

Disability Supported Accommodation Program Consultations Report January 2008

Background

Commonwealth State Territory Disability Agreement

The Commonwealth State Territory Disability Agreement (CSTDA) provides the national framework for the delivery, funding and development of specialist disability services for people with disability.

Under the three agreements signed so far (the first in 1991) all parties are responsible for funding specialist services for people with disability:

- the Australian Government has responsibility for the planning, policy setting and management of specialised employment assistance;
- state and territory governments have similar responsibilities for accommodation support, community support, community access and respite; and
- support for advocacy and print disability is a shared responsibility.

Through the Agreement, the Australian, state and territory governments strive to enhance the quality of life experienced by people with disabilities through assisting them to live as valued and participating members of the community.

Senate Inquiry into the Funding and Operations of the CSTDA

An examination of the appropriateness of the current Commonwealth state/territory joint funding arrangements was completed by the Senate Standing Committee on Community Affairs in their Inquiry into the Funding and Operations of the CSTDA. The final report was released on 8 February 2007 and included an analysis of the levels of unmet needs and, in particular, the unmet need for accommodation services and support.

The primary recommendation of the Senate Inquiry identified the need for the Commonwealth and state/territory governments to commit to substantial additional funding to address the identified unmet need for specialist disability services, particularly accommodation services and support.

Many submissions to the Senate Inquiry expressed concern about what would happen to a son or daughter with disability when their older carer died or had to enter residential aged care.

The Senate Inquiry also found that funding through the CSTDAs has not improved the outcomes for people with disability by reducing unmet need, particularly in the area of accommodation and support services, despite significant injections of funding by the Commonwealth and the states and territories.

Disability Assistance Package

On 28 June 2007, in recognition of the contribution made by older carers and in response to the above recommendation of the Senate Inquiry, former Prime Minister, the Hon John Howard, announced the Disability Assistance Package of \$1.8 billion in new funding over five years.

The aim of the package was stated as being to give practical support and peace of mind to older carers of people with disability as well as deliver assistance to families of children with severe and profound disability and provide further assistance to disability business services.

In announcing the package, the former Prime Minister highlighted the concerns of older carers who have been looking after their middle aged children with disability for many years.

Under the Disability Supported Accommodation measure in the Disability Assistance Package, over half a billion dollars over five years was intended to supply around 1,750 new supported accommodation places across Australia. The funding was in addition to funding provided by the Australian Government through the CSTDA to assist state and territory governments to provide accommodation.

The Rudd Government has committed to bring the \$962 million allocated by the former government for accommodation, respite and in home support back into the CSTDA and to make this funding available to the states and territories on a dollar for dollar matching basis. This approach would result in an injection of \$1.9 billion in funding for people with disability and their carers.

Key messages from the consultation process

There were consistent messages emerging through responses to the Disability Supported Accommodation Program discussion paper – whether in face to face meetings or submissions. In addition to providing input into designing the nature and shape of the program, the following issues were consistently raised by a range of stakeholder groups, but predominantly parent carers.

Impact of caring

Most of the parent carers who participated in the consultation process by attending public meetings and/or through written submissions were in their 50s, 60s and older. They have been caring for their son or daughter with disability for a long time, many since birth or early childhood. In some instances, parents had been carrying the caring burden for 50 or more years.

Many told of the toll that caring has taken on them emotionally and financially and of the impact on their health and wellbeing. Some are angry at the government and community, as they feel that they and their family member have been let down, through there not being alternatives to keeping their son or daughter at home or sufficient and appropriate support to enable them and their children to experience full and fulfilling lives.

What people want from the Disability Supported Accommodation Program

Parents' biggest worry is what will happen to their sons or daughters when they are no longer able to provide care or when they die.

Parent carers want to know that their family members are well supported to live their lives in a meaningful way – not just existing. They want to know that their sons and daughters have the opportunity to have the life that their parents want for them.

Parents want their son or daughter to have a safe, secure and affordable place to live with the right support. To achieve this, they want individualised funding and the right for their sons and daughters (or parents) to choose the service and support workers to work with them.

Parent carers want their sons and daughters with disability to have the same right as the rest of the community to choose where, how and with whom they live. Parent carers and their sons and daughters with disability want to be supported to maintain existing family and other social networks, as well as to be supported in making decisions and establishing new connections with their communities.

Moving out of home will be a wrench for many people with disability and their parents; it is an emotional and complex time, particularly as people have been living together for so many years. Participants in the consultations stated that both parents and their sons and daughters with disability need a planned, phased approach, with the necessary time and support to adjust to new living arrangements (sometimes up to 2 years); they also need to be given the opportunity to try new things and be allowed to change their minds before settling on the best options for themselves.

Whole of life planning

Many did not agree that the Disability Supported Accommodation Program should be a targeted program. People were of the view that planning for the future life of a person with disability should commence at birth or age of diagnosis of a child's disability. People with disability and their families should be supported through significant (and normal) life transitions – going to school, leaving school and going onto work or further education (or another post school option), and leaving home – at the same ages as their peers. There was a strong view that parents should not have to wait till retirement age to retire from caring and should be able to plan for the futures of their children with disability in the same way as their other children.

Community acceptance

Parent carers, particularly parents of people with intellectual disability, commented during public meetings and in their submissions that their sons and daughters were not well accepted and were vulnerable in the community and therefore needed the safety, security and companionship of being with their peers. Some submissions drew this point out overtly, stating that the general community is not accepting and welcoming of people with obvious disability. Many suggested that a community education campaign is needed to build awareness and acceptance of the rights and capabilities of people with disability to improve their chances of being full members of the communities in which they live, enjoying the same rights and opportunities as others.

Missing voices

There was a notable absence of some groups from the consultations, both in face to face meetings and in written submissions – people with disability, especially those who are currently living at home with their parents; people from culturally and linguistically diverse backgrounds; and Indigenous Australians.

There was a strong call from those who did participate for FaCSIA to undertake targeted consultations with these groups.

Eligibility criteria

Feedback from a range of stakeholders – especially parent carers (both those who fall into the target group and others), advocacy and peak organisations – criticised the eligibility criteria for being too narrow.

Age criteria

Of major concern, were the eligibility criteria around the ages of the person with disability and their parent carer – many considered that both ages were too high and that parents should not be expected to carry the burden of caring for so long before being eligible for assistance. People were particularly concerned about the age of the person with disability (40 years or older). Many people commented that the incidence of disability increases with parental age, with women in their 40s having an increased risk of having children with disability. This means that parents could be potentially in their 80s before being eligible for the assistance available under the Disability Assistance Package, including the Disability Supported Accommodation Program.

Those that supported the age of the parent carer remaining at 65 years or older suggested removing an age qualifier for the carer's son or daughter.

Carer Allowance

People suggested that many people may not be eligible for the Disability Supported Accommodation Program because, even though carers would qualify for Carer Allowance, they were either not aware of the payment or did not want to apply for and receive Carer Allowance for a range of reasons, including distrust of Centrelink. There was also concern that many people who are not eligible for Carer Allowance (for example, because either the carer or the person being cared for is out of the home for more than 63 days in a year) would not be eligible, even though they have been caring for many years.

Feedback indicated that awareness of Carer Allowance should be raised through targeted communication with carers through, for example, Centrelink publications and advertising. There was also some feeling that receipt of (and possibly eligibility for) Carer Allowance should be dropped as an eligibility criterion for the Disability Supported Accommodation Program.

Indigenous and ethnic communities

There was concern expressed about awareness and eligibility of Indigenous Australians and people from culturally and linguistically diverse backgrounds. Family, community and support structures are different; people may not know of or be eligible for Carer Allowance as a result of the way care is shared; information – though widely available and translated into community languages – may not be appropriately targeted or communicated to Indigenous and culturally and linguistically diverse audiences.

Of particular concern in relation to Indigenous people were the age criteria, with a strong message that the criteria should be aligned to other programs that use age as a criterion and that the parent carer's age should be dropped to 45 or 50 years or above and the child's age to 25 years or above.

There was a strong recommendation that FaCSIA undertake specific consultations with both Indigenous and ethnic communities to both increase awareness of the Disability Assistance Package and tailor its measures to meet the needs of these communities.

Bureaucratic duplication

While many participants in the consultations expressed dissatisfaction with the current disability service system, most did not support the creation of a duplicate system and bureaucracy through the Disability Supported Accommodation Program (and arguably, through the Disability Assistance Package measures for older carers more broadly). Many people – whether they be parent carers, service providers or peak organisations – preferred that the funding be directed into the Commonwealth State Territory Disability Agreement (CSTDA) or, at the very least, that the Commonwealth work closely with the states/territories to minimise overlap and duplication.

People were concerned that the extra reporting, accountability and compliance requirements for both government employees and service providers would divert funds (and in the case of services providers, staff) from direct service provision. This would lessen the potential impact of the additional funding under the Disability Supported Accommodation Program to help alleviate unmet need for accommodation and support services.

Parents commented that they and their sons and daughters with disability already found it difficult to negotiate their way through the service maze. They are concerned that another program, with its own gateways, eligibility criteria, assessments and service structure would make the process of navigating the maze more difficult.

Accommodation and support models

People expressed a view that a one-size fits all model will not be suitable for all people and communities, and the public consultations and submissions have helped identify potential approaches to flexibly meeting people's needs.

There was widespread, but not universal, support for the separation of the funding and provision of housing and support.

Quality of life and outcomes

The starting premise for most respondents was that a Disability Supported Accommodation Program should deliver quality of life and quality of outcomes for people accessing accommodation and/or support services.

Comments were focused around four primary areas:

- the centrality and active participation of the person with disability and their family in identifying and following through on needs, goals and plans. People should, as far as possible, be able to lead self directed, fulfilling lives, where:
 - control rests, not with service providers, but with the person themselves (and their family, friends and/or advocates)
 - there is a trust relationship between the person with disability, their family and coordinators and providers, leading to high quality outcomes being able to be achieved
 - people have the right to make choices, change their minds and make mistakes
- an environment in which people with disability are valued, respected and treated with dignity where:
 - people's capabilities are recognised
 - the person is at the centre of thinking and planning, not expected to fit into the way a service operates or the services it provides
 - people are given a range of options and can exercise choice about where, with whom and how they live
- supported accommodation that provides a homelike environment, which provides a safe, secure, supportive and inclusive place to live where:
 - decisions about who lives there are made on the basis of compatibility – not of needs, but of personalities, interests and life stages – and the existing residents have a say
 - people are free to come and go (not locked out during the day or unnecessarily locked in overnight)
 - active community participation and integration is fostered, with social networks and relationships developed beyond the home, as well as maintaining existing relationships with family and friends

- participation in paid or voluntary work is supported
- people have a wide range of activities from which to choose – with the right to choose not to engage
- people’s independence and life skills are supported and developed.

Accommodation

The most common accommodation options put forward in both public meetings and through submissions are:

- cluster living – independent units, collocated on a site, with both private and communal spaces and on-site 24 hour support. Cluster living can involve people with disability and (paid or unpaid support workers); or a mixed community of people with disability and retirees (retirement villages); or intentional communities of people with disability and informal support (for example, a circle of friends, co-tenants with reduced rent in return for some level of support), as well as formal service-provided support
- group homes – generally, no more than 4 or 5 residents in a single residence with shared support
- an Abbeyfield model – where 10 people live on one site (often in bedsits, rather than fully self-contained units) with on-site supervision and/or support available (generally, this would be a housekeeper only, meaning the model would not provide the support required for people with severe or profound disability)
- hostels – a building comprising 10 to 15 apartments or bedsits, with 24 hour support on site (ranging from low to very high care and/or support needs)
- independent living in the community in a range of housing tenures (for example, public, community housing, private rental, ownership) with formal and informal supports (including where desirable and practical, an ongoing role for the person with disability’s parent carer(s))
- for people with disability to remain and be supported in the family home (potentially becoming a group home after the parents have moved out) with formal and informal supports (including where desirable and practical, an ongoing role for the person with disability’s parent carer(s) or other family members).

While there was some support for blending disability and aged care responses to keep families together who wanted to remain so (for example, in a retirement village), there was no support for ‘nursing home’ accommodation for people with disability.

Support

Irrespective of the accommodation model, there was a strong, consistent view that support should be individually planned and provided, and be of sufficient time and quality to allow people with disability to live satisfying and independent lives. Many people commented that people’s lives can be constrained, rather than enhanced, by

insufficient and/or inappropriate support and by support staff not having the relevant attitudes, skills and experience to support people in living fulfilling lives.

Particular areas in which support was seen as crucial to achieving this include:

- supporting people to set and achieve their own individual goals
- individualised personal and medical care, provided as and when it is needed and wanted, not when it is convenient for a service
- living skills training and assistance with daily tasks (for example, in personal care, travel, shopping, cooking, housekeeping, etc) to maximise people's independence
- a wide range of sporting, social and leisure activities, including those aimed at fostering community participation and integration
- maintaining connections with family and friends
- maintaining existing activities, including paid and voluntary employment.

What is needed for success

Common to all accommodation and support options put forward were a range of underpinning elements:

- adopting a case management approach to assist with sourcing support services and accommodation providers over time
- a planned and staged transition phase (from 6 months to 2 years), that allows people to trial changes from care and support being provided predominantly by a parent in the family home to alternative accommodation and/or support arrangements
- ensuring that there is no single service provider in a person's life
- having a home like environment that ensures safety as well as promoting as much independence as possible
- providing security of tenure - allowing options to 'age in place' wherever possible
- acknowledging the needs of the person with disability and that these will change over time
- understanding and building in the continuing role of family and friends in a person's life.

Funding models

Many participants in public meetings and through submissions, questioned the rationale of creating a separate program outside the CSTDA arrangements, commenting that it would be better to augment funding to existing services rather than create separate administrative and accountability structures.

However, if the Disability Supported Accommodation Program were to be implemented as a separate program, most people who commented supported separate funding streams for housing and support. There was general agreement that capital and indexed recurrent funding was needed for the program, with the greater proportion being recurrent.

Parent carers and disability consumer peak organisations overwhelmingly supported individualised funding (people did not identify whether this should be for accommodation, support or accommodation and support). Funding would either be self-managed (by the person with disability and/or their family) or managed by a coordinator on behalf of the person, depending on a person's capacity and wishes.

Service providers favoured block funding or a blend of individual funding and core funding for services to enable them to remain viable and continue to support other people with disability should one person move out and/or discontinue services.

Most people who responded to the consultation process did not support that people with disability should have to pay for core support services, but supported the concept that people with disability should pay rent and a contribution to food, utilities and other running costs of their accommodation (in the same way that any member of the general community would).

There was some support that families and people with disability with income and assets should contribute to support, as well as paying rent and living costs, through arrangements similar to accommodation bonds for residential aged care.

Other funding models put forward include:

- partnership and/or trust arrangements with families (families or groups of families providing the bricks and mortar and government funding support)
- interest free/low interest loans by government to families and people with disability to assist them buy homes
- combining aged care and disability funding packages to enable older carers and people with disability who want to remain together in the family home
- joint ventures or public private partnerships to build homes.

What is needed for success

Many respondents commented on the lack of housing options for people with disability and also on the scarcity of support services available under the CSTDA. To effectively meet the expectations voiced through consultations on the Disability Supported Accommodation Program, funding injections are needed to:

- increase and broaden the available housing options for people with severe and profound disability

- increase the supply of disability (and other community) support services to respond to the needs of people with disability.

Ensuring quality

The national Disability Service Standards (and related state/territory quality assurance processes) were seen as appropriate to be applied to the Disability Supported Accommodation Program. Many people requested that standards for the program be consistent with those of the states and territories for accommodation and support services and that quality assurance processes not be duplicated, as this has the potential to draw funding, staff and attention away from direct services.

Independent accreditation, certification and surveillance audits were supported, which included people with disability as members of audit panels.

There was support for a quality assurance system focussed on quality outcomes for people, not solely on processes. As such, the things to be measured include:

- documented needs and goals and the person's satisfaction with what goals were achieved and also how they were achieved (where appropriate, a person's family, friends, advocates and other services could be involved)
- a person's satisfaction with their quality of life
- satisfaction by the family member (independent of the person) with the services/ supports provided and the way they are provided.

Implicit in this is the expectation that the person would play an active role in the quality assurance process, with the support of their family, friends and/or advocate where this is desirable and wanted. There was a view put forward that parent carers and other family members should themselves play a role, independent of that of supporting their family member with disability, in assessing the quality of accommodation and services.

An accessible, responsive and 'without retribution' complaints process, where issues could be resolved at the earliest point, rather than being allowed to escalate was seen to be an important part of ensuring quality. Again, a person with disability should have access to support mechanisms to help them through a complaints process.

The role of official visitors was also supported, but not as a duplicate arrangement to existing state and territory official visitor programs.

Workforce capacity

Both service providers and parent carers linked the capacity of services to provide high quality support and achieve high quality outcomes to the level of funding provided and also the skills and experience of staff attracted to work in the sector. Respondents commented that current pay scales and career structures made recruiting and retaining the right personnel difficult. Many commented that strategies were needed to increase the profile and status of the sector as an attractive employment prospect.

Suggestions put forward included recognition as a profession, with accredited training and development leading to qualifications; that appropriately skilled and experienced staff should be rewarded; that strategies should be developed to enhance career progression into and through the disability sector.

Respondents considered that staff should be subject to a code of conduct; be accountable for ensuring the needs of people with disability are met and the way in which that occurs; have clear reporting and delegation lines; have access to ongoing training and development; and have their performance regularly reviewed. Services should maintain appropriate staff ratios, relating to the needs and goals of people with disability and the outcomes to be achieved.

Assessment, prioritisation and place management

Most respondents did not address the issues surrounding assessment, prioritisation and place management directly. Those that did stressed that the system needs to be streamlined, open and transparent, based on clear criteria and relative need, not other extraneous criteria (such as capacity to pay).

Models put forward include those used by Western Australia – a one step process to assess eligibility and needs, and assign priority for access to all disability programs funded by the Western Australian government; a modified Aged Care Assessment Team assessment and prioritisation process; or a model like the Housing and Accommodation Support Initiative (HASI) in New South Wales, which involves local level client selection committees comprising the HASI partner providers (accommodation support, mental health and housing providers).

All who commented on an assessment approach stated that it needed to be holistic, looking at all a person's needs, wants, goals and circumstances. Assessments should be dynamic and forward looking, including plans developed with a person for their future. Parent carers were concerned that the views and experience of the parent carer should be respected and taken into account in any assessment – they know the person best.

Some commented that the family unit should be the focus – assessing the whole context and the health and capacity of the family unit as an entity, not focusing just on one person or element. This approach may sometimes lead to a person with disability getting greater or earlier access to programs and supports due to the needs of their primary carer(s), rather than an assessment of their needs in isolation.

Some respondents suggested that assessments should be conducted over a period of up to three months. Others suggested that initial assessment should occur around six months prior to planned access to supported accommodation and regular reviews in the lead up to entry. Reassessments should also occur on request when circumstances and/or needs have changed.

People considered that it was important that while people with disability and their families were waiting for accommodation and/or support services, they receive regular information updates, additional access to respite and in home support services, continued (or new) access to day programs that focus on skills development to equip people with disability to live in the community.

In addition to commenting on assessing needs and priorities for individuals, some respondents made the point that places should be planned for on a population benchmarking basis, similar to that used for estimating the demand for aged care services (projected aged care demand is estimated on the basis of 108 beds/packages per 1000 people aged 70 years and over).

The consultation process

Introduction

On 28 June 2007, the former Prime Minister, the Hon John Howard, announced the Disability Assistance Package, delivering \$1.8 billion in new funding over five years.

The package had several measures to provide reassurance for older parent carers about the future care and accommodation arrangements for their son or daughter with severe or profound disability. This included \$562.6 million for the Disability Supported Accommodation Program.

Consultation process

On 29 August 2007, the former Minister for Families, Community Services and Indigenous Affairs, the Hon Mal Brough, announced that consultations on supported accommodation options would commence from 10 September 2007. The aim of the consultations was to obtain input into the design and development of the Disability Supported Accommodation Program.

Release of the discussion paper

The first part of the consultation process was the release of a discussion paper on 3 September 2007. The discussion paper provided more information on the proposed program and invited people to have their say by either providing a written submission or attending a face-to-face consultation.

The discussion paper was promoted through advertising in metropolitan and regional newspapers, on the FaCSIA website and articles in *disAbility e-news*. The Minister and Department also wrote to a number of stakeholders informing them about the consultations. We know that information about the consultation process was spread further, particularly by interested peaks and other agencies, through articles in e-newsletters.

The information was provided in accessible formats to encourage people with disability to participate in the consultations.

The discussion paper provided information on a dedicated hotline and mailing centre which were established to enable people to:

- request and receive the discussion paper
- register interest for the public meetings
- submit responses to the discussion paper (by mail or electronically).

Face-to-face consultations

The discussion paper encouraged people with disability, their carers, potential service providers, relevant community groups and other interested people to engage in the consultation process. One of the ways they could do this was to attend a face-to-face consultation.

Nationally, more than 1,000 people attended the face-to-face consultations conducted in 27 locations around Australia as follows:

New South Wales	Albury-Wodonga, Gosford, Newcastle, Orange, Parramatta, Sydney
Victoria	Bendigo, Glen Waverley, Melbourne, Morwell
Queensland	Brisbane, Cairns, Caloundra, Gold Coast, Rockhampton, Toowoomba, Townsville
South Australia	Adelaide, Mount Gambier, Port Pirie
Western Australia	Bunbury, Perth
Tasmania	Hobart, Launceston
Northern Territory	Alice Springs, Darwin
Australian Capital Territory	Canberra

Written submissions

Another way people could participate in the process was by providing written submissions by 26 October 2007.

We received approximately 320 submissions from a wide range of people including individuals with disability, advocates, carers, and people representing community groups, organisations, service providers and public sector agencies. Submissions were acknowledged by letter or email.

Keeping people informed

Following the face-to-face consultations, reports covering the key issues raised were posted to the FaCSIA website and letters with the same information have been sent to participants.

Feedback provided to us through the public meetings and submissions is included in this interim report. It is proposed that the report be sent to all participants, whether they provided their input at face-to-face meetings or in submissions and posted to the department's website.