



OFFICE OF THE
PUBLIC ADVOCATE

Submission to the Senate Community Affairs References Committee

Inquiry into the Funding and Operation of the Commonwealth State/Territory Disability Agreement (**CSTDA**)

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Summary and Recommendations

This submission draws to the attention of the Committee issues that are relevant to the funding and operation of the Commonwealth State/Territory Disability Agreement. Six recommendations are made by the Office of the Public Advocate for the consideration of the committee. These are made below and further discussed in the main part of the submission.

The Office is of the view that there is a crisis of unmet need and a range of other significant issues that should be addressed by government in the next CSTDA. The recommendations that are made propose significant action by government. The disability and related sectors need to be reframed to meet the vision that has been articulated within the CSTDA. The Office is also particularly concerned that the CSTDA does not appear to have supported effective policy settings and coordination for the advocacy program.

Recommendation 1: Incorporate the vision contained within the preamble in the full CSTDA framework.

The next CSTDA must preserve the vision of the CSTDA articulated within the current preamble and translate this to the detailed agreement through revised recitals and supporting clauses of the agreement.

Recommendation 2: Revise the Recitals in Part A as follows:

- A. The Commonwealth and the States/Territories wish to make this Agreement, the purposes of which are to –
 - (a) Affirm the shared vision of inclusive communities where people with disabilities, their families and carers are valued and are equal participants in all aspects of Australian life;
 - (b) Develop the previously established national framework so that it is the primary mechanism for governments to work together with other parties to achieve this vision;
 - (c) Outline in the national framework the objective and policy priorities for services for people with disabilities across Australia that will progress the vision over the life of the Agreement;
 - (d) Provide a mechanism for the development of a means for measuring and publicising the progress of governments and communities towards achieving this vision;
 - (e) Outline the respective and collective roles and responsibilities of the Commonwealth and States/Territories in the planning, policy setting and management of specialist disability services that will ensure specialist disability services are compatible with the vision;
 - (f) Provide for accountability of government to the community for achievement of the vision;
 - (g) Review the financial arrangements for making funds available for the provision of specialist disability services so that they have the organisational capacity to support the vision. Funding will be individualised, needs based and portable and facilitate organisational capacity;
 - (h) Define the purposes of services funded under this Agreement so that they are compatible with the vision and acknowledge that persons with disabilities have needs that require services provided outside the Agreement;

- (i) Provide for a nationally consistent approach to quality across specialist disability services based on the vision;
- (j) Establish and maintain a National Disability Commission that will monitor and support progress towards achieving the vision and assist government to address key national and strategic research, development, and innovation priorities. The Commission will also administer key Commonwealth programs that are connected to the achievement of the vision including advocacy; and
- (k) Identify a new funding scheme to be implemented from 2010.

Recommendation 3:

Substantial injection of funds to address crisis of unmet need

The next CSTDA should include new one-off specific purpose grants from the Australian Government to the states and territories in the order of \$640 million over three years to provide accessible social housing for people with unmet accommodation needs. These grants should be tied to the provision of matching state government funding for support packages to meet identified unmet support needs.

Recommendation 4:

Response to disability and ageing population

The next CSTDA must systematically address the issues raised by the ageing population and its impact upon people with disabilities and their carers and families.

Recommendation 5:

Remaining assistance anomalies need to be addressed

Remaining anomalies in the division of funding in areas such as continence aids must be redressed through the next CSTDA.

Recommendation 6:

Establish a cooperative process for the development of a national funding scheme

The next CSTDA should establish a cooperative process for the development of a comprehensive national scheme of funding of disability support and related issues. There should be prior agreement within the next CSTDA from the jurisdictions that the implementation of the new scheme will commence in 2010.

About the Office of the Public Advocate

The Public Advocate in Victoria is appointed by the Governor in Council pursuant to the *Guardianship and Administration Act 1986 (Vic)*. The Office represents the interests of people with a disability, aiming to promote their rights and dignity and to strengthen their position in society. It is a statutory office, independent of government and government services, and can highlight situations in which people with disabilities are exploited, neglected or abused.

The Public Advocate delegates his authority to his staff, who provide advocacy, guardianship and investigation services to people with disabilities. The Office also coordinates the Community Guardians Program, the Community Visitors Program, the Independent Third Person Program and the Private Guardian Support Program. Further information is provided at the Office of the Public Advocate's website: www.publicadvocate.vic.gov.au

The Office response to the terms of reference

Term of Reference (a)

An examination of the intent and effect of the three CSTDAs to date

Intent of the CSTDA

Recommendation 1:**Incorporate the vision contained within the preamble in the full CSTDA framework.**

The next CSTDA must preserve the vision of the CSTDA articulated within the current preamble and align the other parts of the agreement with this vision.

The intentions of the CSTDA agreements are contained within the preamble, the stated purposes of the recitals and the policy priorities of the third agreement. These are reviewed below.

The preamble to the third CSTDA contains a vision that the Office shares. This vision has developed within the Australian community and internationally over the last twenty years. The preamble reflects the fact that this shared and bi-partisan vision is now the basis of government policy. The CSTDA itself is taken to be an instrument of this public policy. This is indicated in the first paragraph of the CSTDA preamble that states the CSTDA is of 'both practical and symbolic importance...to make a positive difference in the lives of people with disabilities'.

While the vision of the main part of the preamble is appropriately aspirational the five strategic policy priorities that are stated in conclusion appear modest in comparison. The Office acknowledges that governments will be able to point to examples of progress against each of these five priorities. In practice though, these priorities seem to be mainly preoccupied with just one aspect of the fourth priority: demand management.¹

An example of this overriding concern with demand management is the recently passed Victorian Disability Act 2006. It continues to define disability in the same terms that were used to frame disability services in the legislation of the 1980s.² People with dual disabilities and conditions such as Huntington's disease and autism spectrum disorder can still find it hard to access services.

The opportunity to enact a more inclusive definition of disability that could be relied upon by individuals, families and carers on the basis of need rather than diagnosis has not been taken by the Victorian Government. This may be due to concerns related to ‘opening the flood gates’ to other people with disabilities. There may also be an apprehension of a lack of expertise in being able to meet the needs of people with other disabilities. There are definitional limitations of this legislation for people who lack capacity to exercise their rights because of their disability arising from head injury and other cognitive disabilities. For example the provisions relating to compulsory treatment only apply to people with an intellectual disability.

While progress can be seen on some of the incremental policy priorities, the Office is concerned that the vision encapsulated within the CSTDA preamble remains elusive. The other parts of the CSTDA that establish the national framework are not directly related to the vision of the preamble. For example, while the term ‘rights’ is used seven times within the preamble as an important remedy for the situation of people with disabilities, the rest of the agreement fails to use the term.

In summary, the view of the Office is that the vision contained within the preamble to the agreement needs to be more than just symbolic. It must also be a continuing reference point to measure progress made through the ‘practical’ measures that are undertaken. The next CSTDA needs to incorporate greater connection between the vision and the terms of the agreement through revised recitals.

Effect of the CSTDA

Recommendation 2:

Revise the Recitals in Part A as follows:

The Commonwealth and the States/Territories wish to make this Agreement, the purposes of which are to –

- (a) Affirm the shared vision of inclusive communities where people with disabilities, their families and carers are valued and are equal participants in all aspects of Australian life;
- (b) Develop the previously established national framework so that it is the primary mechanism for governments to work together with other parties to achieve this vision;
- (c) Outline in the national framework the objective and policy priorities for services for people with disabilities across Australia that will progress the vision over the life of the Agreement;
- (d) Provide a mechanism for the development of a means for measuring and publicising the progress of Governments and communities towards achieving this vision;
- (e) Outline the respective and collective roles and responsibilities of the Commonwealth and States/Territories in the planning, policy setting and management of specialist disability services that will ensure specialist disability services are compatible with the vision;
- (f) Provide for accountability of government to the community for achievement of the vision;
- (g) Review the financial arrangements for making funds available for the provision of specialist disability services so that they have the organisational capacity to support the vision. Funding will be individualised, needs based and portable and facilitate organisational capacity;

Recommendation 2 continued:

- (h) Define the purposes of services funded under this Agreement so that they are compatible with the vision and acknowledge that persons with disabilities have needs that require services provided outside the Agreement;
- (i) Provide for a nationally consistent approach to quality across specialist disability services based on the vision;
- (j) Establish and maintain a National Disability Commission that will monitor and support progress towards achieving the vision and assist government to address key national and strategic research, development, and innovation priorities. The Commission will also administer key Commonwealth programs that are connected to the achievement of the vision including advocacy; and
- (k) Identify a new funding scheme to be implemented from 2010.

Current recitals

The current recitals of the CSTDA have been revised by the Office and some key recitals are discussed below. The revised recitals that have been proposed above reframe the agreement so it is a more effective mechanism for the realisation of the vision. The proposed revised recitals also raise issues that are further discussed below in relation to the other terms of reference.

Measuring Progress

Current recital A(a)

Provide for a national framework outlining the objective and policy priorities for services for people with disabilities across Australia to be progressed over the life of the Agreement, and outline a means for measuring and publicising the progress of Governments towards achieving this national framework (clauses 4 and 7);

The Office accepts that the CSTDA mechanism has established a national framework that outlines the objective and policy priorities for services. The Office also accepts that a means for measuring and publicising the progress of governments towards achieving this national framework has been developed. The Office notes that the framework attempts to build a longitudinal data set to better enable evidence based decision-making.

The concern of the Office is that the public policy concerns of government and the data that is collected are disconnected from the vision of the preamble. While the specialist service system is an important mechanism for addressing the relative disadvantage experienced by Australians with disabilities, the data sets that are collected only indirectly relate to this disadvantage. They have been explicitly developed according to the immediate concerns and priorities of the state and territory governments and administrators. This means that the data collection framework is largely reactive in nature in the absence of a long term strategic framework connected to the higher purpose of the vision contained in the preamble.

The data collection system needs to be realigned so that measuring outcomes arising from service interventions for individuals with disabilities is more robust. Progress could also then be connected to aspirational national benchmarks rather than being limited to the current comparative benchmarks between jurisdictions. The proposed National Disability Commission could assume responsibility for the data collection system.

Outlining Responsibilities

Current Recital A(b)

Outline the respective and collective roles and responsibilities of the Commonwealth and States/ Territories in the planning, policy setting and management of specialist disability services (clause 6);

Outlining these roles and responsibilities has resolved issues of duplication, overlap and program management expertise. The cost of this reform has been the creation of service access rigidities and barriers.

The problems created by these service boundaries are evident in the difficulties services have in responding to people's changing needs, interests and priorities. People with disabilities do not have 'once a lifetime' needs that require a 'one time only' service response. Individuals often remain within a particular service type and funding stream. The CSTDAs have reinforced the funding of inflexible service type streams. This is in contrast with funding individuals on the basis of their changing needs and interests.

In rural and regional areas often the same community based service will be providing different types of services from the different funding streams. They are sometimes able to mix and match service types according to the needs and interests of the individuals. Mostly, though, longstanding clients of services have been largely locked into the service in which they commenced regardless of how well it may be meeting their needs. People who have been in a service for a long time can sometimes feel that they belong to the service rather than it being a matter of their choice.

While in theory the CSTDA enables the transfer of services³ this is usually difficult in practice. It is often difficult for the individual to seek out an alternative service because their friends will remain behind and/or because their options may be limited. These options are often limited because there is no vacant capacity in an alternative service.

The next CSTDA needs to progress individualised portable funding that is needs based. This funding could be authorised through an individualised planning approach. Overlapping funding bands need to be developed so that a person can use their funding in different settings for different services across jurisdictions without unnecessary disruption. This could be implemented through the development of clauses that relate to the recital item that has been suggested.

Monitoring of the CSTDA

The next CSTDA should establish a National Disability Commission for the purpose of monitoring the CSTDA and allied functions and to ensure that the national framework is aligned with the vision. The Commission should have a monitoring, advisory, complaints handling and planning role in relation to services funded by the Australian government. This suggestion draws on the Disability Services Commissioner innovation being implemented in Victoria through s16 of the Disability Act 2006.⁴ The functions that are relevant to the Commission include:

- review and identify the causes of complaints and suggest ways of removing and minimising those causes;
- provide advice or inquire into matters referred by the Minister or the Secretary;
- conciliate where a complaint has been made in relation to a disability service provider;

- provide advice to the Disability Services Board;
- refer issues to the Disability Services Board for advice;

The Commission should also adapt to the Commonwealth the role announced for the Office of Disability in Victoria:

“the new office will promote change across State Government Departments to make public services, infrastructure and programs more accessible to all Victorians with a disability...”⁵

The National Disability Commission would subsume some existing disability complaints related services funded by the Australian Government. The Commission would need to be independent of the key Australian Government service delivery departments. The Commission could operate and have executive authority from within the portfolio of the Minister for Finance and Administration. The Commission would establish protocols with relevant state based offices and with advisory bodies. The Commission would receive complaints relating to services funded by the Australian government and make recommendations to the CSTDA administrators and CSTDA services. The Commission would have other functions relevant to service quality assurance.

Shared responsibility for advocacy

A serious problem in the operation of the CSTDA has been the neglect of the advocacy program. The responsibility for advocacy is a shared responsibility. However the recent national review of the advocacy program has highlighted a lack of coordination between state and Australian governments in how advocacy is provided. This is despite “Clarifying the role of both parties in advocacy” being specified as an activity in the bilateral agreement for Victoria.⁶ Clause 6(1)(g) of the CSTDA calls for joint programs to be complementary. The Office notes the past coordination between the responsible departments in Victoria has previously benefited resource allocation.

The Office has been an associate member of the Victorian Disability Advocacy Network (VDAN) that has developed to support its 37 member advocacy organisations over the past several years. The Network supports collaboration, information sharing and advocacy development activities. It has recently been successful in tendering for an advocacy development resource unit funded by the state government. This is part of a State initiative to support the important role of advocacy. Some of the VDAN organisations are funded by both levels of government. Some are not funded at all. Most are funded by the Australian Government. All the organisations operate with inadequate resources that are not commensurate with the demands upon their organisations for the provision of independent advocacy. The administering Department has undertaken several reviews of the advocacy program during the life of the CSTDAs. The most recent review has been conducted without real consultation with the state government. The affected advocacy organisations have only been funded until the end of 2006. The current review will apparently result in a large scale reorganisation of the funded sector on the basis of the Department’s view about how advocacy should be organised and structured. Reference to existing advocacy reforms at a state level is not apparent.

The administering Department has concentrated its attention on other Commonwealth programs (open and supported employment) for the last ten years. The department seems to lack relevant expertise for policy setting that would see the further development of advocacy. The evidence for this is the Department’s failure to follow through with many of the outcomes of the last review that was instigated in 1999. During this time supported employment business services have been assisted to adapt to a new quality assurance system and an individualised funding approach. Open employment services were transitioned to another department through machinery of government changes.

The Office believes that a vibrant community advocacy sector is vital to the achievement of the CSTDA vision and can make a critical contribution to service innovation and development.⁷ Community based advocacy is also an essential response to vulnerable individuals experiencing systemic disadvantage, discrimination and ill- treatment.

The previously recommended National Disability Commission should be given responsibility for the administration of the Commonwealth advocacy program. The next CSTDA should support improved coordination between the levels of government.

Term of Reference (b)

The appropriateness or otherwise of current Commonwealth / State / Territory joint funding arrangements, including an analysis of levels of unmet needs and, in particular, the unmet need for accommodation services and support

Recommendation 3:

Substantial injection of funds to address crisis of unmet need

The next CSTDA should include new one-off specific purpose grants from the Australian Government to the states and territories in the order of \$640 million over three years to provide accessible social housing for people with unmet accommodation needs. These grants should be tied to the provision of matching State Government funding for support packages to meet identified unmet support needs.

The Office fully supports rigorous accountability measures so that outcomes for people with disabilities are maximised.⁸ The Office also supports the making of robust financial arrangements between levels of government.⁹ The CSTDA has specified the shared responsibility of governments in making demand adjustments. It is the view of the Office that the incremental increase in resources that has been provided through the CSTDA is no longer sustainable. There is truly a crisis of unmet need for services and support for people with disabilities, their carers and families. There needs to be a significant injection of additional resources to address the unmet need that has been endemic in the system for the life of the CSTDA.

This crisis of unmet need in Victoria has been recently documented by the *Coalition for disability rights*.¹⁰ This is a broad based coalition of people with disabilities, families, carers, advocacy bodies, peak bodies and disability support provider organisations. They have calculated that there needs to be a \$365 million increase in recurrent funding in Victoria alone for disability support. They also suggest a need for \$373 million of additional capital funding.

The *Coalition for disability rights* suggest on the basis of their research that \$241 million of capital funding is required to reduce waiting lists for supported accommodation in Victoria. As Victoria represents about one quarter of the nation's disability population this suggests that nationally up to \$960 million of capital funding might be required to address unmet accommodation need. As this would require significant investment by the Australian community it is suggested that it is reasonable to suggest that a very large investment in the order of at least \$640 million is justified in the current circumstances.

As the Australian Government has a key responsibility for ensuring the observance of the human rights of Australians with disabilities they should take lead on responding to the significant unmet need.

Term of Reference (c)

An examination of the ageing/disability interface with respect to health, aged care and other services, including the problems of jurisdictional overlap and inefficiency

Recommendation 4:

Response to disability and ageing population

The next CSTDA must systematically address the issues raised by the ageing population and its impact upon people with disabilities and their carers and families.

Interface Issues

The issue of ageing is a major issue for the Office as its staff and volunteers are confronted with many incoherencies of systems and problems in its daily work of guardianship and advocacy. Some examples of these issues are provided below.

Case study

'Karen' is a 58 year old woman with an intellectual disability. She lives in a state funded Community Residential Unit (CRU) where she had lived for more than 10 years with four other residents. Karen has been diagnosed with dementia and is currently taking cognitive enhancement therapy medication. There are issues with regard to her being able to remain at the CRU as her care needs have increased. She now spends most of her time sleeping or sitting on her bed or sitting on the floor with a blanket over her head. She screams if anyone tries to take her beyond the front gate or in the car. She needs assistance with toileting. Her behaviour is impacting on other residents, especially their ability to go out. An active night (Staff member who is available during the evening) has been introduced into the house so that staff support can be provided when required but the Department of Human Services (DHS) will not continue to fund the increased hours of support required to meet her support requirements as well as those of other residents. The Aged Care Assessment Team assessed her as a high care needs client and recommended that she be moved to a dementia specific nursing home care unit.

Her treating doctor is advocating for her to remain at the CRU with extra support. He believes there would be serious implications for Karen's health in terms of their ability to communicate with new carers in a different environment and she would be likely to deteriorate rapidly.

When the DHS Manager requested further funding they were directed to apply for Commonwealth funding.

It is the view of the Office that someone in Karen's position should be able remain living at the community residential unit for the following reasons:

- It is the least restrictive option
- The required level of support can be offered in the CRU.

- There are no safety or welfare concerns
- The CRU has been home for a number of years.
- The staff at the CRU are very familiar with her personality, methods of communication and care needs. This would not be the case at a nursing home.
- An aged care facility will have little knowledge or expertise managing people with an intellectual disability
- A resident who is non-verbal may be ‘forgotten’ in a larger setting.
- A nursing home cannot offer the 1:1 support currently offered.

There is limited additional funding to meet the needs of people currently living in a shared group accommodation house and whose needs are changing. One example of this is that residents of these group homes have not generally been able to retire and stay at home. This has been because the typical model for shared group accommodation has assumed that residents will be at a day placement.

As a person’s needs are perceived to increase due to the ageing process they may be assessed by ACAS and be found to be eligible for high care residential care. However they may have always required this level of care because of their disability support needs, with the only change being their age. If a person has lived in disability shared group accommodation for many years staff are likely to have gained intimate knowledge of the person’s specific needs, wants and goals. People in this situation should be allowed to remain in their current place of residence consistent with a policy of ‘ageing in place’.

Overlap and inefficiency

Recommendation 5:

Remaining assistance anomalies need to be addressed

Remaining anomalies in the division of funding in areas such as continence aids must be redressed through the next CSTDA.

Despite the general rationalisation of jurisdictions provided for by the CSTDA and other arrangements there are still funding arrangement confusions for many service recipients. In some instances there are still a range of programs addressing the same issue but for different groups. An example of this is the funding of incontinence products. There are a range of programs with differing eligibility requirements offered at both a state and federal level. The consequential inefficiency means that unless a person is a Veteran, or living in an aged care facility, neither the state nor federal government funds incontinence products for people aged over 65 years. The Office has reported incidents of people being forced to wear cloth nappies because of cost.

Term of Reference (d)

An examination of alternative funding, jurisdiction and administrative arrangements, including relevant examples from overseas.

Recommendation 6:

Establish a cooperative process for the development of a national funding scheme

The next CSTDA should establish a cooperative process for the development of a comprehensive national scheme of funding of disability support and related issues.

There should be prior agreement within the next CSTDA from the jurisdictions that the implementation of the new scheme will commence in 2010.

The Office is not able to offer fully developed options for the consideration of the Committee. The unmet needs of people with disabilities are major costs incurred by individuals with disabilities and the community. These issues have long been recognised and are fundamental to the CSTDA itself. It remains that these funding and jurisdictional issues have proved somewhat intractable. When these issues are addressed it is usually through piecemeal measures that do not go towards providing sensible and sustainable solutions. It is hoped that the Committee will receive submissions that provide comprehensive solutions that can then be implemented through the next CSTDA.

Endnotes

¹ The concluding paragraph of the third CSTDA preamble is:

In pursuing the visions expressed above, Commonwealth, State and Territory Governments have agreed on the incremental implementation of five strategic policy priorities. These are to:

1. *strengthen access to generic services for people with disabilities;*
2. *strengthen across government linkages;*
3. *strengthen individuals, families and carers;*
4. *improve long-term strategies to respond to and manage demand for specialist disability services;*
5. *improve accountability, performance reporting and quality.*

² The Victorian Disability Act 2006 (s.3) defines disability as:

"disability" in relation to a person means—

(a) a sensory, physical or neurological impairment or acquired brain injury or any combination thereof, which—

(i) is, or is likely to be, permanent; and

(ii) causes a substantially reduced capacity in at least one of the areas of self-care, self-management, mobility or communication; and

(iii) requires significant ongoing or long term episodic support; and

(iv) is not related to ageing; or

(b) an intellectual disability; or

(c) a developmental delay;

³ CSTDA Recital Clause B(b)

⁴ Disability Act 2006 Act No. 23/2006

[http://www.dms.dpc.vic.gov.au/Domino/Web_Notes/LDMS/PubStatbook.nsf/edfb620cf7503d1aca256da4001b08af/0B82C05270E27961CA25717000216104/\\$FILE/06-023a.doc](http://www.dms.dpc.vic.gov.au/Domino/Web_Notes/LDMS/PubStatbook.nsf/edfb620cf7503d1aca256da4001b08af/0B82C05270E27961CA25717000216104/$FILE/06-023a.doc) accessed 17 August 2006

⁵ New Office for Disability

<https://fac.dhs.vic.gov.au/home.aspx?tabid=11&newsid=149> accessed 17 August 2006

⁶ CSTDA Clause 6(1)(d) and Bilateral Agreement – Victoria.

⁷ CSTDA Recital A(f) and clause 10

⁸ CSTDA Recital A(c) ... accountability to funders in respect of funds contributed by one Government which are expended by another Government (clause 7)

⁹ CSTDA Recital A(d) ... establish the financial arrangements for making funds available for the provision of specialist disability services (clause 8)

¹⁰ Coalition for Disability Rights 2006, Call to political parties: 2006 Victorian State Election, Fitzroy