

Inquiry into Disability Care and Support
Productivity Commission
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Carers NSW submission to the Disability Care and Support Inquiry

Carers NSW welcomes the opportunity to make a submission to the Productivity Commission Inquiry into Disability Care and Support.

About Carers NSW

Carers NSW is the peak organisation for carers in NSW. It is a member of the national Network of Carers Associations and has an exclusive focus on supporting and advocating for all carers in the state.

The core work of Carers NSW is to:

- be the voice for carers in NSW
- undertake research, policy development and advocacy
- provide carer services and programs
- provide education and training for carers and services providers
- build capacity in the sector.

Carers NSW's vision is that caring is accepted as a shared community responsibility and that all carers in NSW are recognised, valued and supported by their communities and by governments.

Who Carers NSW represents

Carers NSW defines a carer as any individual who provides unpaid care and support to a family member or friend who has a disability, mental illness, drug and alcohol dependencies, chronic condition, terminal illness or who is frail.

Carers come from all walks of life, cultural backgrounds and age groups. For many caring is a 24 hour job that is often emotionally, physically and financially stressful. Across NSW there is an estimated 750,000 carers, comprising individuals as young as 8 years of age through to the very elderly.

Format of this submission

Carers NSW will address some of the Terms of Reference of the Inquiry, with a particular focus on carers. This submission will outline some of the principles which the national Network of Carers Associations believe must underpin a National Disability Long-term Care and Support Scheme. (These will be covered in depth by Carers Australia in its submission to the Inquiry.) It will also explore some issues of particular concern to Carers NSW.



1. The role of carers in the care and support of people with disabilities

The Inquiry into Disability Care and Support must be informed by a clear understanding of the important contribution made by carers and the impacts that this role has upon them.

1.1 Contribution of carers

The 2003 Survey of Disability Ageing and Carers (SDAC) identified that:

- 454,000 persons aged 65 and over were carers – almost 1 in 5 persons
- people over 65 accounted for 18 per cent of all carers and 24 per cent of primary carers
- 391,000 provide care for someone living in their household and of these:
 - 48 per cent were caring for someone with a profound or severe limitation in core activities
 - 36 per cent were assisting someone with a moderate or mild limitation
 - 8 per cent were assisting someone who had a long-term health condition without disability
- 28,000 older carers (over 65 years of age) cared for an adult child
- 50 per cent of older primary carers spent 40 hours or more actively caring or supervising.¹

For many Australians with a disability, their carer is the centre of their life and is the person upon whom their wellbeing depends. Often it is the carer who is the decision maker, care coordinator and provider of emotional support. For many, the carer is the one who feeds them, who administers medication and provides physiotherapy and other treatments, as well as all personal care. Often it is the carer who advocates for their right to quality of life and social inclusion.

Data from the 2003 SDAC paints a stark picture of the role carers play in the provision of care and support to people with disabilities. Primary carers are the main source of ongoing assistance to the 1.2 million people who have a profound or severe core activity limitation in Australia. Around 90 per cent (1.07 million) of these people live in private households, 79 per cent of whom received help from informal family carers, and only 53 per cent used formal care services.

The unpaid work of carers underpins the health, aged and disability care sectors in Australia. It is worth noting that carers have been described alternately as the 'invisible health workforce'² and the 'enablers of community care'.³

Research has not only identified the importance of their contribution, but also the high cost of replacing the care they provide. In 2005 Access Economics estimated the replacement value of informal care at \$30.5 billion.⁴ According to the Disability Investment Group, just a 10 per cent reduction in informal care would translate to a 40 per cent increase in demand for formal services.⁵

These statistics are particularly pertinent in the context of an ageing Australian population, and projections of increasing demand for carers and a contraction of the proportion of people available to provide care (the carer ratio). The National Centre for Social and Economic Modelling report *Who Cares?* indicated that the carer ratio has been projected to fall from the current level of 2.5 to less than one over the next 50 years.⁶

1.2 Cost of caring

The personal cost of caring is often very high. Caring can have significant, long-term impacts on all aspects of a carer's life, including their health and wellbeing, socioeconomic status and financial security. The financial costs of caring are quantifiable and should be covered by the Scheme, as should other less tangible but no less significant costs.

1.2.1 Financial costs

The financial costs of caring can be very significant, and may include:

- personal care costs, including special food, utilities and continence products
- cost of medical care and other treatments, such as therapy, medications, physiotherapy, equipment and aids
- transport costs, particularly for regional and rural carers who may face high transport and accommodation costs each time they attend medical and other appointments
- other costs such as housing, home modifications, training, respite and counselling.

1.2.2 Opportunity costs

The financial costs of caring are exacerbated by the opportunity costs for carers, particularly in regards to education and labour force participation, and the associated impacts on income levels and retirement savings.

The lack of flexible workplace arrangements for carers, particularly for carers of adults, combined with the demands of caring mean that many carers are effectively excluded from the labour force, or their career or educational trajectories are limited. In 2005, Access Economics reported that the labour force participation rate for primary carers is just 39 per cent compared to 67.9 per cent for the general population, with participation in full-time employment only 19.2 per cent.⁷

The impacts on income and dependence on government income supports such as the Carer Payment is clear. According to SDAC 2003, around 32 per cent of all carers and 44 per cent of primary carers were living in low income households, compared with 17 per cent of non-carers. In the same survey, 57 per cent of primary carers reported a government pension or allowance as their principal source of income.⁸

The challenge of managing high financial costs on a low income, with little or no opportunity to save for retirement is evident in the high levels of financial stress experienced by carers.

1.2.3 Health and wellbeing costs

The detrimental impact that caring can have on the health and wellbeing of carers is well documented. For example, the 2007 Australian Unity Wellbeing Index Survey found carers to have the lowest collective wellbeing of any known population group, with the wellbeing of carers who live with the care recipient being the lowest ever recorded for a large group of people.⁹

Caring also impacts upon the social wellbeing of carers. As well as poor physical and mental health, relationship breakdowns, social isolation and social exclusion are all common experiences for both people with disabilities and their carers.¹⁰

1.2.4 Role of a National Disability Long-term Care and Support Scheme

The establishment of a National Disability Long-term Care and Support Scheme is an opportunity to address the inequities currently experienced by carers, and improve the sustainability of informal care. The cost of care and support should be shared by the broader community, instead of being almost entirely borne by people with a disability and their families and carers. As disability is a risk that faces everyone in the community, it is the whole community who should share the cost of support.

A Long-term Care and Support Scheme must cover all of the financial costs of caring such as those briefly outlined here. However, these are not the only costs the Scheme should address. A National Disability Long-term Care and Support Scheme must also look to address the other costs of caring for carers. It must remove the barriers to carers' participation in education, employment and society. It must look to ensure that carers enjoy the same basic rights as other Australians, and that they are able to work and study, enjoy good health and good quality of life, and save for retirement.

2. Principles of a National Disability Long-term Care and Support Scheme

A National Disability Long-term Care and Support Scheme for Australia must be a needs-based no-fault system which can provide assistance to all Australians with a disability. The national Network of Carers Associations does not support the limitation of the Scheme only to people with profound or severe disability. All people with disabilities and their carers who are assessed as needing support should be included in the Scheme. It is vital that the creation of a National Disability Long-term Care and Support Scheme does not create a two-tiered disability system which could further entrench the disadvantage experienced by some.

A Long-term Care and Support Scheme should provide funding based on needs and actual costs. The Scheme should include:

- nationally consistent and portable assessments
- early intervention services
- essential care and support services, including personal care, food services, medications, therapy, aids, equipment, home modifications and transport
- carer specific services including information, respite, counselling, training and education, and advocacy skills.

The national Network of Carers Associations would like to see the following principles underpin a National Disability Long-term Care and Support Scheme, to ensure that people with disabilities and their families and carers receive the support they need.

2.1 High quality

The Scheme must provide high-quality services, and focus more on long-term outcomes and less on the short term costs required to achieve them. Services and supports which maximise independence, participation and productivity are needed. The implementation of a National Disability Long-term Care and Support Scheme is an opportunity to recognise that the funding of care and support services is an investment, not a handout.

Services which maximise the independence and participation of people with a disability and their carers must be available. These would include early intervention services, home modifications, aids and equipment and carer-specific supports and services.

The Scheme should also provide innovative services, such as Telecare, which international trials have proven to be very effective. At present, Australia (particularly in

some states and territories) lags behind other comparable nations in terms of the services and supports available to carers and people with a disability and has a relatively poor track record for implementing innovative services and supports.

2.2 Affordable and sustainable

A National Disability Long-term Care and Support Scheme must be sustainable at all levels. First and foremost, the Scheme needs to be sustainable in terms of the long-term needs of people with a disability and their carers. Support must be provided over the life course. Carers need certainty so that they can plan for the future, and they need to be able to trust that if their needs change (e.g if the person with a disability wants to move out of the family home into other available accommodation) or their capacity to care changes (e.g the carer themselves becomes too ill to care), so too will the level of support and choices available to them.

Sustainability also needs to be achieved in regards to capacity, workforce development, infrastructure and research and innovation. Obviously, the Scheme itself needs to be sustainable and affordable, and be able to weather demographic and social changes, and the economic cycle.

There will be different elements of the Scheme and they will require different funding allocations, for example, administration of the Scheme, assessment and service delivery. In relation to the person-centred service model Carers NSW is concerned that due consideration by the Commission be given to:

- individualised packages or consumer directed care (CDC) models which are based on an assumption of competition within the market. The 'market' in community care is constrained, with both limited choice for consumers and limited competition and capacity for responsiveness in providers.
- community care services which are already experiencing difficulties in the recruitment, retention and remuneration of staff. These are likely to continue and increase with the shrinking of the workforce. There are risks that arrangements for under award payments through individual budgets or CDC models may undermine the industry.
- innovation within individual budgets, which is possible and necessary. However, the initiation of new and responsive programs to fill gaps in the services system is likely to require resources for community or program development. Will this be a function of the market and who will pay? Will allocations under the Scheme cover these costs?¹¹

2.3 Portable

The Scheme should ensure portability across jurisdictions, to ensure that limitations are not placed upon the mobility of carers and people with a disability and to avoid duplication, inefficiencies and the risk of people falling through the gaps. People with a disability and their carers should enjoy the same freedom of movement as other Australians, and be able to relocate without fear of jeopardising their access to the care and support they need.

2.4 Fair

The Scheme must be fair. All people with a disability and their carers should be entitled to the support they need. For the Scheme to be fair, support must be given on the basis of need, regardless of what the disability is or how it is acquired. It is important that the Scheme does not exclude people with a psychiatric disability or people with moderate disabilities. The Scheme should be accessible to all people who require assistance due

to disability, and their carers, and not be restricted to those with a profound or severe disability only.

Consistent and comprehensive assessment processes, and simple and accessible appeal and review processes will be an important component of ensuring that the Scheme is fair, and allocates support according to need. (These issues are explored in more detail in sections 3.4 and 3.5.)

2.5 Person and family-centred

The scheme should institutionalise mechanisms to ensure that people with a disability, their families and carers are able to exercise choice and control. There is some evidence from both local and international experiences that self-determination and control has positive impacts on health and wellbeing for individuals and their carers.¹² However, there is also evidence that over time, family carers may experience an increased sense of social isolation and lack of support. They may find it more difficult to navigate crisis points as a consequence of disintegrating formal and informal support structures and lack of information. Over time family carers may see that managing their own care budgets as an increasing burden.¹³

Carers NSW experience of individualised funding has demonstrated to us the importance of not leaving people on their own to navigate the system. Carers NSW has been involved in Ageing, Disability and Home Care (ADHC) Department of Human Services NSW trial of *my plan, my choice*: Individualised (Packaged) Support. A Participatory Action Research Strategy is being undertaken of this pilot (see Attachment A for more details). This pilot program provides support for the carer to be able to make and exercise an informed decision. In the *my plan, my choice* pilot being conducted by Carers NSW the carer receives assistance from a support planner (ADHC) and a support intermediary (NGO). For many carers and people with a disability, similar or other assistance to plan and arrange support will be needed in an individualised-funding model, and as such must be available for all carers and people with a disability if and when they require it.

To date, Australia has been following a trend towards 'individualised funding', similar to consumer-directed care in the United Kingdom and some other OECD (Organisation for Economic Co-operation and Development) countries.¹⁴ Although individualised funding and other individual support arrangements have potential, the Australian Institute of Health and Welfare (AIHW) has expressed concerns regarding the extent of the person-centredness of these services.

Further, it states in *Australia's Welfare 2009* that:

"Individualised funding is one vehicle for increasing individual choice and control but the idea is not to leave people 'on their own'; person-centred service is about enabling people to choose from a range of service types and settings and different funding arrangements, including individualised funding and more traditional funding models, to best meet individual needs and aspirations."¹⁵

For a truly person or family-centred approach AIHW cites research to indicate that there are six criteria:

- choice
- information
- representation and participation
- access
- accountability

- redress.¹⁶

Viewed from this perspective, the individualised funding approaches trialled to date are not truly person-centred within the above criteria as they neglect key factors such as funding levels in relation to need, community attitudes, and the ability of people with disability to access infrastructure and mainstream services such as housing and transport.¹⁷ A National Disability Long-term Care and Support Scheme must go beyond providing choice to create a person and family-centred approach which fosters independence.

There will be challenges in addressing the criteria of person and family-centred services, especially for the choice criterion. To ensure that people can purchase the services of their choice, there will need to be a broad and diverse range of services available to be purchased through the scheme, throughout Australia. This is an issue that will be explored later in the submission.

3. Other issues

3.1 Entitlement of people with disabilities and their carers to care and support

Carers NSW believes that a fundamental shift in the conceptualisation of care and support services is required. The care and support needed by people with a disability and their families and carers should be considered a basic right and access to the care and support that people need should be guaranteed.

Unlike Australia, other nations around the world have legally defined entitlements to the support that carers are assessed as needing. The significant unmet need that persists here under the current system demonstrates that it is not enough to establish optimal standards or services that are then subject to capacity or other limitations and are simply not available. People with disabilities and their families and carers need certainty, and certainty can only be secured through an entitlement or rights-based approach, and through guaranteed access to services.

The ratification by the Australian Government of the *Convention on the Rights of Persons with Disabilities* is a step in the right direction, and provides a basis on which the Scheme could be built. Carers NSW has read with interest submissions to this Inquiry from the NSW Disability Discrimination Legal Centre and the Australian Human Rights Commission regarding the implications of the Convention for a National Disability Long-term Care and Support Scheme.

In their submission to this Inquiry the NSW Disability Discrimination Legal Centre urged the Productivity Commission to

“...ensure that in formulating recommendations for a national support scheme for persons with disability it does not conceptualise CRPD [the *Convention on the Rights of Persons with Disabilities*] rights as expressing optimal conditions that are to be aspired to, but which may not be achievable, either immediately or at all. The CRPD expresses normative conditions that persons with disability are entitled to expect as of right.”¹⁸

The *Convention on the Rights of Persons with Disabilities* includes the rights of people with a disability to habilitation and rehabilitation, work and employment, health, education, to live independently and be included in the community, and to personal mobility. Carers NSW believes that a National Disability Long-term Care and Support

Scheme must be established on the basis that people with disabilities are entitled to enjoy full and equal enjoyment of the full range of human rights for people with disability,¹⁹ and that carers are also entitled to enjoy the full range of human rights and opportunities enjoyed by the rest of the population.

Carers NSW recommends that the Productivity Commission consider the need for a legally defined entitlement to care and support for people with a disability and their families and carers, to ensure that these rights are protected. A legally defined entitlement would mean that when a person is assessed as needing certain services or supports, there is an obligation on the agency/department responsible to ensure that they receive these services. This is the best, and perhaps only way, to ensure that the current situation where people's needs, however serious, can be ignored.

3.2 Service availability

A fundamental challenge to the effectiveness of a National Disability Long-term Care and Support Scheme will be ensuring that diverse and adequate services are available. Mechanisms will be needed to ensure that the services people need are actually available for them to purchase equitably across Australia. The funding people receive would be worthless if the services of their choice are not available, or worse, there are no services available for them to purchase. For the Scheme to be successful there will need to be a diversity of services available for all Australians, across the country, not just in metropolitan and regional centres.

3.2.1 Services for people in rural and remote areas

Service provision in regional, rural and remote areas will be a particular challenge. The premise of the National Disability Long-term Care and Support Scheme discussed in the issue paper seems to be that of a market environment, where demand for services, and the ability of service-users to 'vote with their feet', will ensure that consumer focussed, diverse services will be created.

Carers NSW fears that service availability in rural and remote areas in particular cannot be left to market forces. The Productivity Commission must consider the following questions:

- Who will provide services in an area where there is not a critical mass of demand for a particular service?
- Will there be sufficient demand for service providers to take on the challenges of service delivery in rural and remote areas, including those relating to workforce and infrastructure requirements, and distance?
- Will there be enough demand in rural and regional areas for multiple service providers and a diversity of services to be offered?
- Will funding allocations take into account the higher costs involved in delivering and accessing services in these areas?
- Will funding allocations take into account the costs of transport and accommodation if carers and people with a disability need to travel to major metropolitan centres or different geographical regions to access services not available in their area?

3.2.2 Services for Aboriginal and Torres Strait Islander people

The needs of Aboriginal and Torres Strait Islander carers will also require special consideration by the Commission. As with rural and remote service provision, the capacity of market forces to ensure diverse and culturally competent service provision to Aboriginal and Torres Strait Islander people needs to be examined.

The needs of Aboriginal and Torres Strait Islander people and carers are considerable, and may differ to those of non-Indigenous Australians. Aboriginal and Torres Strait Islander people have lower life expectancy and are more than twice as likely as the general population to need help with core daily activities because of disability.²⁰ The high prevalence of disability and disease in these populations has implications for the needs of carers. According to the 2006 Census, Aboriginal and Torres Strait Islander carers were up to three times as likely as other carers to need assistance with core activities themselves.²¹ This has obvious implications for the impacts of care provision on their health and wellbeing, their capacity to care, and their own level of need for services and support, both as carers and in their own right as individuals.

The provision of diverse and culturally competent services is vital if Aboriginal and Torres Strait Islander people are also to enjoy real choice. Aboriginal and Torres Strait Islander people may have different cultural understandings which impact on the accessibility and appropriateness of services. Examples of different cultural understandings may include concepts of kinship and family relationships, community and the individual, disability, place, healing, communication styles, gender relations and protocols. Another significant factor may be widespread mistrust of government or social services within Aboriginal and Torres Strait Islander communities, which has been formed by their communities' experience of these organisations.²²

The possibility of direct employment of family members to provide care services should be considered as an option for Aboriginal and Torres Strait Islander people with a disability and their carer. However, supports and standards need to be incorporated into this provision, such as relevant attendant care capacity or training to develop this capacity in family members (either Certificate III or IV in Community Care training, or, for example safe lifting, mobility training, or dealing with challenging behaviours) as well as appropriate financial accountability measures.

Carers NSW recommends that an Aboriginal and Torres Strait Islander Advisory Group be appointed to advise a National Disability Long-term Care and Support Scheme on the delivery of accessible and culturally competent services to Aboriginal and Torres Strait Islander people with a disability and their families and carers.

3.3 Supported accommodation

Carers NSW agrees with the Disability Investment Group that "of all disability services, the most significant unmet demand and the greatest anxiety for families relates to housing and accommodation".²³ The extensive, urgent need for supported accommodation for people with a disability is a challenge that must be met by the National Disability Long-term Care and Support Scheme. This issue is a clear example of what has been discussed here regarding the need for mechanisms to ensure that people receive the supports they need, and that sufficient service capacity is created.

Carers NSW has chosen to emphasise this particular issue not to act as a case study for these issues, but because of the significance of this issue to a large number of people, whose need is so great that they are at breaking point. Under the current system it seems that unless carers do 'break' (or die), accommodation will not be provided. Sadly, in these cases 'breaking' means leaving the person with a disability at respite or in hospital, effectively relinquishing the caring role and with it the opportunity to have any say in the future of the person with a disability. That such desperate and traumatic measures have become the effective access point for entry into supported accommodation is an indictment of the current system.

It is families, carers and people with a disability who have been leading the way in the development of supported accommodation models for people with disabilities. The Productivity Commission must consider the models being developed by families and carers who have been forced to take matters into their own hands, and examine the possibilities for a National Disability Long-term Care and Support Scheme to realise such developments within other appropriate models, including public housing.

3.3.1 Co-operative owned housing

Co-operative owned housing would make possible the creation of the supported accommodation that people choose, and that will meet their needs. Housing co-operatives have the capacity to meet the unique economic, social and cultural needs of the people who require accommodation and their carers. Co-operative housing would be characterised by:

- joint ownership of infrastructure, acquired with funds provided under the Scheme and private contributions when possible
- tenancy management, selection and property maintenance managed through a brokered management company
- care and support services contracted independently of the accommodation model, on an individual/family basis.

Obviously, co-operative housing would not be an option for everybody, but is one choice that should be available, especially for the existing groups of families, carers and people with disabilities that are already developing accommodation models and advocating for funding to realise these developments.

Funding individuals to develop co-operative owned housing may be a particularly important component of a Scheme, particularly in light of the failure of state and territory governments to develop the infrastructure required to meet the need for supported accommodation.

RASAID – A case study

An example of a potential housing co-operative that could be developed through funding from a Scheme is Ryde Area Supported Accommodation for the Intellectually Disabled (RASAID). RASAID is a group of 19 families who have been working together for over five years with the goal of achieving supported accommodation for their family members with disabilities. RASAID has developed plans for a clustered residential model for 20 residents, consisting of a congregation of four or five houses. They believe their model has the following advantages:

- the person with a disability would remain in their local area
- the person with a disability would live with a group of disabled peers with whom he/she has grown up, allowing for the maintenance of social networks, whilst maintaining their privacy
- the person with a disability remains close to their work or day programs
- the transition to accommodation would be planned and the person would be supported by their carer throughout the support arrangements will be enhanced by assistance from the carers who live close by and would maintain their relationships with the people with disabilities.²⁴

Perhaps the greatest strength of this and other models developed by families and carers is that they have been designed by the very people who need it, with much time, consideration and thought invested in the final product. These are the models of their

choice, and they are informed by an intimate knowledge of the person who needs accommodation, and a genuine commitment to their wellbeing.

3.3.2 Partnership-delivered supported accommodation

There can be no one size fits all approach to supported accommodation. Options other than co-operative housing must also be available. The model employed by the *Housing and Accommodation Support Initiative (HASI) for people with mental illness* program in NSW is illustrative of another approach which some people may choose.

HASI is a partnership program between NSW Health, the Department of Housing and the non-government (NGO) sector that provides housing linked to clinical and psychosocial rehabilitation services for people with psychiatric disability.²⁵ Each HASI client receives services from three local service providers:

- a housing provider, generally public or social housing (funded by the Department of Housing) who provides long-term, secure and affordable housing, as well as property and tenancy management services
- an NGO who provides accommodation support and rehabilitation associated with disability (funded by NSW Health)
- specialist mental health services, which provide clinical care and rehabilitation.²⁶

The structure of the HASI program is designed to separate support functions so that each client receives the services and housing that suits their particular needs. Although services are delivered in partnership, and providers do sign a Service Level Agreement, the separation of these functions enables each service provider involved to focus on their area of expertise. The Service Level Agreement defines the major roles of each partner, and establishes processes for communication, information exchange, dispute resolution, reporting, review and evaluation.²⁷

Similar models have been applied to other population groups in NSW, including the *Disability Housing and Support Initiative (DHASI)* funded by ADHC under *Stronger Together* for people with an intellectual disability or an acquired brain injury. 50 places in the program were created in the first two years of *Stronger Together*.²⁸

3.3.3 Accessible and adequate public housing

As explored earlier in this submission, a truly person and family-centred system where people with a disability and their carers enjoy the full range of human rights that they are entitled to requires much more than the provision of specific services or funding to these groups. Universal services and infrastructure such as education, health, transport and public housing must also be accessible for people with disabilities and their carers to avoid limiting their participation in society. Although some people with a disability and their carers may need or choose supported accommodation options such as those outlined here, other people may choose public housing as the option that best suits their needs. Adequate, affordable and safe public housing in local communities must be available to people with disabilities and their carers, as it is to other Australians who require such assistance.

Carers NSW recommends that supported accommodation be a priority issue for the Productivity Commission, and that consideration is given to the capacity of a National Disability Long-term Care and Support Scheme to support the realisation of family and carer developed supported accommodation models. Carers NSW suggests that the Productivity Commission also examine work done by Carers Victoria for more direction regarding supported accommodation and public housing, as Carers Victoria has suggested in the public hearing for the Inquiry.²⁹

3.4 Carer assessments

A National Disability Long-term Care and Support Scheme must meet the needs of carers. In order to do this, a nationally consistent assessment for carers must be adopted so that their needs are appropriately and consistently identified. This was a recommendation of the *Who Cares...? Report on the inquiry into better support for carers*.³⁰

The Australian Department of Health and Ageing (DoHA) in conjunction with state and territory governments and the community care sector is developing national assessment tools for assessing carer needs including the *Carer Eligibility and Needs Assessment-Revised* (CENA-R), which will:

- guide a detailed assessment of a carer's functional capabilities
- prioritise needs for a service referral and/or more extensive assessment for the carer
- store and/or export carer information and assessment outcomes (consistent with privacy and consent provisions) to reduce the need for re-assessments.³¹

The CENA-R has been in development for several years. It is important that nationally consistent assessment processes are used in a National Disability Long-term Care and Support Scheme, including a specific, comprehensive and consistent assessment of carers needs, such as the CENA-R.

Research by Carers Victoria and Carers NSW to inform a Draft Discussion Paper on Consumer Directed Care identified that some problems with program guidelines for individualised support, based on person-centred rather than family centred care. They:

- may ignore the needs of caring families for direct assistance and support in needs assessment, funding allocations and care planning. Family carers can be invisible.
- may fail to engage with caring families when the decision making capacity of the person needing care is an issue.
- may increase the care tasks and responsibilities of caring families in direct care management. Participation in consumer directed care must be governed by choice.

The question of whether family carers should receive payment out of individual budgets is a contentious one.³² It can ensure responsive support is available in rural and remote areas, but can risk commodifying informal care and blurring its boundaries with formal care.³³

3.5 Appeal and review processes

Nationally consistent assessment processes must be accompanied by simple, non-intimidating appeal and review processes for people with a disability and their carers. This is especially important for people from culturally and linguistically diverse populations (Aboriginal carers; Gay, Lesbian, Bisexual, Transgender and Intersex carers; and carers from non-English speaking backgrounds), carers with low literacy levels and carers with hearing or vision impairment.

3.6 Carer advocacy

It is important to note that while the needs of people with a disability for advocacy services are generally acknowledged and provided the situation for carers is not. *The Who Cares...?* report recommended that the National Disability Advocacy be extended:

- to provide formal advocacy for carers in their own right when this is required, and
- to provide family advocacy services which better recognise the role of carers providing individual advocacy on behalf of, and with, care receivers.³⁴

The Commonwealth Government in its response to the *Who Cares...?* report rejected this recommendation stating that the National Disability Advocacy Program is to protect the interests of the person with disability in line with the *Disability Services Act 1986*. It assists people with disability to overcome barriers that impact on their daily lives and their ability to participate in the community. The Commonwealth Government stated that given this, it would not be appropriate to extend the National Disability Advocacy Program to provide formal advocacy services for carers in their own right.³⁵ It indicated that this Program already included a family advocacy stream that included parents, family carers and family members. It also indicated that advocacy for carers of aged people and people with disabilities are provided under the Home and Community Care Program.

However, Carers NSW believes that carers need their own advocacy services because:

- carers in their own right are service users
- carers access health, social and financial benefits and services
- carers are included in various policy programs and legislation as a population group with distinct needs
- carers often act on behalf of those for whom they provide care.

The Government's rejection of this recommendation also conflicts with the Australian National Audit Office's (ANAO) report on the Administration of the Commonwealth State/Territory Disability Agreement (CSTDA), which identified that some jurisdictions do provide advocacy services to families and carers of people with a disability, as well as people with a disability themselves. ANAO recommended that:

"FaHCSIA (through consultation) should establish the eligibility for criteria for advocacy services currently in place in the jurisdictions and, based on the findings from such an investigation, consider extending access to advocacy services to the families and carers of people with disabilities in any future CSTDA."³⁶

Therefore, there is an anomaly between the perceived advocacy service in place for carers and the reality for carers. Carers NSW receives many calls from carers who are frustrated because they cannot access services, are faced with inappropriate services or who are having difficulty finding organisations that can assist them to advocate for relevant resolutions. This difficulty means further distress for carers who already often have a stressful and demanding caring role.

Conclusion

Carers NSW appreciates the opportunity to provide a submission to the Inquiry into Disability Care and Support. If you require any further information about Carers NSW submission to this Inquiry, please contact Alison Parkinson on 02 9280 4744 or email alisonp@carersnsw.asn.au.

Yours sincerely,

A handwritten signature in black ink, appearing to read 'Elena Katrakis', written in a cursive style.

Elena Katrakis
CEO
Carers NSW

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