

Senate Review of the Commonwealth State Territory Disability Agreement

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1. Introduction

The Commonwealth State Territory Disability Agreement (CSTDA) is the roadmap to provide services for people whose disability was evident before the age of 65 years. The current CSTDA is the third Agreement and spans from 2002-03 to 2006-07.

Under the current CSTDA the Australian Government has the responsibility for the planning, policy setting and management of specialised employment assistance. It provides 20% of funding for the provision of disability services administered by the State and Territory Governments, which provide the remaining 80 percent.

Disability services covered under the CSTDA include accommodation support, community support, community access, respite, employment, advocacy, information and print disability. Many people with a disability are reliant on their family and friends for care and assistance. Indeed, the availability of family members (and occasionally others) to provide this support underpins the formal community care disability services.

Carers Australia believes that appropriate disability services in Australia should meet both the needs of the person with a disability and their family carer, as the assistance and support provided can be quite extensive and demanding. The needs of family members should be considered in a holistic approach to disability support.

The current CSTDA has five policy priorities. One of these is "to strengthen individuals, families and carers. However, the current CSTDA has not managed to provide sufficient supports and services for people with disabilities, their carers and their families.

The expiry of the current CSTDA in 2007 provides an opportunity for all Australian governments to revise the planning and funding of services for people with disabilities to enable them to live as independently as possible in the community with the support of their families and friends. A new agreement should:

- Provide services that meet the needs of the person with a disability and their family carer as a whole,
 rather than as separate entities
- Recognise the vital role of carers and families in sustaining community care services for Australians with disabilities
- Expand community care support services to supplement the work of carers of people with disabilities
- Support carers with choices in their caring role and reduce the unacceptable level of carer poor health and wellbeing
- Provide appropriate support services to encourage carers to participate in the workforce to help sustain the economy and reduce carers' financial disadvantage
- Address the consequences of an ageing population and the future decrease in the availability of carers
- Address the consequences of people with lifelong disabilities living longer, and the needs of ageing parents to plan appropriate supports for their sons and daughters
- Improve the coordination between CSTDA services, the Home and Community Care (HACC) program and the National Respite for Carers Program (NRCP) to met the needs of people who require multiple services
- Address the growing unmet need for services as high cost institutional and health care services are replaced with care in the community, particularly for people with mental illness and chronic conditions

- Plan and monitor the provision of quality CSTDA-funded services, including qualifications of service providers
- Include tools to measure that the new CSTDA meets its objectives.

Some State and Territory Governments have negotiated, or are negotiating, with members of the Network of Carers Associations about future disability plans. A new CSTDA should incorporate these plans.

2. About Carers Australia

Carers Australia is the national peak organisation dedicated to improving the lives of the 2.6 million carers in Australia. Our members are the eight state and territory carers associations (the "Network"), which directly provide services to carers in their communities.

Carers Australia delivers in partnership with the Network a range of carer services as well as identifying gaps in services.

Australian Government funded services delivered through the Network include information referrals, counselling and some education and training designed to meet the support needs of carers. These services are funded by the Australian Government Department of Health and Ageing (DoHA). DoHA also provides core funding to Carers Australia. The Network also delivers a Young Carers Program funded by the Australian Government Department of Families, Community Services and Indigenous Affairs (FaCSIA).

3. Who cares in Australia

Carers can be parents, partners, brothers, sisters, friends or children. In some cases, a neighbour may take on the role of carer.

According to the ABS 2003 Survey of Disability, Ageing and Carers¹ there are:

- 2.6 million carers in Australia
- of whom nearly 500,000 are primary carers—the people who provide the most care to disabled or frail aged people
- 71% of primary carers are women
- 75% of primary carers are under 65 years
- the largest proportion of this group are aged between 45-54 years
- around the same percentage of primary carers care for a child, spouse or parent.

Many carers spend substantial amounts of time on caring tasks:

- 37% of primary carers provide care for 40 or more hours each week
- 60% of carers over 15 years have cared for five years or more
- one-third have cared for over ten years
- some have cared for over 30 years.

The top five reasons for caring are:

- family responsibility = 58.4%
- could provide better care = 39.1%

- emotional obligation = 34.5%
- no other family or friends available = 23.5%
- had no other choice = 18.4%.

4. Economic contribution by carers

The contribution by carers to the Australian economy is significant. According to *The Economic Value of Informal Care* by Access Economics (2005)² in 2005:

- 1.2 billion hours of care was provided by 1.2 million to people with a disability or chronic condition, or who were frail aged
- the value of replacing this care with formal services in the home would be at least \$30.5 billion annually
- associated tax forgone by Australian governments equals \$1.36 billion
- the cost to the public of a primary carer is \$9,000
- the cost to the public of a high-care residential placement is \$48,710.

The Australian Institute of Health and Welfare³ (AIHW) indicates that the unpaid assistance to people with disabilities who live in the community provided by carers and friends equates to the cost of about 1 million full-time employed persons.

5. The personal cost to carers of caring

The personal economic and health and wellbeing costs to carers of their caring are also significant.

5.1 Economic cost to carers

Carers often experience income inequality because of their reduced levels of paid employment. ABS (2003)⁴ data indicates:

- 39% of primary carers participated in the workforce compared with 68% of non carers
- 46% of primary carers were employed full-time compared with 70% of non carers
- 54% of primary carers were employed part-time, compared with 31% of non carers
- carers are over-represented in the lower household income quintiles and under-represented in the top income quintiles
- the mean gross income per week of a primary carer was \$237.00.

ABS (2005)⁵ data indicates that the mean gross income per week of a person in Australia in 2002-03 was \$542.00. This is a big disparity.

Research⁶ also indicates:

- main barriers to prevent sole parent carers working are:
 - lack of and cost of child care, which includes more than the cost of the child care itself it
 involves transport for child and parent
 - a reduction in their Centrelink payment and loss of entitlements, which means that they could be worse off financially
 - lack of flexible working hours

- 4 in 5 households with a dependent person with a disability spend household income on medical costs, including medications, wheelchairs and other specialist equipment
- one-quarter of all households spend more than 20% of the household budget on these medical costs
- half of all households spend between 5% to 14% of the household budget on these medical costs.

5.2 Health and wellbeing of carers

The National Survey of Carer Health and Wellbeing⁷ found that the physical, mental and emotional health and wellbeing of most carers was poorer than non carers because of their caring responsibilities.

As a result of caring:

- over half of all carers suffered a decline in physical health
- one-third of all carers had been physically injured in the time they had been providing care
- two-thirds of carers felt their mental and emotional health had been affected by providing care
- constant pressure of caring, stress, disturbed or lost sleep and providing mobility such as lifting and transferring were the most common reasons reported for affecting health
- around one-third of carers reported that they found it difficult to undertake or delayed having treatment such as visits to the doctor, hospital treatments, operations, and therapies such as physiotherapy, chiropractic or podiatry, because of their caring duties.

In a 2005 study, the University of Queensland and Carers Queensland8 found:

- 25% of 1200 carers surveyed were clinically distressed
- many of the carers were surveyed twice with a three-month interval, and reported the same distress level at the time of both surveys.

International data is similar. The 2001 United Kingdom Census⁹ indicates there is an important link between caring full-time, ill-health and the age of the carer. Carers in the youngest age groups are significantly more likely to suffer from ill-health than the equivalent non carer population. This shows that the younger a carer, the more at risk their health will be from caring full-time. Many of these carers will be caring for a son or daughter with a disability, which can be a long-term (or lifetime) commitment. Others care for a partner, which also tends to be a longer term commitment and raises similar long-term health issues.

The UK Census data indicates carers are more than twice as likely to have poor health compared to non carers. The evidence shows that this is due to the lack of appropriate support, isolation, financial stress and lack of information.

Carers Australia believes that caring is a personal, social and public responsibility shared by individuals, families, business and community organisations, public institutions and all levels of government. A new CSTDA should include strategies to reduce the financial disadvantage and unacceptable level of poor health and wellbeing carers experience because of their caring role.

Carers Australia recommends the new CSTDA should:

- 1. include carer recognition and support
- 2. recognise the significant contribution of carers as part of the care management team and increases funding for carer support structures so they can maintain their own health and wellbeing, which is essential to their caring role
- 3. ensure that community care systems can respond to individual care situations
- 4. address the requirements of carers of workforce age for flexible working conditions and child care and respite services support
- 5. address the need for financial protection for carers injured in their caring role by compensation or longterm insurance.

6. Disability in Australia

Australia's welfare 2005¹⁰ indicates that:

- 3.9 million Australians or one in five people were affected by a disability
- 2.6 million were under 65 years
- 2.3 million of Australians with disabilities who live in households require assistance to manage their health conditions or cope with daily living activities
- in 2003 over 1.25 million Australians were affected by a profound or severe core activity limitation.

According to AIHW (2005)¹¹ CSTDA-funded services data during 2003-04 includes:

- 187,806 service users accessed CSTDA-funded services
- 43,326 (23%) services users accessed two or more services
- the 20-24 age group were the highest service users, regardless of gender
- around 59% of service users were male.

This data also indicates that in 2003-04:

- 42% of service users indicated that they had a carer
- 69% of service users with a carer reported this was their mother
- 79% of service users under the age of 15 were most likely to report having a carer
- 48% of service users aged 15-24 years reported they had a carer
- 20% of services users did not indicate this information.

Although, AlHW indicates that this is the first time data has been collected over a full year. Missing data is expected to be better reflected in future data collections.

For the first time, the 2006 Population and Housing Census includes questions about caring for people with disabilities. The data is expected to provide valuable carer and disability data to assist with future planning of services to meet carer and family needs.

7. Unmet need

Two areas of unmet need to be considered in a new CSTDA – current and projected needs.

7.1 Current unmet need

According to the Australian National Audit Office¹² (ANAO) in its 2005 Audit Report of the CSTDA administration, of the nearly 4 million Australians who identify as having a disability, only a small percentage are eligible for, and access, government-funded CSTDA disability services. Although many of these people may access other community support services or purchase services, many rely on family carers for their support. Carers are also required to manage and facilitate access to available services for the people they care for.

ANAO (2005) identified the demand for services exceeds the number of available services:

- in June 2003, 900,000 people may need to access specialist disability services at some point
- in 2003-04, 187,806 people used CSTDA-funded specialist disability services
- some people accessed more than one type of service during this period.

Although the Australian Government allocated additional funding over the second and third CSTDAs to help address this unmet need, more analysis is required to identify how best to meet the need for disability services.

The Home and Community Care (HACC) program provides services for older people, people with disabilities, and their carers. This program is jointly funded by the Australian Government (60%) and by State and Territory Governments (40%).

HACC Program data13 indicated in 2003-04:

- HACC provided 170,100 services to users under the age of 65
- the average number of services used by HACC clients was 1.8
- centre-based day care was the most accessed HACC service.

The Network has identified that many service recipients are wait-listed for services once their assessment deems them eligible. They may be wait-listed by a service provider, while another service provider has the capacity to meet their needs. Sometimes people are on more than one waiting list. It is also important to ensure that there is also a match between the service provider and the families' needs. This lack of coordination of services means that many clients, their carers and families are seriously disadvantaged and often face extreme situations.

Often parents with an older son or daughter with a disability decide they can no longer continue their caring role. When this occurs, parents need appropriate replacement care options so they can be confident that their son or daughter is receiving adequate care.

The availability and cost of equipment is also an area of concern to many carers and the person for who they care. Under the current CSTDA once a person has received special equipment, that person is not eligible to receive the same equipment even if their need changes. This means that many people with disabilities and their carers are forced to compromise with inadequate equipment as they are unable to

afford an appropriate replacement or home modification. Sometimes inadequate equipment means that carers face injury through lifting or other activities.

Additional respite services have been identified as a major unmet need for some carers (see 9. Respite services).

7.2 Projected ageing, carer availability and need for services

Other important trends are likely to impact on the care of people with disabilities:

- the continuing rise in the number of women working and an increase in the hours they work
- the ageing of Australia's population
- people with an early onset disability are living longer, which has implications for their ageing carers (some of whom have been caring for over 25 years).

The ageing of Australia is a demographic reality. According to the Productivity Commission¹⁴ the effects over the next 40 years will be pronounced. One quarter of the population will be aged 65 years or more by 2044-45, roughly double the present proportion of the population in that age group. The proportion of those 85 years and over will increase even more, from 1.5% to 5% over this period.

One of the implications of an ageing population is that many more Australians will require assistance because of disability. According to the ABS (2003)¹⁵ the rate of disability increases with age – 4% of children 0-4 years have a disability compared with 41% of people aged 65-69 and 92% of people aged 90 and over.

The ABS estimates that the number of Australians with disabilities can be expected to increase over the next 50 years as the population ages. This is influenced by people living longer and acquiring disabilities as they age, as well as people with existing disabilities living longer.

According to the AIHW (2000)¹⁶ this influences not only the longevity of the caring relationship, but also patterns of service use in health and community care.

Similarly the National Centre for Social and Economic Modelling (NATSEM)¹⁷ estimates large increases in the ageing disabled population over the next 25 years. It indicates that the number of people aged over 65 needing care is projected to increase by 160%, from 539,000 people in 2001 to 1,390,000 in 2031 based on the current rates of disability and need for assistance.

In contrast, the numbers of younger disabled (under 65 years) is projected to increase by only 25 percent.

NATSEM (2006) projects that the number of potential carers will increase but not at a rate that will meet the increased demand over the next 25 to 50 years:

- there will be a steady fall in Australia's "caretaker ratio" the ratio of the number of people most likely to provide care to the number of people most likely to need care
- in 2000 the caretaker ratio was around 2.5
- over the next 50 years the caretaker ratio is projected to fall to below one.

This means the projections on ageing and disability have obvious implications for the future of community, hospital and residential care. The demand for supported accommodation is anticipated to increase as a consequence of the ageing and death of parent carers of people with lifelong disabilities over the coming decades.

Governments will need to address policies and planning to meet these increased needs.

Carers Australia recommends that in the new CSTDA:

- 6. the Australian Government should increase its funding proportion to increase its influence in planning, policy setting and monitoring of disability services
- 7. Australian, State and Territory Governments should address the need for improved service linkages among aged care, disability services and carer support programs
- 8. Australian, State and Territory Governments should increase their funding commitments to provide the required number of supported accommodation and community support and access services to reduce the unacceptable unmet need in disability services
- Australian, State and Territory Governments should consider strategies to meet the anticipated increase in supported accommodation of older sons or daughters with disabilities as their carer becomes frail or dies
- 10. Australian Government should develop and monitor service provision indicators so that people with disabilities, their carers and their families have timely and appropriate access to support services. This is consistent with the Australian Government's emphasis on the need to develop and implement whole-of-government approaches
- 11. Australian, State and Territory Governments should identify and remove barriers to accessing CSTDA-funded, including being wait-listed by one service provider when the service is available through another service provider with capacity to provide the assessed needs
- 12. State and Territory Governments should investigate better use and coordination of local networks for consultation, identification of needs, planning and referral
- 13. Australian, State and Territory Governments should increase support services for carers so they can maintain their caring role.

8. Disability, ageing and carer support services coordination

Many carers have dual caring roles. They care for a child with a disability and care for a frail aged parent or a partner with a disability at the same time. Many carers who have cared for a child with a disability for a long time now require their own age care services. People over 65 years with disabilities are also accessing CSTDA-funded services. As a consequence of these situations, many carers are interacting with service providers from CSTDA, HACC and NRCP funded services.

A common eligibility assessment tool would remove the need for many carers and the person for whom they care to undergo multiple assessments to achieve the mix of services required. Often assessment is required by different service areas within the same agency or provider.

The respective responsibilities of disability and aged care service providers to the needs of the group must be determined. Very elderly carers of a son or daughter with a disability who are 65 years and over will not be well supported if their son or daughter becomes ineligible for disability services and if alternative support options are unavailable in the aged and community care systems. Ongoing care by family members should not be assumed, and the new CSTDA should address the longer term care planning issues. This is a key issue for ageing carers.

Carers Australia is concerned that under the new national Work Choices legislation, many people with disabilities assessed as able to work (whether or not there is a job available) may be placed on Newstart Allowance and not the Disability Support Pension. This potentially affects their access to services for people with disabilities.

Carers Australia recommends that the new CSTDA should:

- 14. improve coordination of CSTDA, HACC and NRCP services as some people with disabilities and their carers receive services provided by two or more of these services providers or agencies
- 15. ensure there is no gap or reduction in service for people in the transition between disability and aged care services
- 16. introduce a common assessment tool for use by CSTDA, HACC and NRCP.

National consistency in assessment of eligibility, support needs and service priority

ANAO (2005)¹⁸ identified that there was no consistent model to identify an individual's needs for services and determine priority. To address this, the CSTDA Disability Administrators were to undertake a research and development project on the National Assessment and Resource Allocation Framework. The project is to be completed by June 2007 when the current CSTDA expires.

Carers Australia believes that the new CSTDA should include a national framework for the provision of services to meet the needs of people with disabilities in Australia. Such a framework should take a holistic approach to the needs of the person with a disability and their carer, and be based upon person-centred assessment. It should also recognise that many people have more than one disability and different services are often required to meet these different conditions.

Carers Australia recommends that the new CSTDA should:

- 17. implement and monitor a National Assessment and Resource Allocation Framework as an imperative to ensure that the Australian, State and Territory Governments jointly deliver appropriate and consistent disability support services that meet the needs of people with disabilities, their carers and their families
- 18. include a rigorous review of compliance standards to ensure the delivery of quality and timely support services for people with disabilities and their carers
- 19. examine the ageing and disability interface with respect to health, aged care and other services including the problems of jurisdictional overlap and inefficiency to reduce duplication, identify service gaps and to achieve cost-effective disability support and service provision in Australia.

10. Respite services

The current CSTDA includes the provision of respite services that provide a short-term and time-limited break for families and other carers of people with a disability. The 2004-05 Federal Budget included a bilateral funding offer to all States and Territories for additional respite for older carers, and the 2006-07 Federal Budget included additional respite provision for older parents of sons or daughters with a mental illness

AlHW (2005)¹⁹ indicates that 20,547 users accessed CSTDA-funded respite services during 2003-04. However, AlHW (2006a)²⁰ indicates that among primary carers of children aged 0-14 years with a disability:

- an estimated 32,200 (59%) provided more than 40 hours of care per week to a son or daughter with a severe or profound core activity limitation
- 47.7% wanted more support
- 40% indicated more respite services was their greatest need.

Carers Australia believes respite services should be carer-focussed, carer-responsive and support carers in their caring role. All carers should have access to respite services that are relevant to their individual caring situation, including short-term residential care.

A recent AIHW (2006b)²¹ report found that in aged care, people who use both community care services (such as personal care, help around the house and transport assistance) and short-term residential care, remain in the community longer than those who use residential respite care only.

The review of the current CSTDA provides the opportunity to examine ways in which respite services can be more effectively targeted to specific categories of carer need, as well as which forms of respite are the most effective.

Carers Australia recommends that the new CSTDA should:

- provide adequate respite services for all carers that are determined by needs-based assessment and planning
- 21. review respite guidelines to reflect the diverse respite requirements of carers and the people for whom they care
- 22. review respite guidelines to provide supplementary support for the next age cohort of carers.

11. Carer advocacy

Under the current CSTDA, advocacy services are defined as services to enable people with disabilities to increase the control they have over their lives through the representation of their interests and views in the community.

The current CSTDA defines advocacy services as being <u>only</u> for people with disabilities and <u>excludes</u> families and carers of people with disabilities. Carers need 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.

Although ANAO (2005) indicated 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

FaCSIA (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.²²

Carers Australia recommends that the new CSTDA should:

 extend advocacy services to benefit the care situation of people with disabilities and their families and carers.

12. National Disability Advisory Council and Disability Advisory Bodies

In the current CSTDA the Disability Advisory Bodies and the National Disability Advisory Council "provide a conduit for people with disabilities, their families, carers and other people with knowledge of, or experience in, matters relevant to the disability sector to provide advice regarding the planning, delivery and evaluation of services."

Carers Australia notes that carers of sons or daughters with disabilities sit on some State and Territory Disability Advisory Bodies, but that the National Disability Advisory Council has not met since 2005, and has effectively been disbanded. Although discussions have occurred about its successor, the model and appointments are still to be determined.

Carers Australia believes that these advisory bodies need to include carers of people over the age of 15 with disabilities, as many people with disability over 15 are unable to be self-advocates because of intellectual disability, mental illness or some other disability.

Carers Australia recommends that the new CSTDA should:

- 24. include representatives of carers of people over 15 with severe and profound disabilities in the State and Territory Disability Advisory Bodies and the new national advisory body
- 25. urgently establish the successor to the National Disability Advisory Council.

13. Data collection

Carers Australia acknowledges the contribution of the AlHW in the analysis and dissemination of data on disability in Australia through the bi-annual *Australia's Welfare* and *Australia's Health* reports and other reports on disability, ageing and caring in Australia. Carers Australia is a member of the AlHW Advisory Committee on Functioning and Disability Data (ACFADD), formerly the Advisory Committee on Australian and International Disability Data. ACFADD's objectives include improving the relevance and quality of function and disability data in Australia.

Carers Australia recommends that the new CSTDA should:

- 26. acknowledge the significance of the work of the AIHW
- 27. make provision for the Australian Government to provide additional funds to enable AIHW to expand its data collection and analysis on disability and carers to enhance policy development and service planning in Australia.

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