve better outcomes if these services are not of a high quality. Feedback systems and a focus on ongoing improvement are key to this principle.

## The definition of long term

In addition to these principles, the concept of ‘long term’ could substantially change the focus of the scheme and those able to apply for support under it. As the issues paper notes, “The focus of this report is on long-term needs, but it is not yet clear how long-term should be defined, or how often a person’s needs should be assessed as they age.” Carers Australia believes that ‘long-term’ should not necessarily refer to the length of time an individual experiences disability.

The issues paper suggests that short-term disability may refer to those who are only expected to experience disability for 7 to 12 months and this would exclude short-term disability from coverage under the scheme. Those disabilities with relatively short expected time frames can often have long-lasting impacts on the lives of those experiencing them, particularly without support, for example in the case of terminal illnesses, or mental illnesses that are episodic in nature. The intensity of short-term disability should not be overlooked.

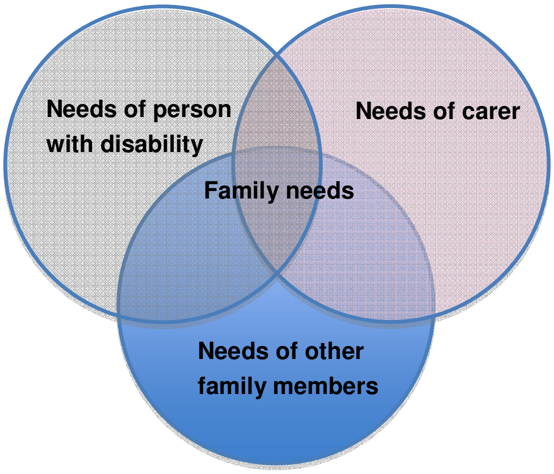
Many of the family carers that Carers Australia consulted with did have long-term needs or had been caring for someone for many years, several cared for adult children with a disability. However, there was also an expressed belief by many of these carers that those with short-term care needs should not be excluded from the scheme.

## Family-centred assessment

The issues paper asks about “the factors that affect how much support people get and who decides this.” Carers Australia believes is it essential for the scheme to adopt a family-centred approach to determine access to support. This involves looking at family as a whole and assessing family need and under this, assessing individuals within the family and their needs.

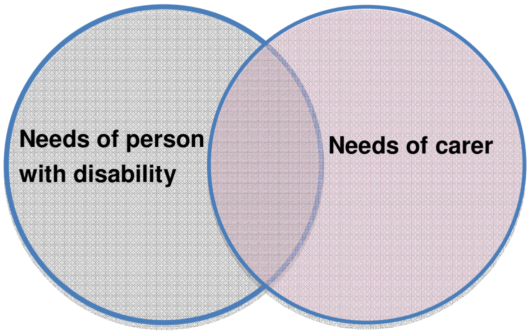
A family-centred assessment process would involve assessments that consider:

- the needs of the person with a disability
- the needs of the carer
- the needs of other members of the family, such as siblings or partners.



*Care for a family member: separate needs assessments for the needs of all members of family*

It should also be noted that a family-centred approach may take into account other caring relationships that occur outside of direct family relationships for example where a friend provides care to another friend.



*Care for a friend: separate care assessments for friend and person needing support*

Further, many people with a disability will not have any family members or friends who provide them with care and support and instead receive support through formal care arrangements. In this case the person with a disability should still receive a single comprehensive assessment of their needs. Regardless of the individuals involved in the caring situation, emphasis needs to be on the whole picture of care provision and those involved in it.

These assessments should then be used to inform the allocation of services as required. This kind of holistic thinking provides the family with a balanced approach to the provision of care. When the needs of all individuals are given adequate attention, a family-centred approach will provide a perspective that recognises that individuals are different and that one size doesn’t fit all.

These assessments should not be used to ‘rank’ severity of need, but to assess and reassess the different needs of individuals with different circumstances. All parties should have a good understanding of how the system views their level of need. Further, like the scheme itself, the assessment process must be nationally consistent and portable.

In terms of who administers assessments, Carers Australia believes that professionals have a role to play in directing people to access the services they need and undergo assessment. In many cases hospitals and specialist services will be the place of diagnosis. Carers in our consultations have also noted that Centrelink is well positioned to deliver information on a range of issues and perhaps even to provide information pertaining to assessments. It is likely however, that a separate body will be required to oversee the work of trained assessors.

Some carers raised parallels with the ACAT assessment for aged care support and services, stating that it could provide a model for a new form of care assessment under this scheme. However it was also noted that the ACAT process was not extensive enough to provide an assessment of the needs of family carers.

## The costs of care

Additional costs are experienced in families where there is a disability or illness. These are the costs that family carers find eat into savings and add significantly to household expenses. Any package for the person with a disability and their carers must include funding to offset the additional costs of care.

These costs include:

- essential care – e.g. day to day costs of personal care, special food, additional utility costs, continence products, transport, medical care – e.g. range of therapies (speech,occupational,physio), medications, equipment and aids, accessible housing
- other costs – home modifications, home help
- carer support costs - training, respite, support groups, counselling, advocacy
- opportunity costs – e.g. impact on the carer of not being in the labour force (therefore impact on government of lower tax bucket and additional costs in income support), replacement value of the care provided by families.
- social and emotional costs – e.g. relationship breakdowns and its cost impact, social exclusion – i.e. not being in the workforce and social isolation because of disability and/or caring for that person.

Family carers have provided Carers Australia with tangible examples of their own caring costs and the impact this has had on their wellbeing and financial situations. One such case study is attached at the end of this submission (see Attachment A).

## The needs of people with a disability

The support needs of people with a disability include practical supports which would be identified under a family-centred assessment process. This may include supports such as paid care provision, therapies and aids and equipment. There are also important supports that fall outside of those that may be seen as the 'essential' care needs of the person with a disability.

It is important that the scheme is made comprehensive enough to cover services that meet other primary needs of the person with a disability. This includes support outside of the home such as support at school and day care, and services to assist young people with a disability in education and work and the costs associated with transport including vehicle modifications.

It is also vital that the scheme has the capacity to fund supported accommodation, social housing and other alternative housing and care options. Currently people are waiting years or even in many cases decades for this form of support to become available. Accessibility and availability of these important services is also a key issue.

"I have other children who say they would look after their brother, but I don't want them to have to life I've had. We need more accommodation options for our adult disabled children"

## The needs of carers

The Issues Paper asks "How can the scheme take account of the needs of carers?" and "should carers' needs be factored into eligibility" As carers are the main provider of care in the community, the scheme must take their needs into account. A simple scenario to demonstrate the importance of this occurs where the carer is unable to continue caring because of illness, injury or other life events. In this case the impact on the systems is two-fold.

The needs of family carers are linked to the needs of the person with the disability, but carers also have individual needs including counselling, practical assistance, education and training, financial security, workforce participation, retirement funds and planning. The availability of all of these supports can also have significant impacts on their health and wellbeing outcomes and life choices.

### Respite

Respite is a key service for many carers. We often hear that respite is still difficult to access, and those who do access it find that is does not meet their needs, or that there simply aren't enough hours available to allow them to have a real break (see for example the case study at Attachment B).

Respite must be included in the services that can be accessed under the scheme, particularly given that it has a history of being delivered as a form of disability support.

It should be considered however that a lot of the respite currently delivered does not take into account the needs of carers, but is instead designed to account for the care requirements of the person with a disability. Carers are also often hesitant to utilise respite because of perceptions about quality or appropriateness of services.

"I haven't had a holiday in longer than I can remember. The last time I had respite my daughter was mistreated. She fell and broke her hip and no one got her medical treatment."

Other supports may include respite for vacations to allow the carer to have a substantial break. There was a strong expressed need among the carers consulted for this submission that other forms of respite to allow the carers to access volunteer opportunities, attend training sessions and support groups could be considered in the delivery of respite services.

The AIHW has suggested also that “Paid recreation leave for carers could help carers meet the extra costs associated with taking a holiday, e.g. paying for a family member to come and look after the person with a disability for a few weeks.”[vi] This is a formal process that should be included under the scheme.

### Counselling

Counselling for carers is a vital service that maintains and supports their emotional wellbeing and capacity to provide good quality care in the long-term. Counselling can be delivered in many ways such as face to face, over the phone, on line and in groups. Carers consulted have raised the importance of counselling to their wellbeing and the need for increased counselling services.

Carers Australia believes counselling for carers must be included under the scheme.

### Education and training

Evidence suggests that education and training significantly improves carers’ capabilities and resilience and this can have ongoing benefits for their health and wellbeing. [vii] Education is also shown to be an important psycho-social intervention that can lessen the negative impact and improve the carer’s capacity to manage and continue in their caring role.[viii] Training in injury prevention for example can significantly reduce the risk of injury as a result of caring.

Many carers are under-prepared for the level and intensity of care that is needed, particularly where the care involves a high level of physical lifting, medication and other health care management, therapies and emotionally supporting their family member. Often carers are left to ‘learn as they go’.

Ensuring family carers have the necessary skills and knowledge at the right times in the caring journey is an essential component of carer support and preparedness. It would be greatly beneficial to have education and training for carers included under the scheme.

### Financial security

> “Owning our own home and not having to pay rent is the only thing that helps us survive financially”
>
> “If we [family carers] were paid the same wage amount as a paid care worker we could pay tax and have superannuation”

Caring is not financially sustainable for many carers and this is just one of the pressures that can increase the difficulty of providing care in the home. Carers currently carry an unfair load of the cost of care comparative to government expenditure on supporting their needs.

Many carers receive financial support through Centrelink in the form of Carer Payment, Carer Allowance and other payments, but still find that it does not offset the costs related to caring.

Carers Australia believes that the current inquiry should investigate the feasibility of a superannuation scheme to assist carers to plan for retirement and as one solution for providing increased financial security for carers.

### Employment support

> “Cannot work with the inconsistency of service providers so I learned to live with the fact that I cannot return to work. It took a number of years to get over that I had to leave work, but I liked what I did.”

Work provides income and the ability to save, but also a sense of self-worth and opportunities for socialisation.

Carers often have difficulty engaging in the paid workforce because of the demands of their caring role. Carers currently experience significantly lower levels of workforce participation than the general population. The labour force participation rate for primary carers is only 39%.[ix] In total, only 56% of all carers are in the paid workforce compared to 68% of people without caring responsibilities. Given there are 1.8 million carers of workforce age in Australia, the population affected is considerable.

Importantly, in an environment of skills shortages, carers are also a significant group of skilled workers that are underutilised in our present economy. Almost half (47.9%) of carers have a qualification at certificate level or above, only marginally below that of non carers (50.8%).

Many carers consulted highlighted the value of workforce engagement (even where it was part-time) in providing another form of respite from their caring role and a wish to engage in the workforce. Carers Australia believes that all carers who wish to participate in paid work should be supported to do so, and incentives to support carers to work should be considered for carers and employers under the scheme.

## Overarching needs

There are some needs that are relevant to all parties involved in care and support and can be met through the existing services of sectors outside of the scheme. It has been noted in particular that health and wellbeing needs should be supported for all individuals involved in family-centred assessments.

Carers Australia believes that services to address broader health needs should remain under the health system, however there is potential to fund services and supports to improve the health and wellbeing of carers and those for whom they care.

A study by Deakin University found that carers have the lowest health and wellbeing of any group yet studied[x] and as such, carers may benefit greatly from funded interventions such as preventative health checks. We believe the commission should give consideration to the inclusion of targeted health support for carers and people with a disability and their families under the scheme.

The AIHW has also suggested that "carers injured in their caring role need access to compensation or insurance."[xi] This issue should be considered under the scheme.

Measures that address social inclusion, and support a sense of self worth and purpose, or provide the ability to pursue interests and goals has also been highlighted as an important area of support for both carers and those who they care for. Emotional and social needs must also be addressed through specific supports and services.

## Specific needs

One of the benefits of assessing individual needs of all parties using the family-centred model is that other situational factors or additional needs can be identified and better addressed. These may include supports that focus on the needs of particular groups of carers or people with a disability such as older carers, Indigenous Australians, those from CALD backgrounds, carers in regional and remote areas, Gay, Lesbian, Bisexual, Transgender, Intersex (GLBTI) carers and young carers.

## Reassessment and review

Carers consulted about the scheme were quick to note that there may be a need for ongoing assessments to determine access to services under the scheme as circumstances change. The principle of flexibility applies here in that the scheme should ensure that people are not 'locked in' to one package of care and support.

It has been suggested in consultation that, based on the principle of enhancing self-determination, individual carers should prompt reassessment. Reviews asking carers to confirm the status of the person they care for have not worked well in the past (see section on proving eligibility).

However, other carers have noted that they would prefer an automated system where they did not have to 'remember' to request reassessment. Agreeing on times for review on first assessment would provide clarity for carers and avoid situations commonly occurring where reviews ask about changes in conditions that have stable qualities over time and request proof of the ongoing nature of such disabilities or conditions. This is often very traumatic or upsetting for family carers.

A system that allows for reassessment on request but has timeframes agreed upon for review of the assistance or package of care and agreed at time of first assessment may be a good solution that meets the needs of those who experience changes in circumstances.

### Appeals and complaints process

The issues paper asked "how to give people with disabilities or their carers more power to make their own decisions (and how they could appeal against decisions by others that they think are wrong)"

The scheme must involve some form of independent appeals process for family carers regarding the services they or the person they care for has been allocated and the process for determining eligibility. The model used for the Aged Care Complaints Investigation Scheme may have some merit as a starting point for an independent complaints process. It is important that carers are encouraged to use any such service and do not feel that doing so may lead to loss of services or retribution through service providers.

In the implementation phase of the scheme there must also be clear processes to provide feedback on its progression and usefulness. The direct feedback of family carers and their unique perspective could assist greatly in the improvement and effectiveness of the scheme.

Family carers also often note that there is no formal national and independent complaints process for respite services and other carer and disability support services. There is a significant need to consider the introduction of such a complaints scheme that accounts for respite service delivery.

## Funding issues

In summary, Carers Australia believes funding for a Long-term Care and Support Scheme should cover

- nationally consistent and portable family-centred assessments
- an accurate reflection of the costs of care
- early intervention services
- essential care and support services including personal care, food services, medications, therapy, aids, equipment, home modifications, transport
- carer specific services including information, respite, counselling, advocacy skills and training
- an appeals and complaints process

### Taxpayer funded

The issues paper asks "how to finance a new scheme so that there is enough money to deliver the services that are needed and provide greater certainty about adequate care in the future."

Consultations with carers have indicated they would be supportive of a Medicare-style scheme that is taxpayer funded and distributed by the government. It has been suggested that it is important to see the funding of disability care and support as a community responsibility, with all members of society, who have the means to do so, contributing.

It was not suggested however that the scheme should necessarily closely resemble the current Medicare system in any other regard. Elements of the Medicare scheme including the levy process, rebate system or bulk billing process would not necessarily be appropriate for the funding of a Long-term Care and Support Scheme.

There was optimism that this could be a reform delivered on the same scale as the introduction of Medicare and that a similar name may even help to build community support for the scheme.

Carers Australia believes for example that a rebate-style system would disadvantage some carers who would not have the initial funds to cover the access to services upfront. It is important that carers are provided with services that are fully-funded from the outset, or that carers are provided with allocated funds that can be used to purchase services. They should not be left out-of-pocket when accessing services, even in the short-term.

## No insurance model!

There was a very clear message provided during consultations that this scheme should not operate as an insurance scheme or be named as such. The central reason expressed for this was the belief it would not encourage carers to engage with the scheme or the community to support the scheme due to negative associations with the idea of insurance. These negative associations include commonly held views that insurance processes are generally complex, difficult to claim and act in the interests of profiteering for private companies rather than benefiting individuals accessing the insurance.

## Consumer directed care or individualised budgets

In terms of the allocation of funding to those eligible under the scheme, there is general agreement among carers consulted that if the scheme is person and family centred it will allow for some form of Consumer Directed Care (CDC) in the funding of services, or option to access service paid for using a CDC model.

It should be recognised that some carers will not wish to negotiate the complexities of service delivery, others will. Carers want choice, to opt-in or out of a scheme, and to choose their level of involvement and interaction with a scheme and the services it provides.

Many see CDC and individualised budgets as key to providing carers with choice and Carers Australia believes it could assist carers to get the most out of allocated funding and feel more involved and in control of the process of services they access. Individualised budgets could be allocated separately for the person with a disability and the carer. However it is structured, choice is important as is the ability to opt in or opt out.

## Brokerage and case management

If an individualised budget system is introduced there must be safeguards for those who are not well-equipped to make this level of decision or seek out services or have no wish to do so. Brokerage is an option for those who could not or do not want to organise their own individualised budget.

Many carers have suggested that it would assist them greatly to have someone who had a good knowledge of services to take over the coordination aspect of their role and inform them of services they may be eligible for through a ‘case management’ process. This may also be an effective way to assess the needs of individuals within a family centred assessment process.

Family carers that Carers Australia consulted discussed the benefits of accessing someone who was designated to their family to assess needs and inform them of services and support available and assist in filling out forms and negotiating application processes. If a family-centred assessment takes place, assessors may be able to also perform some case management duties to ensure that initial access to services is managed effectively and to provide information on other forms of support.
Carers Australia would suggest that the inquiry give consideration to the direct funding and provision of a model of case management services under the scheme for those carers wanting to access it.

### Purchase of additional services

Carers Australia also believes the scheme should allow for the additional purchase of services. Individuals should be able to purchase services and support separately where they can afford to do so but it is imperative that this does not come at the expense of access to services for others and should not provide a better 'standard' of service. All services provided must be high-quality.

In our consultations with carers it was discussed that it may be very important in particular to have the capacity to contribute additional funds to upgrade aids and equipment where required, however this is largely due to the reported inflexibility in the aids and equipment available under the current system.

## Improvements to the system

The issues paper asked "how to improve service delivery — including coordination, costs, timeliness and innovation."

There was a very clear message in our consultations that *availability* of services and support alone is not the only challenge. It also essential that services are good-quality. There are several key improvements that could assist in the quality of formal care and services currently provided.

### Workforce issues

Training for support workers is a key element of the delivery of good-quality services. It is greatly needed and without it, services will not be better delivered. Some carers believe the current workforce is under funded and under qualified, others noted that they do not have the capacity to choose the workers who best meet their needs. Skills and attitudes are equally important for any workforce especially in relation to workers valuing the expertise of family carers.

Many carers find ways of securing the support workers they want to work with through careful negotiation of the system, but note the complexities in doing so (see for example the case study at Attachment B). Some carers also noted that they provide formal care workers with personal training regarding the best ways to provide care for the person they care for in their absence and find this is the best way to ensure that formal care is of good quality and delivered appropriately.

There must be consideration given to current processes that prevent carers and those they care for accessing the supports that will best suit their needs.

### Streamlining funding

"Centralise the funding into one national body so everyone doesn't get a bit of it before it gets to us."
In consultations many carers expressed frustration with the delivery of funding through the state and territories and a preference for funding to be managed at a national level. It was felt that bypassing state and territory-level

administration would simplify the process, provide overall cost savings and greater clarity regarding where and how funds for services were being spent.

## Improved information provision

A familiar phrase when carers are talking amongst themselves is “why didn’t someone tell me about that? Or “why wasn’t I told?”

Many carers are unaware of the services and support available. There is a strong need for carers to be well informed about any support or services to be funded under the scheme and the operation of the scheme itself.

For example, the AIHW has shown that respite services tend to be underutilised by carers often simply because they do not have enough information about services available.[xii]

## Duplication in system

The issues paper asks about “getting rid of wasteful paper burdens, overlapping assessments (the ‘run around’) and reducing duplication in the system.”

“Every 12 months I have to go get my older son’s condition reviewed by the doctor. He is not going to get better!”

Carers have expressed a preference for information that could be used across multiple applications for services, particularly where the application process would require the certification of a medical professional. The costs associated with making appointments with medical professionals to fill in forms can be significant and may be avoidable with improvement.

There has been an expressed need in consultations to reduce the need to repeatedly prove eligibility for different forms of support. The scheme could play a role in streamlining processes where carers would be providing similar information to access different services. The overarching family-centred assessment process suggested in this submission may assist in this challenge, providing a single assessment to access multiple services.

## Unintended consequences

Carers Australia is always greatly concerned about the impact of unintended consequences of new policy, programs or legislation on family carers. Given their vulnerability to significantly reduced outcomes in a number of areas, carers often cannot afford to be negatively impacted by these consequences.

Carers Australia advocates for the inclusion of a ‘Carer Impact Statement’ in all new policies and programs of relevance to carers to assist in the mitigation of any potential negative outcomes that may arise.

Family carers have raised the following potential negative outcomes of the introduction of the scheme in consultations:

- limitations on current funding or loss of current services
- increased costs to be base rate of services to meet any additional funding provided
- public misconceptions around lack of need for support
- increases in ‘top heavy’ bureaucratic models
- the creation of a service industry designed only for profit
- families being uninformed about changes
- little real change or action

- increased difficulty in accessing Centrelink payments.

All of these potential negative outcomes should be given serious consideration in the design of the scheme through the inclusion of a Carer Impact Statement in the introduction and design of the scheme where relevant.

# Linkages

Linkages with other sectors and services including education, income support, health, aged care and housing must be considered in the design of the scheme. Carers Australia believes that services available in these sectors should remain under the umbrella of the sectors. However, it is important that the scheme consider ways in which essential supports could be made easily accessible as a result of the scheme and funded through the introduction of processes across these broader portfolios.

## Aged care

The interface between disability care and aged care is of particular concern regarding access to this scheme. The restriction of the scheme to those not suffering ‘aged related disability’ could result in many additional complexities in the lives of individuals who are ageing with a disability, those who acquire a disability at a later life-stage, and those who are not ‘aged’, but experience traditionally age-related illnesses such as younger onset dementia.

Importantly, once a person with a disability is over 65 they must be able to access whichever system suits them best: disability or aged care system. There should not be an assumption that once the person reaches 65 they will automatically shift to the aged care system.

There is also a concern regarding how people who are not aged, but have disabilities that are typically seen in aged populations, will be treated. For example, carers of people with Younger-onset Dementia believe the expertise currently exists only within the aged care system.

## Centrelink

Many carers receive income support from Centrelink or live with others who do. Carers Australia believes any new scheme introduced should not impact on the income support provided to carers and people with a disability by Centrelink.

Centrelink has also introduced processes to streamline the collection of information. These processes may assist also in streamlining information required under assessments for this scheme to determine eligibility. The government agency was also identified in consultations as having the capacity to play a key role in informing people about the scheme and services and support provided.

## Existing services

The issues paper asks “how to ensure that any good aspects of current approaches are preserved.”

There is a clear need for a way of identifying positive services and safeguarding the current services and packages that are working well for people with a disability and their carers. There may be a need for a mechanism that has the capacity to consider individual circumstances and ensure that people are not worse off under the changes introduced through the scheme. For example a case management process or complaints system may be effective mechanisms to support this aim. There should also be no obligation to switch from current services to those provided under the new scheme.

Whether these potential difficulties will arise will also depend in part on the design of the scheme. It is as yet undecided whether the scheme will sit alongside existing arrangements or will provide a new overarching approach that encompasses existing services. For example, feedback from carers indicates that programs and services which focus on early intervention have proved very valuable for many and should be maintained, or replaced with equivalent services.

The issues paper has asked “how long would be needed to start a new scheme, and what should happen in the interim?”

During consultations with family carers there was clear feedback provided that despite the length of time that it may take to see this scheme implemented, there is an urgent need for ongoing improvements to the current service system. Solutions to this issue cannot wait for the realisation of a Long-term Disability Care and Support Scheme.

Many carers in consultations discussed the benefits of the packages that they had been able to secure for the person they cared for or themselves. They were very clear that they would be greatly disadvantaged if the changes in the system removed services, even in the interests of supporting others. Generally it was recognised that more was required for the majority of carers even where certain elements of support currently accessed met many of their needs.

## Conclusion

There is potential for a Long-term Care and Support Scheme, if developed and implemented in the right way, to have significant long-term benefits for families and individuals for generations to come.

Creating a scheme that reflects the key principles provided is essential. This can be achieved through an assessment process for qualification that takes into account the variety of individual needs within families through a family-centred approach and comprehensive individual assessments for all family members. Family carers often have their needs overlooked and this must be amended under any new design for the disability sector including the proposed scheme.

Through this scheme individuals and families should be able to get what they need, when they need it, to ensure they have every opportunity to reach their full potential. As a community we need to put an end to current inequities that see Australians with disabilities, their families and carers receiving different levels of support depending on how, when and where their disability is acquired or where they live. We as a society must accept caring as a government, family and community responsibility.

## Attachment A: Case study — costs of care

Below is a breakdown of costs spent in one year by a carer (single parent of a child with severe disabilities) trying to ensure her son has a quality of life. Her parents have also contributed $70,000 over a ten year period to ensure his care needs are met. Wherever possible this carer accesses government funded programs (such as PADP) to cover the costs of equipment and appliances but this is not always possible and not all pieces of equipment are covered.

## Costs of caring per annum as at May 2008 - May 2009

### Equipment

| | |
|---|---|
| Maintenance and repairs to wheelchair and scooter per annum | $200 |
| AFO's per annum | $1400 |
| Shoes @$20- per pair 2x monthly | $480 |
| New glasses every 2 years @ $200- a pair | $100 |
| Contributions to PADP per annum | $100 |

### Medications/Dressings etc

| | |
|---|---|
| Medications and Pain Relief | $702 |
| Efalex liquid formula @ $46- per bottle x 6 per annum | $276 |
| Wound Dressings/ supports/bandages/other dressings/treatments per annum | $160 |

### Treatments/Therapy

| | |
|---|---|
| Homeopathic Treatments, consultations and remedies per annum | $2000 |
| Osteopathic Treatments - 6 per annum @ $60- per session | $360 |
| Horse riding with RDA once per week @ $15- Per session and $100- per annum for insurance | $820 |
| Private Swimming Lessons once per week @ $20- per lesson | $1000 |
| Memberships @ $ 20- per annum x 2 | $40 |

### Car maintenance

| | |
|---|---|
| Petrol (for travelling to and from several appts each week), a full tank at least once per week, @ $70- min. | $3640 |

(No car servicing costs or parts, new tyres or repairs are included in this breakdown)

### Specialists

| | |
|---|---|
| Orthopedic Surgeon/Rehabilitation Specialists @$200- per appt x 4 annually approx. | $800 |
| Accommodation & expenses in Sydney for treatments 3 x per year, every 2 years | $500 |
| Accommodation and other expenses related to treatments in Brisbane per annum | $200 |

(Medicare will reimburse part of this figure but the fees need to be paid up front.)
IPTAAS (NSW Health Dept program) can also reimburse part of the accommodation costs, but the wait can be up to 3 months. The fees must be paid up front before reimbursement can occur.

### Technology

| | |
|---|---|
| Software literacy support programs | $350 |
| Repairs and maintenance to laptop, for school per annum | $300 |
| **SUB TOTAL per annum** | **$13,428** |

**Note:**
These costs do not include:

- phone calls
- internet plan to enable research and resource relevant information directly related to providing care
- additional washing and electricity usage.

**Recent correspondence from this carer**
*The last few months have been particularly traumatic as my son had some minor surgery at the end of September and was only supposed to be in hospital for 4 days and developed some major complications and a very nasty infection in his knee so ended up having to be in hospital for 5 weeks!*

*My son is still unable to walk and is still incredibly unwell thanks to the 'minor procedure' and severe infection he had. He is only back at school for half a day as he is so tired, drowsy and nauseous from the high doses of antibiotics he is on 4 times a day because of the infection. I have spent most of time (when I'm not nursing him or taking him to appointments or helping him with his medical issues) advocating for support and better follow up services post operatively for him as it felt like we were dumped and forgotten.*

It should be also noted that because this carer lives just over the border in New South Wales and has to attend hospital in Brisbane subsidised accommodation is limited.  This is at an additional cost.

## Attachment B: Case study— respite

“The reason I have not written sooner is that I have been sick on and off for months and I finally gave in late last week and took myself to hospital (yes, I really did drive myself) as I suspected I might be a little sicker than just a virus..... It turns out I have pneumonia and I was hospitalised for 4 days on oxygen, fluids and very very very expensive antibiotics.

Why did it take me so long to give in? It’s because I am a carer! Who was going to hold down the fort caring for my high energy, high functioning autistic children whilst my husband travelled to New Zealand for 8 days, my mother went into hospital for her second hip replacement and whilst I am STILL battling to get any form of adequate respite?

Answer.... No one. There was NO ONE. The world literally stopped in my house and my mother had to cancel her operation and my husband has to risk employment discrimination and stability by cutting the biggest trip of his year short to come home and help me whilst I am on bed rest (I was discharged late Monday afternoon).

Why am I telling you this story? Respite and recognition for carers (let’s just say the dire circumstance I was in was lost on some of the less aware hospital staff and the lack of option provided by community services was sadly obvious). Now, as for the respite worker secret tip....

We have been allocated the same respite service again this year [...] Four weeks after I contacted them, they got back to me, set up an appointment and because the case worker for my family had the flu she never showed to the appointment […] I reiterated the urgency of the situation and was told it would be dealt with. That was 10 days ago and until this morning when I emailed them with a rather curt note explaining that I had become sick and the world stopped I finally get a response.

So I am STILL without respite regardless whether I fell ill or not, I had already told them I was approaching an emergency situation.[…] so I’ve been sourcing private options for in home help. Turns out an old high school friend of mine is a respite worker with 20 years experience with disability and is about to become my “nanny” so to speak during the hours I work on this contract. My friend works for a different agency than the one we have been allocated but I figured it was worth a try to not only have this worker come in and do the private work for me but to ask for her as our respite worker too seeing as she will be known to the boys, trusted by me and experienced (dream come true).

In my curt note to my existing agency I mentioned I wanted to swap agencies and mentioned the name of the agency I wanted to move to with the request of advice on how I go about making this happen. I got a response fairly quickly after that explaining my agency can outsource […] So now I can request my friend be the respite worker when I use the package (and will DEFINITELY be secretly contacting her about availability and planning to save my time) but I shall also definitely be investigating if I get “charged” extra in the funding package for the outsourcing.

If you followed all of that you are indeed a genius and the sad thing is that many of us in caring roles are not geniuses or at least too exhausted to put our brains to such dastardly scheming and therefore fall through the cracks and get no help.”

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