The Senate

Standing Committee on Community Affairs

Funding and operation of the Commonwealth State/Territory Disability Agreement

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From 11 September 2006 [1]

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Substitute Member

Senator Siewert, AG Western Australia to replace Senator Allison for the inquiry and Senator Ferris, LP South Australia to replace Senator Adams on 6 October 2006

Participating Members for the inquiry

Senator Guy Barnett	LP, Tasmania
Senator Andrew Bartlett	AD, Queensland
Senator Jan McLucas	ALP, Queensland
Senator Gavin Marshall	ALP, Victoria
Senator Ruth Webber	ALP, Western Australia

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[1] The Senate Committee system was restructured on 11 September 2006 to amalgamate the former legislation and references committees. The membership of committees was varied as part of the restructure. Inquiries that were current on 11 September continued with the same terms of reference and reporting dates.

Senate Community Affairs References Committee

Until 10 September 2006

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Senator Judith Adams	LP, Western Australia
Senator Lyn Allison	AD, Victoria
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Senator Helen Polley	ALP, Tasmania

Substitute Member

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Senator Gavin Marshall	ALP, Victoria
Senator Ruth Webber	ALP, Western Australia

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4.150 That Commonwealth, State and Territory governments jointly commit as part of the fourth CSTDA to substantial additional funding to address identified unmet need for specialist disability services, particularly for accommodation services and support.

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6.30 That a review of alternative funding arrangements be undertaken through the research and development program of the next CSTDA which specifically considers, amongst other elements:

- the likely costs and benefits of individualised funding;
- the issues encountered in the introduction of alternative funding overseas;
- provisions and alternatives to allow people with disabilities to choose the level of self-sufficiency with which they are comfortable;
- the provision of decision support tools and services to assist people with disabilities, their families and carers.

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Recommendation 29

7.29 That Commonwealth, State and Territory governments ensure that people with disabilities and their families are not discouraged from accessing care services in their homes because of potential occupational health and safety liability.

CHAPTER 1

INTRODUCTION

Terms of reference

1.1 On 11 May 2006 the Senate referred the following matter to the Community Affairs References Committee for inquiry and report by 7 December 2006:

An examination of the funding and operation of the Commonwealth State/Territory Disability Agreement (CSTDA), including:

(a) an examination of the intent and effect of the three CSTDAs to date;

(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;

(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; and

(d) an examination of alternative funding, jurisdiction and administrative arrangements, including relevant examples from overseas.

1.2 The Community Affairs Committee continued the inquiry following its establishment and the reporting date was extended till 8 February 2007.

Conduct of the inquiry

1.3 The inquiry was advertised in *The Australian* and on the Internet. The Committee invited submissions from Commonwealth, State and Territory Governments and interested organisations and individuals.

1.4 The Committee received 119 public submissions and five confidential submissions. A list of individuals and organisations who made a public submission or provided other information that was authorised for publication by the Committee is at Appendix 1.

1.5 The Committee held seven days of public hearings in Melbourne (28 September); Sydney (3 October); Perth (5 October); Adelaide (6 October); Canberra (13 October); Brisbane (17 November) and Hobart (22 November). Witnesses who give evidence at the hearings are listed in Appendix 2.

Background

1.6 In 1991, the Commonwealth entered into a Multilateral Agreement with the States in order to define the roles and responsibilities of the Commonwealth and State and Territory Governments in the delivery of specialist disability services. The Commonwealth State/Territory Disability Agreement (CSTDA) is now in its third iteration with the fourth agreement due to commence in July 2007. A history of the CSTDAs is provided in Chapter 2.

1.7 A reference of the CSTDA to the Committee was initially moved in March 2006. It was noted in the debate that there had been criticism of the CSTDA on many fronts: by people with disabilities; by advocacy groups; by State and Territory Governments; and by the Australian National Audit Office (ANAO). The ANAO's report pointed to the lack of a system of monitoring expenditure; lack of systems to collect data; lack of analysis of unmet need; and a lack of coordination within Commonwealth departments about policy for people with a disability.[1]

1.8 A number of issues were raised in debate to support an inquiry. People with a disability had pointed to a lack of clarity in the intent of the Agreement and changes to the Agreement over time. As a result, people with disabilities and their advocacy organisations and services commented that they were unsure and unclear about what the detail of the Agreement actually entailed. People with disabilities reported a lack of consistency in the application of the Agreement, not only State to State but also within States and Territories. They also stated that there is no portability of funding and support for those moving between States and Territories. It was also noted that people with a disability are ageing and that there was therefore a need to understand nationally the interface between the ageing portfolio and the disability portfolio.

1.9 Senator McLucas, the mover of the proposed reference, argued that an inquiry into the CSTDA would 'give clarity to the way the Commonwealth and the States negotiate about people with disabilities and their services…[and] give clarity to people with disability about what the intent is of both parties so that they can understand what will be delivered'.[2]

1.10 The referral of the CSTDA was negatived by the Senate in March but in a reworded form was subsequently referred to the Committee on 11 May 2006.

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[1] ANAO *(Administration of the Commonwealth State Territory Disability Agreement)* Audit Report No.14 2005-2006.

[2] *Senate Hansard*, 2.3.06, p.29, Senator Jan McLucas.

CHAPTER 2

THE AGREEMENTS – INTENT AND EFFECT

2.1 This chapter provides an overview of the history and impact of the previous two agreements and outlines the provisions of the current agreement.

Background

2.2 In 1983, the Commonwealth sought to reform services for people with disability in response to the growing trend for people with disabilities to be assisted to establish patterns of life that were close to, or the same as, those of society generally. Accordingly, the Commonwealth instigated a review of programs developed under the *Handicapped Persons Assistance Act 1974*. The report of the review, *New Directions*, contained criticisms of existing services based on institutional living arrangements, sheltered workshops and activity therapy centres.[1] It noted that people with disabilities wanted to live in a community setting, have access to paid employment, opportunities for community participation and community acceptance, and a choice in the services they used. The Review also pointed to:

- a significant lack of coordination between Commonwealth and State Governments;
- the lack of any clearly specified program objectives;
- a focus on large service providers running institutionally based care at the expense of smaller, community based services; and
- the low priority accorded to consumers by governments and service providers.

2.3 The Review concluded that substantial improvements were required in the accountability of subsidised organisations for service content and quality, and that major changes were needed in the programs themselves to reflect a consumer outcomes focus. A restructuring of services, funding and other resources was also required.

2.4 The Review formed the basis of an overhaul of Commonwealth programs for people with disabilities and impacted on service providers. The implementation of the Review's recommendations was achieved mainly through the *Disability Services Act 1986* which replaced the Handicapped Persons Assistance Act. Ms Raelene West, a PhD student studying disability service delivery, noted that the Disability Services Act 'sought to reduce models of service delivery that promoted a reliance on charity and welfare models of service delivery and instead sought to provide a full range of

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[1] Report of the Handicapped Programs Review, *New Directions*, AGPS, Canberra, 1985.

support services to assist people with a disability to live independently in the community'.[2]

2.5 The Disability Services Act provided the legislative basis for the funding of organisations and of States providing services for people with disabilities. It covered a much broader range of services than the Handicapped Persons Assistance Act and each service type was more broadly defined. The inclusion of the States was a major change, with the then Minister for Community Services stating that:

> …it reflects the fact that most States are already involved to varying degrees in service provision, and the many potential opportunities for co-operative efforts in this field. The new legislation will permit the Commonwealth to provide funds to the States for services provided by them covered under the legislation. The intention is that such funding be provided on similar conditions to those relating to eligible organisations. The legislation will also permit the joint Commonwealth-State funding of services and projects considered as being of joint interest. This will overcome a major restriction of the Handicapped Persons Assistance Act 1974 and will enable a more co-ordinated effort on behalf of people with disabilities who are part of the target group - for example in relation to the provision of housing or meeting the needs of people with more severe disabilities.[3]

2.6 The Act linked funding of services to their capacity to achieve specific, agreed outcomes for participants in their services with transitional provisions for those services which would not immediately meet the new funding criteria. Organisations were allowed until 30 June 1992 to meet the new, more stringent conditions. Two new service types were also created: competitive employment, training and placements services; and supported employment services.

2.7 The Act was also accompanied by a Statement of Principles and Objectives to be followed in the administration of the legislation and to be applied to individual services. The Principles recognised that people with disabilities have the same rights as do other members of society and advocated the application of 'the least restrictive alternative' principle in assisting them to realise their individual potential. The Objectives related to service delivery.

2.8 The Disability Services Program (DSP) was the name given to the range of services funded by the Commonwealth under the Act. The DSP was supported by the then recently established, and Commonwealth funded, Home and Community Care (HACC) program and Commonwealth Rehabilitation Service (CRS).

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[2] *Submission* 44, p.7 (Ms R West).

[3] *Senate Hansard*, 12.11.86, p.1978, Second Reading Speech (Senator the Hon Don Grimes).

Commonwealth State Disability Agreement (1991-1992 to 1996-1997)

2.9 Following the implementation of the Disability Services Act, there was 'considerable overlap and confusion in the funding arrangements for disability services by the different levels of government'.[4] Delays with processing requests and unwarranted interference across the dual levels of government were reported as creating difficulty and confusion in implementing the objectives of the Act. Ms West commented that 'it was surmised that neither the State/Territory's or Commonwealth Governments alone would be able to meet the outcomes of the Act and that a significant restructure in funding arrangements would be required with the existing multilayered government framework in implementing a service model based on independent community living'.[5]

2.10 The first Commonwealth State Disability Agreement (CSDA) was aimed at defining the roles and responsibilities of the Commonwealth, State and Territory Governments in the delivery of specialist disability services. Before the implementation of the CSDA, responsibility for disability services was unclear. The Commonwealth funded a range of employment, accommodation and community-based services for people with a disability under the DSP. At the same time, the States and Territories provided similar services, and much greater levels of overall funding, under separate legislation. The Commonwealth noted in its submission that:

> The first Commonwealth State Disability Agreement marked a turning point in the provision of services for people with disability. Previously services for people with disability were not well coordinated across the Commonwealth and state and territory governments. This had resulted in overlap, duplication and gaps in service provision.[6]

2.11 The aim of the rationalisation was to:

- improve consumer information, assessment and referral systems;
- simplify access to services for consumers;
- provide greater clarity for service providers;
- ensure better planning and integration of services;
- improve consistency and coverage of data on disability services;
- reduce costs of administration; and
- achieve, where possible, a shift away from direct service provision by the Commonwealth and the States (because of a perceived conflict of interest where governments were both service providers and funders).

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[4] Yeatman, A, *Getting Real: The Final Report of the Review of the Commonwealth State Disability Agreement*, July 1996, p.ix.

[5] *Submission* 44, p.8 (Ms R West).

[6] *Submission* 96, p.7 (Australian Government).

Major features

2.12 The Agreement was signed by all Heads of Government at a Special Premiers Conference in July 1991. Each State and Territory enacted legislation complementary to the Commonwealth *Disability Services Act 1986.* This ensured that disability services in each State and Territory would be required to adhere to the Principles and Objectives enshrined in the Disability Services Act (DSA) as well as moving, over time, to outcome based funding, service agreements and regular service reviews and from an emphasis on specialist to improving access to generic services, all of which were important features of the DSA. The objective was to increase service accountability and consumer focus in State-based services as the DSA had done in Commonwealth services.

2.13 Under the CSDA, the Commonwealth undertook responsibility for administering employment services and labour market programs, consistent with its general responsibilities for employment and its links with the Social Security system. The State and Territory Governments undertook responsibility for administering accommodation, community support, community access, respite and other support services. As a consequence, some State and Territory services that were predominantly employment-based were transferred to the Commonwealth and some Commonwealth services that were predominantly day activity-based were transferred to States and Territories. The CSDA provided for joint Commonwealth-State responsibility for advocacy, research and development and involved both jurisdictions in planning, priority setting and program evaluation.

2.14 In recognition of the lack of adequate and consistent data on disability services, the CSDA set out broad data requirements. Subsequently, the Australian Institute of Health and Welfare (AIHW) developed a minimum data set comprising core, non-financial data to be collected by the Commonwealth and State Governments to build up a national picture of disability services.

Funding

2.15 Following implementation of the CSDA, the funding which the Commonwealth previously contributed to the services transferred to the States in the Agreement was paid to the State Governments as specific purpose (tied) payments, thus ensuring that the money is spent only on disability services. Approximately $200 million was allocated for this purpose in each of the first five years. The Commonwealth provided, in addition, $145 million over five years to improve the quality of services transferred to the States and an additional $100 million over five years to provide for growth in these services. Transferred services were to continue to be funded at existing levels or above for the first 12 months following transfer. After that, funding for individual services could be varied either up or down, but overall funding to disability services by either level of government was not to fall below 1989-90 levels.

The views of consumers and service providers

2.16 While recognising the potential benefits which might be realised from implementation of the CSDA, peak bodies and others consulted in development of the Agreement raised a number of concerns, including:

- inadequate consultation;
- inadequate attention to grievance procedures;
- fear that States would fail to honour the philosophy of service;
- provision enshrined in the Principles and Objectives of the DSA; and
- fear that States would reduce their financial commitment to disability services.

2.17 Many of these concerns were addressed in the Agreement, which required States to espouse the Principles and Objectives of the Disability Services Act and stipulated that neither Commonwealth nor State governments could reduce the level of their financial commitment to disability services.[7]

Impact of the first CSDA

2.18 The Tasmanian Government stated that the first CSDA was a significant event for people with disability and the disability sector:

> For the first time the issue of provision of specialist disability services was framed within a national context with particular emphasis on common standards of service provision and comparable performance data.[8]

2.19 The Review of the first CSDA, published in 1996, identified five achievements:

- it restated the fundamental principles already adopted in the DSA that people with disabilities are persons 'with the same basic human rights as other members of Australian society';
- it represented a division of labour between the two levels of government with regard to the provision of disability services – a demarcation agreement regarding which level of government is responsible, and thus accountable, for what;
- it provided an opportunity for a joint and cooperative governmental approach to policy, planning and funding for disability services in Australia;
- it enabled the adoption of an 'outcomes' approach to services for people with disabilities, that is, an emphasis on the results these services achieve in

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[7] Lindsay M, *Commonwealth Disability Policy 1983-1995,* Background Paper 2 1995-96, Parliamentary Library, p.34.

[8] *Submission* 69, p.1 (Tasmanian Government).

enabling people with disabilities to realise their capacities and to attain a reasonable quality of life; and

- it required each State/Territory government to pass legislation in accordance with the principles and objectives of the Commonwealth *Disability Services Act 1986*.[9]

2.20 The Commonwealth also pointed to the benefits arising out of the first CSDA and cited the introduction of parallel Commonwealth-State disability services legislation, which included shared Principles and Objectives. Other major benefits identified included the clarification of government responsibilities through the delineation of Commonwealth and State government roles; a real increase in total disability funding; provision of opportunities for cooperative planning and priority setting and ensuring a coordinated approach across the range of services for people with disability; and the establishment of National Disability Service Standards (National Standards) to underpin consistent quality assurance processes.[10]

2.21 The Review of the CSDA also indicated that the Commonwealth and States and Territories had maintained real funding at or about the 1989-90 base levels. The Review estimated that total (Commonwealth and State and Territory) CSDA funding of government and non-government organisations at over $1.2 billion annually. This represented an increase of 25 per cent from the amount identified in the CSDA as the funding base for 1989-90. Expenditure on accommodation services comprised 71 per cent of the total CSDA expenditure.[11]

2.22 However, some major shortcomings of the first CSDA were identified by the Review, the most significant of which were:

- it made no practical provision for establishing and resourcing a jointly owned, intergovernmental management capacity to plan and develop the disability service system;
- in creating separate areas of responsibility for each level of government, it did nothing to plan or provide for the issues of coordination that then arose between these separate responsibilities;
- it instituted no system for setting performance targets for the reduction of unmet demand in relation to an effective, intergovernmental strategy to bring growth monies into the system;
- it arbitrarily excluded equipment and disability-related therapy services, except as early intervention services for children below school age;

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[9] Yeatman, A, *Getting Real: The Final Report of the Review of the Commonwealth State Disability Agreement*, July 1996, p.2.

[10] *Submission* 96, p.7 (Australian Government).

[11] Yeatman, A, *Getting Real: The Final Report of the Review of the Commonwealth State Disability Agreement*, July 1996, p.23.

- it did not formally target the needs of the primary carers of people with disabilities;
- it left the issues of how the CSDA was to interface with the HACC, CRS and mental health programs, undealt with;
- users of the disability service system did not see the CSDA as having led to improvements in service availability and adequacy;
- users did not see the CSDA as having made access to services fairer and more equitable; and
- in the areas of joint responsibility (advocacy and information services) there had been a neglect of how these services need to be developed and resourced if they are to support access to disability services in accordance with the principles and objectives stated in the text of the first agreement.[12]

A lack of publicly available information on expenditure and performance under the CSDA was seen as a major deficiency.

2.23 Despite these numerous and considerable difficulties, the Review overall recommended a further renegotiation of the CSDA funding arrangement. However, the Review made extensive recommendations to improve the next CSDA. The recommendations included the need for greater accountability of service delivery by all governments, improved monitoring and assessment criteria of service delivery, work to identify more accurately the cost of unmet need, the introduction of improved standards and definitions of disability and the development of a reliable data set. The Review also recommended the inclusion of the disability component of the HACC program and CRS into the funding parameters of the CSDA and that formal services targeted to primary carers be flexible in design. The Review further recommended the development of, and joint reporting against, nationally agreed performance targets with a primary goal of the second agreement to establish phased targets to address the critical levels of unmet demand.[13]

2.24 Ms West commented that while the goal of the CSDA was administrative convenience and streamlining of funding for disability services between the Commonwealth and State Governments some commentators argued that the first CSDA instead appeared to entrench the fragmentation of service provision for people with disabilities across Commonwealth and State/Territory Government divisions. The CSDA funding arrangement meant that an array of disability services and programs were spread across both levels of governments and sourced through multiple

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[12] Yeatman, A, *Getting Real: The Final Report of the Review of the Commonwealth State Disability Agreement*, July 1996, p.3.

[13] Yeatman, A, *Getting Real: The Final Report of the Review of the Commonwealth State Disability Agreement*, July 1996, p.xiii.

entrance points so that the development of integrated and complementary services was hampered.[14]

2.25 The difficulties of this service model were highlighted in the 1995 review of the Commonwealth Disability Services Program. The review heard recurrent complaints from those who made submissions that the CSDA had made it more difficult for people to get services. Many submissions commented on the dissonance between things that were done for logical administrative reasons but which had unfortunate consequences for services for individuals.[15]

2.26 For example, a person with a disability living independently in the community and in search of employment would access HACC services for daily support care needs funded by the Commonwealth (but administered by the States), access assistive aids and equipment from State services, access employment related services that were administered by the Commonwealth and utilise accommodation services provided by the States.[16] The Tasmanian Government also noted that the identification of interface issues with other programs was not a focus of the CSDA.[17]

2.27 In addition, the state-by-state funding of disability services through the CSDA meant that a wide array of differing programs and differing models of disability service delivery where constructed in each State and Territory. As a consequence, the delivery of disability services in each jurisdiction was governed by differing arrays of legislation and guidelines, administered through differing forms of management and administrative processes and utilised various forms of classifications.[18] This also undermined attempts to make State comparisons of the delivery of disability services and to develop a nationally consistent picture of disability services.

2.28 Inefficiencies soon became evident in the duplication of bureaucracies and cost shifting resulting from the lack of agreement on appropriate roles between the Commonwealth and State/Territory Governments. Overall, it appeared difficult to see visible improvement in service delivery that the implementation of the CSDA and Disability Act had sought to achieve.[19]

2.29 The Commonwealth concurred that there were shortcomings with the first CSDA and pointed to:

- identification of gaps and interface issues with other programs;

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[14] *Submission* 44, p.11 (Ms R West).

[15] Baume M & Kay K, *Working Solutions: Report of the Strategic Review of the Commonwealth Disability Services Program,* AGPS, January 1995, p.28.

[16] *Submission* 44, p.11 (Ms R West).

[17] *Submission* 69, p.1 (Tasmanian Government).

[18] *Submission* 44, p.11 (Ms R West).

[19] *Submission* 44, p.12 (Ms R West).

- lack of strategic planning to meet growth in demand for services; and
- lack of accountability and lack of comparable performance data.[20]

Commonwealth State Disability Agreement (1997-1998 to 2001-2002)

2.30 The Commonwealth stated that the second Agreement built on the achievements of the first Agreement and attempted to address some of its shortcomings.[21] Bilateral Agreements between the Commonwealth and the States and Territories were introduced to complement the single Multilateral Agreement and 'provided a means for the Commonwealth to work in partnership with individual State and Territory governments to address disability issues of local importance and joint interest'.[22] The first interstate service portability protocols were developed.[23] Ms West noted that the Bilateral Agreements were included in an effort to improve reporting mechanisms on service delivery effectiveness and accountability to the Commonwealth. Performance indicators were negotiated into the CSDA in an attempt to monitor the effectiveness of services based around client service delivery outcomes.[24] The division of responsibilities between the Commonwealth and the States was retained.[25]

Funding

2.31 The total funding for CSDA services in 1997-98 was $1.82 billion, a real increase of 5.7 per cent from the level in 1996-97. Approximately 70 per cent ($1.27 billion) of all CSDA funding came from State and Territory Governments. The Commonwealth provided the remaining funding which included $317 million in transfer payments to the States and Territories.[26] By 2001-02 funding for CSDA services had expanded to meet demand and need for disability services with total government expenditure on CSDA services of $2.7 billion in 2001-02.[27]

2.32 In 2001, the Commonwealth offered the States and Territories $150 million over the last two years of the second Agreement to help State and Territory Governments address unmet need for services. This funding was provided on the proviso that States and Territories contribute at least a similar amount. States and

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[20] *Submission* 96, p.7 (Australian Government).

[21] *Submission* 96, p.8 (Australian Government).

[22] *Submission* 96, p.8 (Australian Government).

[23] *Submission* 69, p.1 (Tasmanian Government).

[24] *Submission* 44, p.13 (Ms R West).

[25] Monro D, 'The Role of Performance Measures in a Federal-state Context: The Examples of Housing and Disability Services', *Australian Journal of Public Administration*, 62 (1):70-79, March 2003.

[26] Productivity Commission, *Report on Government Services 1999*, p.807.

[27] Productivity Commission, *Report on Government Services 2003*, p.13.8.

Territories contributed $366 million over the two years and this funding has been continued in the third Agreement.[28]

Impact of the second CSDA

2.33 Achievements associated with the second CSDA included:

- providing a national framework for disability services and bilateral capacity to target funding in strategically important directions;
- an injection of additional funding to assist the States and Territories address unmet need for services;
- a shift towards public accountability through transparent funding contributions and improvements in quality assurance;
- research and development on a range of key policy, interface and transition issues;
- commencement of work on better data collection; and
- the development of the first interstate service portability protocols.[29]

2.34 However, as with the first CSDA there were shortcomings in the second Agreement which the Commonwealth identified as:

- the Agreement did not contain broad strategic policy directions which interfaced with other programs;
- while there were high level performance outcome measures, these were inconsistent with performance reporting for other Specific Purpose Payments;
- there was a continued lack of clarity regarding funding arrangements and areas of responsibility, which impeded service development and provision; and
- there was a continued lack of long-term strategies to address and manage growth in demand.[30]

2.35 The Tasmanian Government stated that one of the main failings of the second CSDA 'was the narrow focus on management and operation of specialist disability services with an absence of any broad strategic policy direction in terms of engagement and interface with other comparable programs, particularly in the health, aged care, home and community care and housing sectors'.[31]

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[28] *Submission* 96, p.8 (Australian Government).

[29] *Submission* 96, p.8 (Australian Government).

[30] *Submission* 96, pp.8-9 (Australian Government).

[31] *Submission* 69, p.2 (Tasmanian Government).

2.36 Ms West also noted that the utilisation of performance indicators in the second CSDA had not resolved the problem of accountability of service utilisation or provided any accurate gauge as to the quality of service delivery. Data problems appeared to be hampering any coherent utilisation of performance indicators and the establishment of any effective benchmark with which to compare State by State performances. Data problems included limited forms of data collection; difficulties in obtaining comparable data from each State and Territory in light of differing accounting practices and varying levels of administrative efficiency; differing management systems between the States and Territories resulted in difficulties in interpreting the results in relation to service utilization; and a lack of clarity as to classifications of disability. As a consequence, there was 'not only a lack of coherency and understanding in how well services were being delivered, but a clear inability of the CSDA funding arrangement to deliver equitable and uniform delivery of disability services nationally'.[32]

2.37 The Steering Committee for the Review of Government Service Provision (SCRGS), Report on Government Services 2002 noted that, while there had been significant steps made in improving the comparability and scope of reporting on disability services in 2002, concerns remained over the comparability of some results because jurisdictions use different methods of data collection. The Report commented that expenditure estimates for all jurisdictions except South Australia and the Northern Territory were generally comparable while the expenditure data from South Australia and the Northern Territory may understate the full accrued cost.[33] The Report also noted that data was not comparable across jurisdictions as governments employed different methods to apportion administrative costs.[34]

2.38 The SCRGS Report commented that gaps in reporting service quality and the availability of snapshot day data only, rather than whole of year data, impacted on the reliability of performance indicators. The SCRGS stated that the Review would address these limitations in subsequent reports.[35]

Commonwealth State Territory Disability Agreement (2002-2003 to 2006-2007)

2.39 The current Agreement features both a preamble and five key policy priorities which are consistent with the Government's social and economic policy directions. The five priorities are to:

- strengthen access to generic services for people with disabilities;
- strengthen across government linkages;

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[32] *Submission* 44, p.14 (Ms R West).

[33] SCRGSP, *Report on Government Services 2002*, p.718.

[34] SCRGSP, *Report on Government Services 2002*, p.724.

[35] SCRGSP, *Report on Government Services 2002*, p.727.

- strengthen individuals, families and carers;
- improve long-term strategies to respond to and manage demand for specialist disability services; and
- improve accountability, performance reporting and quality.

2.40 The introduction of the preamble to the Agreement 'moved the Agreement away from solely describing a joint funding arrangement and articulated the vision and values that drive the commitment of the Commonwealth, States and Territories to people with disabilities and also set national strategic priorities'.[36]

2.41 The third Agreement retained the two-tiered arrangement of multilateral and bilateral agreements but with the bilateral agreements shifting their emphasis from Commonwealth funding of particular local projects to both jurisdictions working in partnership in key strategic areas of recognised need to address policy priorities.[37]

2.42 The third CSTDA introduced a schedule that specifies the annual production of performance indicators as part of the accountability measures for all governments, indicators relating to service access and expenditure. These were produced for the first time in 2002-03 and published in the National Disability Administrators' first CSTDA Public Report. The second Public Report, using 2003-04 data, was released in 2005.[38]

2.43 The Commonwealth noted that it has made substantial efforts to improve the accountability, quality, efficiency and effectiveness of the specialist disability services it funds under the *Disability Services Act 1986* through two key initiatives:

- the progressive introduction of an individualised, case based funding model for open and supported employment services from July 2004 has enabled funding provided to more closely match the support need of service users. It has also resulted in an increase in the effective utilisation of employment services from around 80 per cent of all funded places in 2003 to around 95 per cent in June 2006; and
- the introduction of a legislated Quality Assurance system involving independent third party quality audits of employment services. From January 2005, all employment services funded under the *Disability Services Act 1986* were quality assured and a 2005 evaluation of the measure reported a demonstrable lift in the quality of employment services provided to jobseekers and workers with disability as a result of the measure.[39]

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[36] *Submission* 3, p.8 (Western Australian Government).

[37] *Submission* 96, p.9 (Australian Government).

[38] AIHW, *Australia's Welfare 2005*, p.208.

[39] *Submission* 96, p.9 (Australian Government).

2.44 In the 2004-05 Budget, the Commonwealth committed $72.5 million over four years, subject to matching commitments by State and Territory Governments, to provide:

- up to four weeks respite care to parent carers over 70 years;
- up to two weeks respite care for parent carers aged between 65 and 69 years, who needed to spend time in hospital.

The additional respite for older carers measure is implemented through bilateral agreements with each State and Territory Government under the CSTDA. Negotiations were protracted with some jurisdictions; however by May 2006, all State and Territory Governments had signed bilateral agreements.

2.45 The Commonwealth's submission indicated that the main deliverables of the current CSTDA have been:

- an additional $6.1 billion has been committed to specialist disability services. Of this, the Commonwealth’s contribution is $1.641 billion while the States will contribute $4.471 billion;
- an increase in the number of services provided and the proportion of people with disability receiving services; and
- improvements in transparency and accountability for Commonwealth funding, including the production of three CSTDA Annual Reports.[40]

2.46 During the course of the Agreement, whole of year data about the people who use CSTDA-funded services and the services they use became available. Previously, only part year and snapshot data were available. As a result, a more detailed national picture of services delivered under the CSTDA was gained and enabled a baseline to be established for future, cross year, comparisons.[41]

2.47 Despite these achievements, the Commonwealth saw the need for improvements:

- there is an acknowledged level of unmet need, but data collected and made available by the States and Territories does not allow an accurate assessment of the level and nature of this need;
- a lack of consistency in quality assurance systems across jurisdictions; and
- while transparency and accountability have improved, there has been little improvement in all jurisdictions' understanding of the nature, quality and durability of outcomes for people with disability accessing CSTDA services.[42]

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[40] *Submission* 96, p.10 (Australian Government).

[41] National Disability Administrators, *CSTDA Annual Public Report 2003-04*, p.4.

[42] *Submission* 96, p.10 (Australian Government).

2.48 In its 2005-2006 Performance Audit Report on the administration of the CSTDA, the Australian National Audit Office (ANAO) commented on a number of issues where improvements could be made. The ANAO stated that 'despite a number of avenues for monitoring and reporting performance, there are currently no adequate measures of whether, or to what extent, the CSTDA is meeting its objectives'. The ANAO also noted that while there had been improvements in the quality of data collected, it is 'not yet sufficient to allow robust comparisons of equity and efficiency between jurisdictions, or of the same jurisdiction over time'. The ANAO concluded that:

> These shortcomings in performance information limit the capacity for FaCS to influence the jurisdictions to improve the efficiency, effectiveness or quality of services the States and Territories are primarily responsible for administering under the CSTDA.[43]

2.49 State and Territory Governments also pointed to areas where the third CSTDA did not meet expectations. The Tasmanian Government noted that in contrast to the second CSDA, the third Agreement 'did not include any commitment towards unmet need'.[44] The Tasmanian Government also saw the CSTDA as primarily a funding agreement that lacked long term agreed strategies to address and manage growth in demand and unmet need. The need to improve the management of growth and the need for growth funding was also highlighted by other governments.[45]

2.50 Other shortcomings of the CSTDA identified included the lack of a framework for achieving whole-of-government coordination and collaboration around access to generic services.[46] Ongoing gaps and interface issues with other program areas, particularly aged care, home and community care, housing and health was also raised, with the NSW Government pointing to difficulties and obstacles which have occurred in dealing with one Commonwealth Government department in relation to matters pertaining to another department.[47]

2.51 The Victorian Government commented that the CSTDA has been successful as a vehicle for promoting relationships and learning across jurisdictions but that 'the overall success of the CSTDAs to date has been impeded by its focus on inputs and bureaucratic processes and controls'. In addition, the government saw the reporting requirements as onerous and that no real incentives or framework existed for pursing

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[43] ANAO, *Administration of the Commonwealth State Territory Disability Agreement, Department of Family and Community Services,* Audit Report No.14 2005-06, p.17.

[44] *Submission* 69, p.2 (Tasmanian Government).

[45] *Committee Hansard* 13.10.06, p.57 (ACT Government); *Submission* 84, pp.4-7 (NSW Government).

[46] *Submission* 69, p.2 (Tasmanian Government); *Submission* 84, pp.4-7 (NSW Government).

[47] *Submission* 69, p.2 (Tasmanian Government); *Submission* 84, pp.4-7 (NSW Government).

improvement or for measuring the extent of outcomes achieved for people with disability.[48]

2.52 The Western Australian Government commented that the CSTDA has provided clarity for the respective administrative responsibilities of each jurisdiction 'but has not delivered clarity on funding responsibilities' and pointed to funding inequities amongst the States and Territories.[49] The Government also argued that the responsibility for funding of some areas has been blurred by Commonwealth policy changes as part of the welfare reform agenda 'that have resulted in cost shifting from the Commonwealth to the States'.

2.53 While noting that the Agreements were 'somewhat effective' in setting a national direction, the Western Australia Government stated that the progress anticipated through the National Disability Administrators projects had been hampered by an excessive and overambitious workload and the narrow focus by the Commonwealth on accountability.[50] In relation to the Bilateral Agreements, the Western Australian Government contended that they had proven to be 'cumbersome' and that 'while at officer level there is willingness to progress, little has been achieved to date in areas of mutual interest'. The Commonwealth had 'provided little input to the implementation work plan and the State typically ends up reporting its areas of progress and deferring to the Commonwealth '.[51]

2.54 Many of the non-government witnesses argued that the current CSTDA had failed to improve the delivery of services to people with disabilities and to provide adequate resources for those services.[52] The Australian Federation of Disability Organisations described the current CSTDA in the following terms:

> Unfortunately, the CSTDA is far from being a coordinated, high level strategic policy document. Despite its broad aim and the priority placed on access to generic services, the current CSTDA retains a narrow focus on service delivery, particularly disability-specific services, to people with disability aged under 65 years. The CSTDA is crisis driven, with the result that short-term, individually focussed interventions are prioritised over systemic reforms. For example, the provision of accommodation support services dominates expenditure under the CSTDA.[53]

2.55 The reasons for these failures were varied but included the lack of an all-of-government approach; inadequate growth funding, limitations to the data available to

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[48] *Submission* 99, p.10 (Victorian Government); see also *Submission* 69, p.2 (Tasmanian Government).

[49] *Submission* 3, p.5 (Western Australian Government).

[50] *Submission* 3, p.7 (Western Australian Government).

[51] *Submission* 3, pp.13-14 (Western Australian Government).

[52] *Submission* 45, p.1 (ACROD).

[53] *Submission* 90, p.6 (AFDO).

establish the level of need; and a lack of a real commitment to improve the resources available. ACROD pointed to the failure to:

- deliver the resources required to meet the substantial need for disability services across Australia;
- require multi-year budgetary planning based on demand growth and the increasing cost of service delivery;
- deliver a consistent robust approach to service quality;
- produce sufficient data to enable comprehensive and meaningful performance comparisons across jurisdictions; and
- build strong linkages and easy-to-navigate pathways between disability service systems administered by different governments or between disability and other programs such as aged care, health, education and transport.[54]

2.56 AFDO also identified other major challenges which impact on the effectiveness of the CSTDA:

- maintaining the viability of essential services targeted at small population groups;
- reduced availability of individual advocacy services;
- poor capacity of providers of generic services to recognise invisible impairments such as mental illness and brain injury and to respond to the needs of people with multiple impairments; and
- continued reliance on indicators of medical rather than functional impairment.[55]

2.57 Of major concern to many witnesses was the huge range of service delivery models between and within jurisdictions which remain under the third Agreement. Ms West pointed to the CSTDA Annual Report 2003-04 which showed the array of different approaches and strategies being undertaken by each State and Territory. Each of the States and Territories continue to fund disability services at different rates and with differing levels of accountability. Each State and Territory is governed by differing legislation with differing obligations and priorities to users. Ms West commented that these differences exist for services which assist a national population of only 20 million people and with only a relatively small percentage of that population utilising some form of funded disability service:

> Under the current form of CSTDA funding, each state continues to roll out their own gamut of programs, services, strategies and policies, creating further inequities in the system on a national level. Service delivery on the

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[54] *Submission* 45, p.1 (ACROD)

[55] *Submission* 90, p.8 (AFDO).

> ground therefore continues to be disparate, with real mapping and contrasting of service delivery remaining difficult.[56]

2.58 This situation also poses problems for recipients of service delivery who move between jurisdictions. Service recipients are often forced to renegotiate an entirely new system of programs and services. AFDO indicated that a survey of its members indicated that people with a disability find navigating the services system exhausting and frustrating. People are not offered flexible service and support options, and are required to coordinate support from a range of different services. Many other witnesses identified the lack of coordination as one of the main shortcomings of the CSTDA with the result that services are used to solve crisis situations rather than the delivery of properly planned care.[57]

2.59 The array of service delivery systems also caused interface issues with many witnesses pointing to problems accessing and coordinating services delivered through State or Territory funded programs and HACC services funded by the Commonwealth. ACROD also supported the need to build strong linkages and easy-to-navigate pathways between disability service systems and other programs such as aged care, health, education and transport.[58]

2.60 Ms West concluded that:

> Instead, the current delivery of funded disability services nationally therefore appears to remain within these state silos and held together by these CSTDAs, despite significant reforms of the CSTDA structure. Little political will or significant international influence promoting holistic restructure, progressive development or nationalised reform of the disability service delivery sector however appears visible. In terms of solutions, the implementation of a nationalised disability services framework would best appear to address the complexities associated with the CSTDA in its current form. Only a nationalised disability services framework would provide the necessary platform to ensure equity and uniformity of disability service delivery across Australia.[59]

2.61 The Disability Coalition WA commented that the vision contained in the Preamble is expressed in terms of the focus on five policy priorities 'phrased in limiting terms'. The priorities do not provide clear goals to aspire to, nor a detailed plan on how to achieve them. There was also a management approach to demand which 'falls short of what is required – that of meeting demand'. Overall, the Disability Coalition described the third CSTDA as short of the forward thinking and goal setting embodied in the first CSDA. The Disability Coalition concluded:

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[56] *Submission* 44, p.17 (Ms R West).

[57] *Submission* 93, p.11 (MS Society); *Submission* 95, p.6 (NCOSS).

[58] *Submission* 45, p.1 (ACROD).

[59] *Submission* 44, p.21 (Ms R West).

> The effect of the CSTDAs has not been as intended…the potential contained in the first CSTDA has been lost over the life of the subsequent agreements with the watering down and exclusion of key principles and objectives required for best outcomes for people with disability and their families…
>
> The entailing system has become too crisis driven and fails in meeting the stated objective of strengthening people with disability, their families and carers. The shortcomings of the current CSTDA result in a very heavy cost to people with disabilities and their families, to government and to the taxpayer.[60]

2.62 The Office of the Public Advocate Victoria considered that the vision contained in the preamble was 'appropriately aspirational', the five strategic policy priorities 'appear modest in comparison' and that in practice the priorities 'seem to be mainly preoccupied with just one aspect of the fourth priority: demand management'. The Office pointed to the use of definitions of disability which act to restrict access to services by people with dual disabilities and conditions such as Huntington's disease and autism spectrum disorder. The Office concluded that:

> 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.[61]

2.63 Limitations of data continued to be identified by witnesses as a significant problem. Data limitations were seen as weakening the CSTDA Bilateral Arrangements and 'although the arrangements provide opportunities for coordinated planning and service delivery across governments, joint service mapping and accurate trend trajectories remain virtually impossible under the current framework'. Ms West concluded that 'consultation processes and service building partnerships will continue to remain siloed by State/Territory jurisdiction, with the objective of creating streamlined and equitable delivery of services at a national level, locked within these individualised bilateral funding arrangements'.[62]

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[60] *Submission* 60, p.10 (Disability Coalition WA).

[61] *Submission* 94, p.5 (Office of the Public Advocate).

[62] *Submission* 44, p.18 (Ms R West).

Conclusion

2.64 It is clear to the Committee that the delivery of disability services in Australia is highly complex and the delivery of services to meet individual needs in an appropriate and timely way is extraordinarily difficult. The reform processes commenced in the 1980s have gone some way to overcome these complexities and difficulties. The three Agreements have been central to the reform process and significant improvements can be identified which are directly attributable to the rationalisation of the delivery of services and the clearer funding arrangements.

2.65 However, there still remain many concerns about the delivery of disability services in Australia. First and foremost, the level of unmet need is largely unknown and pressures within the system, including an ageing population, will result in an ever increasing demand for services. The appropriateness of joint funding arrangements including the level of contributions by the Commonwealth and State and Territory Governments, the level of indexation, equity of funding arrangements and cost shifting between governments need to be addressed to ensure that scarce funding resources are efficiently and effectively utilised.

2.66 As has been the case with many of the Committee's previous inquiries into the health and welfare system, the multiplicity of services, programs, models and funding arrangements has led to inefficiencies, gaps in service delivery, and service interface problems. This has led to difficulties for users to access services to address their needs in an appropriate way and to the degree required.

2.67 While the CSTDA should remain the basis for the delivery of disability services, the Committee does not consider that it is an adequate national strategic policy document. In order to ensure a coordinated national approach to improving the delivery of disability services, to ensure that people with disability services access the services they require throughout their lives, to address interface issues within the disability sector and to ensure that future need for services is adequately addressed, a renewed national strategic approach is required. The Committee considers that a national disability strategy would reaffirm our commitment to equity and inclusiveness in Australian society for people with disability.

2.68 The following chapters address these issues and identify possible ways in which the next Commonwealth State Territory Disability Agreement may be improved.

CHAPTER 3

APPROPRIATENESS OF JOINT FUNDING ARRANGEMENTS

Introduction

3.1 This chapter will examine the appropriateness or otherwise of the current joint funding arrangements under the CSTDA and focuses on the overall structure of the arrangements. Issues in relation to unmet need are discussed in Chapter 4.

3.2 Part 6 of the current CSTDA outlines the responsibilities of the parties to the Agreement. All parties have continuing responsibilities under the Agreement for funding specialist services for people with disabilities. While funding responsibilities are shared between the levels of government, the CSTDA divides the responsibility for funding specialist disability services from their administration. The Commonwealth has responsibility for the planning, policy setting and management of specialist disability employment services. The State and Territory Governments have responsibility for the planning, policy setting and management of specialist disability services except employment services. These services include accommodation support, community access, community support and respite care.

3.3 The Commonwealth, State and Territory Governments also share administrative responsibilities for planning, policy setting and management of advocacy services, print disability services and information services as well as participating in and funding research and development.[1] The current agreement expires on 30 June 2007; a fourth CSTDA is in the early stages of negotiation.

3.4 As part of their joint funding responsibilities under the current CSTDA governments have committed $17.1 billion over five years. There is roughly a 80/20 split between the funding contributions of the States and Territories Governments and the Commonwealth for specialist disability services other than employment services. For example in 2005-06 $3.552 billion was made available under the Agreement. This was made up of $1.056 billion from the Commonwealth and $2.496 billion from the State and Territory Governments. Of the Commonwealth's contribution, $450 million was spent on the provision of specialised disability employment services and $605 million was transferred to the States and Territory Governments for the provision of specialist disability services other than employment.

3.5 The Commonwealth makes CSTDA funding available as financial assistance to the State and Territory Governments as a Specific Purpose Payment (SPP). In the Agreement, this funding is described as the total amount required to meet the

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[1] *Commonwealth State Territory Disability Agreement 2002-2007*, Part 6.

Commonwealth's responsibilities for the management and administration of all specialist disability services other than employment, 'a global amount to be allocated on the basis of need' by the State and Territory Governments.[2] The Commonwealth does not impose any requirements on the way funds are allocated, except that they are used to fund services that are eligible for funding under the CSTDA.

3.6 The Commonwealth's other contributions to people with a disability and their carers are not included in the CSTDA arrangements. These include income support payments such as the Disability Support Pension ($7.9 billion per annum), the Carer Allowance ($1.1 billion per annum), the Carer Payment ($1.1 billion per annum), the Mobility Allowance and the Disability Pension for Australian Defence Force veterans. People with a disability may also be eligible to receive Commonwealth-funded services through the Home and Community Care Program (HACC) or other services and the Commonwealth Rehabilitation Service. Both these programs are also not part of the CSTDA arrangements.

3.7 Table 3.1 is extracted from the CSTDA and provides the funding contributed by each party.

Bilateral Agreements

3.8 The Commonwealth has signed individual bilateral agreements with each of the States and Territories under the current CSTDA. Bilateral Agreements were introduced under the second CSDA. The purposes of these Bilateral Agreements are to: provide for action on strategic disability issues; provide a continuing procedure for negotiation and agreement between the Commonwealth and individual States/Territories on the transfer of responsibility for particular services from one level of government to another; and to bring into the scope of the CSTDA specialist disability services not yet included.[3]

3.9 In practice, the Bilateral Agreements provide the Commonwealth with a level of influence over the provision of State and Territory disability services. Bilateral Agreements also create a degree of flexibility to the joint funding arrangements, providing the opportunity to address specific issues such as increased access to respite care for older parents caring for their sons and daughters with a disability or the transfer of services between the levels of government.

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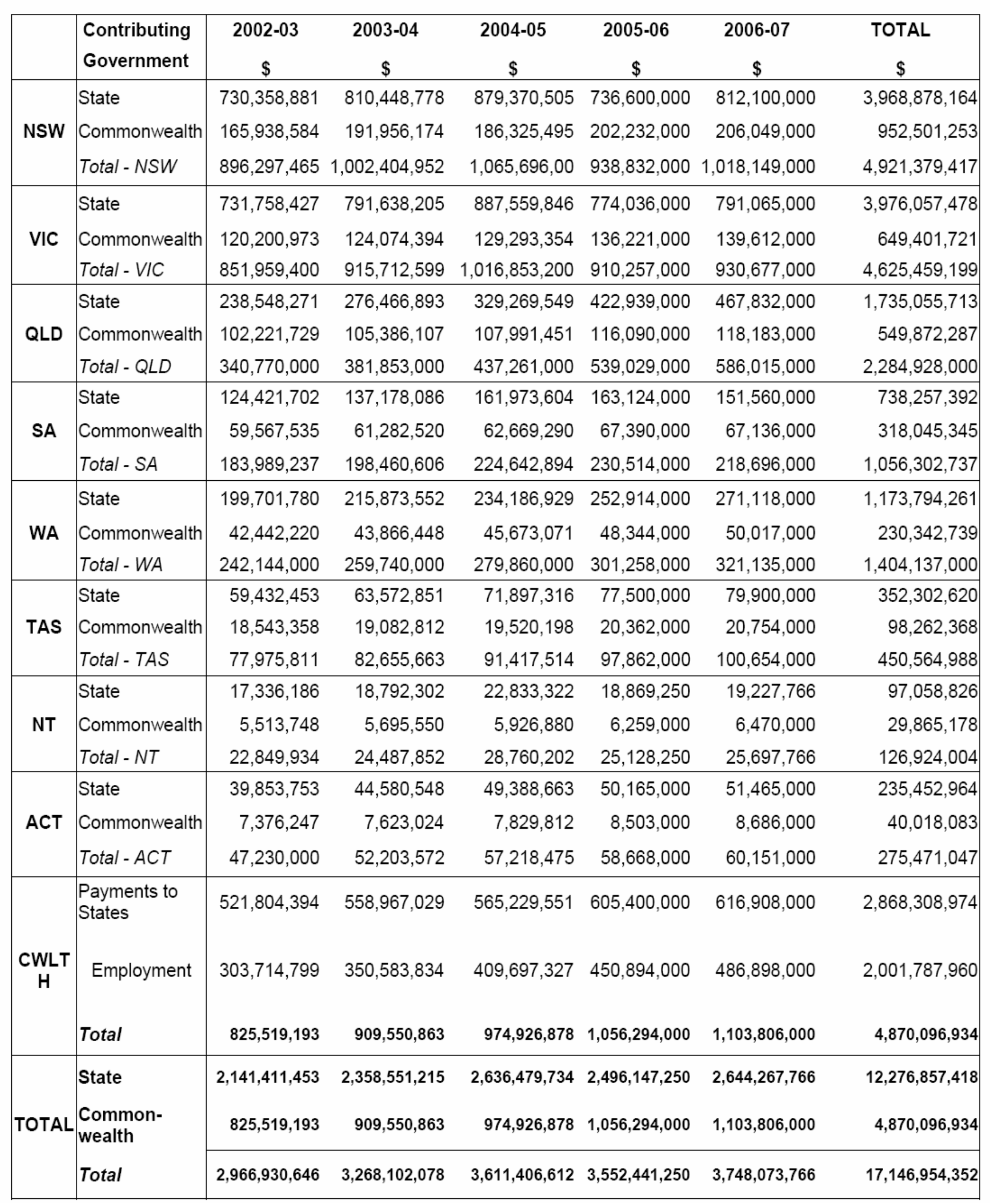
[2] *Commonwealth State/Territory Disability Agreement 2002-2007*, Part 8(6).

[3] *Commonwealth State Territory Disability Agreement 2002-2007*, Recital B.

Table 3.1: CSTDA funding contributions by jurisdiction



	Contributing Government	2002-03	2003-04	2004-05	2005-06	2006-07	TOTAL
		$	**$**	**$**	**$**	**$**	**$**
NSW	State	730,358,881	810,448,778	879,370,505	736,600,000	812,100,000	3,968,878,164
	Commonwealth	165,938,584	191,956,174	186,325,495	202,232,000	206,049,000	952,501,253
	Total - NSW	896,297,465	1,002,404,952	1,065,696,00	938,832,000	1,018,149,000	4,921,379,417
VIC	State	731,758,427	791,638,205	887,559,846	774,036,000	791,065,000	3,976,057,478
	Commonwealth	120,200,973	124,074,394	129,293,354	136,221,000	139,612,000	649,401,721
	Total - VIC	851,959,400	915,712,599	1,016,853,200	910,257,000	930,677,000	4,625,459,199
QLD	State	238,548,271	276,466,893	329,269,549	422,939,000	467,832,000	1,735,055,713
	Commonwealth	102,221,729	105,386,107	107,991,451	116,090,000	118,183,000	549,872,287
	Total - QLD	340,770,000	381,853,000	437,261,000	539,029,000	586,015,000	2,284,928,000
SA	State	124,421,702	137,178,086	161,973,604	163,124,000	151,560,000	738,257,392
	Commonwealth	59,567,535	61,282,520	62,669,290	67,390,000	67,136,000	318,045,345
	Total - SA	183,989,237	198,460,606	224,642,894	230,514,000	218,696,000	1,056,302,737
WA	State	199,701,780	215,873,552	234,186,929	252,914,000	271,118,000	1,173,794,261
	Commonwealth	42,442,220	43,866,448	45,673,071	48,344,000	50,017,000	230,342,739
	Total - WA	242,144,000	259,740,000	279,860,000	301,258,000	321,135,000	1,404,137,000
TAS	State	59,432,453	63,572,851	71,897,316	77,500,000	79,900,000	352,302,620
	Commonwealth	18,543,358	19,082,812	19,520,198	20,362,000	20,754,000	98,262,368
	Total - TAS	77,975,811	82,655,663	91,417,514	97,862,000	100,654,000	450,564,988
NT	State	17,336,186	18,792,302	22,833,322	18,869,250	19,227,766	97,058,826
	Commonwealth	5,513,748	5,695,550	5,926,880	6,259,000	6,470,000	29,865,178
	Total - NT	22,849,934	24,487,852	28,760,202	25,128,250	25,697,766	126,924,004
ACT	State	39,853,753	44,580,548	49,388,663	50,165,000	51,465,000	235,452,964
	Commonwealth	7,376,247	7,623,024	7,829,812	8,503,000	8,686,000	40,018,083
	Total - ACT	47,230,000	52,203,572	57,218,475	58,668,000	60,151,000	275,471,047
CWLTH	Payments to States	521,804,394	558,967,029	565,229,551	605,400,000	616,908,000	2,868,308,974
	Employment	303,714,799	350,583,834	409,697,327	450,894,000	486,898,000	2,001,787,960
	Total	**825,519,193**	**909,550,863**	**974,926,878**	**1,056,294,000**	**1,103,806,000**	**4,870,096,934**
TOTAL	**State**	**2,141,411,453**	**2,358,551,215**	**2,636,479,734**	**2,496,147,250**	**2,644,267,766**	**12,276,857,418**
	Common-wealth	**825,519,193**	**909,550,863**	**974,926,878**	**1,056,294,000**	**1,103,806,000**	**4,870,096,934**
	Total	**2,966,930,646**	**3,268,102,078**	**3,611,406,612**	**3,552,441,250**	**3,748,073,766**	**17,146,954,352**

Source: Commonwealth State Territory Disability Agreement 2002 -2007, Schedule A1.

Joint funding arrangements

Responsibilities

3.10 The previous and current agreements have been recognised as clarifying administrative responsibilities between the Commonwealth, State and Territory Governments. However, many submissions identified problems with the joint funding arrangements of the CSTDA, in particular the lack of clarity regarding the shared funding responsibilities and accountability. The lack of clarity regarding responsibilities for funding disability services was highlighted as enabling both levels of government to shift responsibility for the inadequate funding of specialist disability services.

3.11 The CSTDA arrangements divide responsibility for the administration (the planning, policy setting and management) of disability services from responsibility for their funding. However, for the purposes of accountability for service delivery these roles are linked. The inadequate provision of disability services can result from either inadequate administration or insufficient funding. Submissions also noted concerns about where accountability rests in the division between funding and administration responsibilities in the CSTDA.

3.12 Consistently submissions and witnesses expressed frustration at the lack of clear accountability in the CSTDA arrangements.[4] Ms Di Shepard submitted:

> The current bureaucratic split between State and Commonwealth allows for endless 'argy bargy' about who is accountable. The States say they are doing their bit, but the Commonwealth is falling short. The Commonwealth says just the opposite. Frankly, I don't care about playing the 'blame game', I just want the system to work. It can't work properly until there is a fixed point of accountability.[5]

Mr Richard Deirmajer commented:

> One of the biggest issues we have also had between the states and the federal government is that, when we lobby the state government… the states seem to blame the federal government because they are not getting enough funding. So we go and see the federal government, and they blame the states.[6]

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[4] *Committee Hansard* 22.11.06, p.14 (Tasmanians with Disability); *Committee Hansard* 5.10.06, p.29 (National Council on Intellectual Disability); *Committee Hansard* 5.10.06, p.68 (Ms D Croft); *Committee Hansard* 5.10.06, p.76 (CASA); *Committee Hansard* 13.10.06, p.7 (Ms S Richards); *Submission* 107, p.3 (National Ethnic Disability Alliance).

[5] *Submission* 82, p.1 (Ms D Shepard).

[6] *Committee Hansard* 5.10.06, p.77 (Mr R Diermajer).

Ms Deidre Croft in her submission stated:

> The States and Territories Governments have consistently maintained that the Commonwealth/States and Territories Disability Agreement was based on a commitment to joint funding of disability support services. The Australian Government, on the other hand, continues to assert that the funding of disability support services (other than employment services) is a State and Territory responsibility.[7]

3.13 However, the NSW Minister for Disability Services the Hon John Della Bosca noted the advantages of State and Territory government administration of services in allowing a level of local accountability in the provision of disability services.

> I think that in general the states—and I am speaking for New South Wales—are better placed to facilitate local planning and community engagement and to make sure there is local accountability to provide those services directly. We are the people—in the case of New South Wales—who are already running significant public services and facilitating the non-government organisations to participate in our programs.[8]

3.14 Many submissions and witnesses identified specific criticisms with individual State and Territory governments in relation to specialist disability services. Ms Brown of the National Carers Coalition commented on the 'shocking performance' of the NSW Government in provided adequate funding for disability services in the past.[9] NCOSS cited the comparable information listed in the Report on Government Services produced by the Productivity Commission to identify a number of areas where NSW has low proportions of people with disabilities using disability services.[10] The Disability Advocacy and Complaints Service of South Australia described their advocacy efforts for individuals who had severe shortages in their care hours and urgently needed aids and equipment:

> We sent 76 individual letters to the Minister, the Premier and the Treasurer of South Australia. Three years on half of the urgent needs have been picked up, the other half are still waiting.[11]

3.15 There was overwhelming evidence that there is not enough funding for disability services but some witnesses commented that they believed that there could be more effective delivery of services at the State and Territory level.

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[7] *Submission* 101, p.18 (Ms D Croft).

[8] *Committee Hansard* 3.10.06, p.48 (NSW Minister for Disability Services).

[9] *Committee Hansard* 3.10.06, p.28 (National Carers Coalition).

[10] *Submission* 95, p.4 (NCOSS).

[11] *Submission* 68, p.4 (Disability Advocacy and Complaints Service of SA).

Inflexible interfaces

3.16 The nature of the division of administrative and funding responsibilities for specialist disability services to each jurisdiction and level of government has lead to different approaches to the provision of services. In some cases it has created program silos leading to inflexible interfaces between disability services at each level of government or jurisdiction. NCOSS in their submission emphasised that this frequently did not result in optimal outcomes for people with disability or their carers:

> Government funding programs stream people into designated service categories, eg disability services, residential aged care facilities, community care etc. This streaming can serve to reduce the desired flexibility of service provision thus promoting a system which is driven by the service system and not by individual needs. Clients are accepted because they "fit" the service provision, not the other way around.[12]

UnitingCare Australia commented:

> The current demarcation between jurisdictional responsibilities means that people wishing to transfer between options or undertake a mix of options are required to negotiate their way through two different service systems with differing policy and funding priorities.
>
> A need exists to simplify the system to make it easier for consumers to access and navigate. This means ensuring that improved pathways between Commonwealth and State funded services are two–way thereby enabling a smooth transition into and between programs and services according to people’s changing needs at different times and life stages.
>
> Cross jurisdictional approaches to service provision need to be further developed to encourage people to experiment with new or a mix of options without risking the security of their placement.[13]

Commonwealth services - State/Territory services interface - transitions

3.17 The problems of inflexible interfaces in the current system were highlighted by Jobsupport Inc. While the cap on the Commonwealth funded Disability Employment Network can prevent those persons capable and willing to work from attempting to enter open employment, the State funded Post School Options program also discouraged people from attempting open employment by making it difficult to return after leaving the program.[14] Jobsupport stated:

> Firstly, the Commonwealth program is capped, so everyone who wants to work cannot work, even if they are capable of doing so and it would save the taxpayer money and, secondly, the state government in turn tends to want to shut the door behind people. In our view, there is an opportunity to

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[12] *Submission* 95, p.10 (NCOSS).

[13] *Submission* 57, p.9 (UnitingCare Australia).

[14] *Submission* 85, p.1 (Jobsupport Inc).

> actually save money, to let the people who want to work do so, and all we really need to get it together is a more flexible interface between the two levels of government.[15]

3.18 ACROD also noted that this interface was 'problematic' and 'fraught with risk' for people with disabilities involved in employment transitions such as supported employees seeking retirement or people moving from post-school option programs to open employment.[16]

State/Territory services interface – portability

3.19 A concern repeatedly raised with the Committee was the portability of disability services and benefits to other States or Territories. Witnesses expressed their frustration at the lack of consistency and equity in the availability of services between jurisdictions. For example Mrs Jean Tops of the Gippsland Carers Association stated:

> 'You are not a citizen of Australia. You are only a citizen of the state in which you live'…If you leave Victoria, you cannot take any of your services with you. You will have to start again on the waiting list in the place you are going to get a service back. That ties families to the state in which they live, to the region in which they live and to the services that they currently have.[17]

3.20 In July 2000 a National Disability Administrators paper 'Moving Interstate: Assistance to People with Disabilities and their Carers' in relation to the portability of funding for disability services was endorsed at a meeting of Ministers responsible for Disability Services. These recommendations provided that: individuals seeking to move interstate may access that State or Territory's service through transparent demand management processes based on relative priority of need; individuals may register their request for service prior to any planned transfer; and where the move is urgent, unplanned or due to circumstances beyond the control of the individual, the State of origin agrees to give consideration to the transfer of funds for up to 12 months.[18]

3.21 In practice these provisions do not appear to have provided a real choice for people with disability who wish to move between jurisdictions. Mr John Nehrmann of the Department of Health and Human Services in Tasmania commented:

> In terms of clients or consumers there is a huge level of uncertainty if you want to move. As I said, initially all you are getting is 12 months and then you have to hope you are getting the same level of service at the same time. The other issue is that you are not always able to get the same type of

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[15] *Committee Hansard* 3.10.06, p.2 (Jobsupport Inc).

[16] *Submission* 45, p.19 (ACROD).

[17] *Committee Hansard* 29.9.06, p.33 (Gippsland Carers Assoc.).

[18] NDA, 'Moving Interstate: Assistance to People with Disabilities and their Carers' available from www.dhs.vic.gov.au.

> service from one jurisdiction to another. You might have an individual funding program in one jurisdiction that allows you to buy certain services that include certain things and yet when you move suddenly there are different business rules and different things covered. Even though the program is roughly the same, it is not quite the same.[19]

3.22 Ms Raelene West also indicated the current CSTDA funding framework was 'highly problematic' for people wishing to move jurisdictions:

> Service recipients are often forced to renegotiate an entirely new system of programs and services, and receive differing and often only entitled to reduced levels of funded services if living in another State/Territory other than original 'jurisdiction'.[20]

3.23 However there were also links made between the level of unmet need for disability services and the lack of portability of services. Ms Lois Ford of the ACT Government commented:

> The assessment of need is based on the level of need the individual has and the resources that we have available—and I would say this is true for most states and territories—to meet that need. I guess that it is more about meeting demand and growth within disability services so that people with disability can transfer or shift from place to place like any other citizen. I would suggest that it is less about the portability of funding and more about demand for and growth of services in each area.[21]

3.24 While the problem of portability has been recognised in the past, moving between jurisdictions is still extremely difficult because of the complexities of needing to negotiate new services within a different system combined with differing limitations on resources arising from underlying levels of unmet need.

Recommendation 1

3.25 That State and Territory governments provide a specific service that assists people with disability transferring between jurisdictions to negotiate programs and services to achieve a comparable level of support.

Dual diagnosis and multiple disability

3.26 The Committee was also concerned about implications of the lack of flexible interfaces in the provision of services for people with disability requiring services in relation to other health needs. Brightwater Care Group commented:

> Dual diagnosis is a challenge whether it is somebody who has palliative issues, mental health issues or substance abuse issues—even if you are Aboriginal, basically. As soon as you have an issue that puts you with a bit

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[19] *Committee Hansard* 22.11.06, p.9 (Tasmanian Government).

[20] *Submission* 44, p.17 (Ms R West).

[21] *Committee Hansard* 13.10.06, p.66 (ACT Government).

> of a foot in both camps, you find that neither camp wants you and can find strong reasons for you to belong somewhere else. It is the need to break down those jurisdictional boundaries and get agencies and funding organisations talking to each other to see how to address the issues.[22]

3.27 However Dr Ken Baker of ACROD highlighted the problems facing service providers caring for people with disability who also had other care needs:

> People can rarely be neatly slotted into one box and not others…I think the main complaint from among disability service providers is that they are expected as disability service providers to respond to the total needs of a person, and that is not really what they are equipped to do. They would have to respond to a person's mental health or drug and alcohol issues as well as their disability rather than getting easy access to another system. In a sense, it is an institutionalised view of governments that, once you are in the disability sector, that is the institution that has to take total care of you. I think that is a flawed view, but it is also, in a way, a dangerous view because it is preventing a person from getting access to other service systems which ought to be responsive to their disability.[23]

3.28 Mr Arthur Rogers of the Victorian Government commented on the definition of disability in the *Disability Services Act 2006*:

> Certainly in our operational practice there is no impediment to people, as long as they have a disability within the meaning of the Act. So if they had a mental illness they would not get in, but if they had an intellectual disability and a mental illness we would cover them for the disability.
>
> Part of the difficulty around service provision is that where people have multiple disabilities they have complex support needs and they do not fit into some of the more generalist services. By 'generalist' I mean a house catering for people with an intellectual disability. A person with an intellectual disability and a mental health issue and maybe a physical disability has quite specific needs. You need to make sure that the service response is tailored to those needs, not just to intellectual disability. So I think the issue is the complexity of their support needs rather than the definition in the Act.[24]

3.29 There appears to be two problems emerging in relation to the recognition and support of people with dual or multiple disabilities: the first is where the interaction of multiple disabilities means that existing programs and services are ill-equipped or unable to meet the complex, higher level needs of a client; the second is the issue of 'handballing' where existing programs or services are suggesting the existence of a second disability is an excuse to pass-the-buck to another program or service and

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[22] *Committee Hansard* 5.10.06, p.43 (Brightwater Care Group).

[23] *Committee Hansard* 13.10.06, p.40 (ACROD).

[24] *Committee Hansard* 28.9.06, p.80 (Victorian Government).

effectively deny support. There is also a clear need to provide appropriate specialised services.

Recommendation 2

3.30 That the next CSTDA clearly recognise the complex and interacting needs of, and specialist services required by, people with dual and multiple diagnosis, and people with acquired brain injury.

Complexity and overlap

3.31 The division of funding and administrative responsibilities between the Commonwealth, State and Territory Governments creates overlap and duplication in bureaucratic and administrative arrangements for the provision of disability services as well as a lack of uniformity and equity between jurisdictions. In her submission Ms West commented:

> Each of the States/Territories 'jurisdictions' continue to fund disability services at different rates and with differing levels of accountability. Each State/Territory is governed by differing legislation with differing obligations and priorities to users. This is despite a national population of only 20 million people and with only a relatively small percentage of this population utilising some form of funded disability service. Under the current form of CSTDA funding, each state continues to roll out their own gamut of programs, services, strategies and policies, creating further inequities in the system on a national level. Service delivery on the ground therefore continues to be disparate, with real mapping and contrasting of service delivery remaining difficult.[25]

3.32 The complexity in the arrangement under the current CSTDA also causes additional burdens for disability services users. Ms Teresa Hinton of Anglicare Tasmania, who had recently completed a research project on disability services, commented on difficulties with the fragmented nature of services.

> To receive personal care and support, somebody might be dealing with three or four different agencies, each with their own assessment process, different disability support workers and so on. Being able to coordinate that for individuals was very problematic and difficult for them, for individuals and also carers who might have been taking on the case management role.[26]

Cost-shifting

3.33 During the inquiry a number of issues regarding cost-shifting between the levels of government were raised. Cost-shifting may occur where funding arrangements allow responsibility for services to transfer to a program funded by another party without their agreement. The complex arrangement of the division

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[25] *Submission* 44, p.17 (Ms R West).

[26] *Committee Hansard* 22.11.06, p.25 (Anglicare Tasmania).

between the levels of government of responsibilities in relation to areas which overlap with disability such as health, ageing, employment and education may provide opportunities and incentives to shift the costs of service delivery. Cost-shifting between governments can also contribute to problems such as accountability for disability services.

3.34 ACROD encapsulated this issue by stating in its submission that:

> For governments, funding is clearly a contentious issue. In the past, negotiations have been marred by suspicions of cost-shifting and accusations from each level of government that the other provides less than its fair share of funding for State-administered services.[27]

3.35 The Commonwealth pointed to an increased usage of services under the Home and Community Care (HACC) program by people with disability.

> People with disability are estimated to comprise over 24 per cent of the total number of HACC clients. However, they are estimated to consume 30 per cent of the funding because proportionately more people with disability access higher levels of service.
>
> The proportion of younger people (those under 65 years) accessing HACC services has increased from 18.5 per cent in 1994-95 to over 24 per cent in 2004-05. Given that the percentage of young people in the general population has declined over the same period, the growth in young people as HACC clients suggest that outside of HACC, disability services delivered by the states and territories have not grown in line with demand.
>
> CSTDA data indicates that there has been significant decline in the number of service users aged 60-64 years compared to those aged 55-59 years across all CSTDA funded service types…There is a concern that this decline reflects a trend for older people with disability ending up in inappropriate aged care or hospital services due to a lack of appropriate disability services.[28]

3.36 Ms West also identified that shortfalls in State and Territory disability services had "forced" people with disability to utilise HACC program services.

> Ideally, a significant expansion and increase in funded disability services could move people requiring disability services off HACC funding and onto specific disability support programs and funding arrangements alone, increasing clarity of service need and providing specialised disability support.[29]

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[27] *Submission* 45, p.9 (ACROD).

[28] *Submission* 96, p.18 (Australian Government).

[29] *Submission* 44, p.19 (Ms R West).

Whole of government coordination

3.37 The need for better coordination between Commonwealth, State and Territory jurisdictions and departments was also raised with the Committee. The responsibility for ensuring that Commonwealth and State/Territory programs are having a complementary impact is shared by all the parties in the current CSTDA.[30] Ms Lyndall Grimshaw of Brain Injury Australia commented:

> If we look at government policy and program development, what we see is fragmentation and program silos…There is little evidence from our perspective of interdepartmental cross-policy program collaboration, both across and between the Commonwealth and state and territory levels.[31]

3.38 The point was made that despite the interrelationships in the services covered by the CSTDA, such as health and employment, the only Commonwealth Department a party to the Agreement was the Department of Families, Community Services and Indigenous Affairs (now FaCSIA). The Department of Health and Ageing and the Department of Employment and Workplace Relations have not been parties to the CSTDAs. ADFO for example commented:

> A major barrier to the effective oversight of progress towards the achievement of the aim of the CSTDA has been that no single agency has been given the task and authority to do this. At a Commonwealth level alone, direct services to people with disability are provided by at least seven departments and most of these are not involved in the Agreement.[32]

3.39 In 2004 responsibility for administration of open employment services operating under the CSTDA moved from the Department of Family and Community Services (now known as FaCSIA) to the Department of Employment and Workplace Relations. Supported employment services for people with disability continue to be administered by FaCSIA. MS Australia commented that as a result of this change:

> FaCSIA remains the lead Agency at the Australian Government level in regard to disability services despite being the smallest and least involved agency in the delivery of disability services. This is a situation that has definitely hindered development of the sector, due to its inability to lead and champion disability issues across Australian Government portfolios including employment, education and health.
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> This problem is mirrored in the States where key areas such as infrastructure, transport and health are not directly included in the CSTDA work of the lead disability departments who are CSTDA signatories, and where the general policy response is limited.[33]

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[30] *Commonwealth State Territory Disability Agreement 2002-2007*, Part 6(1)(g).

[31] *Committee Hansard*, 28.9.06, p.20 (Brain Injury Australia).

[32] *Submission* 90, p.8-9 (AFDO).

[33] *Submission* 93, p.20 (MS Australia).

3.40 ACROD commented:

> Governments are hierarchical entities. If a whole of government approach is to be effective it needs to become a priority of central government agencies and, ultimately, requires leadership by the heads of government.[34]

3.41 The Mid North Coast Disability Committee also suggested there is potentially a greater role for local government in the delivery and co-ordination of specialist disability services.[35]

3.42 Governments are working at improving the coordination of disability services. At the July 2006 meeting of the Community and Disability Service's Ministers' Conference, Ministers agreed on three priority areas of shared concern that would likely benefit from national collaboration for a fourth CSTDA. These were service improvement, demand management and interface issues.[36]

A national approach?

3.43 The argument was made to the Committee in a number of submissions that problems associated with the CSTDA joint funding arrangements may be addressed if the Commonwealth assumed sole responsibility for funding of services in relation to disability.[37] These arguments reflect long-standing and on-going debates regarding the balance of Commonwealth, State and Territory responsibilities for Australia's health care system and the issue of cost-shifting.[38]

3.44 A Commonwealth 'take over' of disability services was seen as broadly addressing a number of perceived systemic problems with the current joint funding arrangements. These included greater accountability, a uniform approach service delivery, the more equitable allocation of disability services and improved co-ordination across service systems. Ms West elaborated on the advantages of a national approach in her submission:

> Benefits would appear to be considerably improved standardisation and uniformity in the level of funded disability service programs, increased coherency and consistency of available services and clearer expectations for clients as to available services and resources. In terms of administration, a national approach would significantly reduce as previously highlighted,

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[34] *Submission* 45, p.18 (ACROD).

[35] *Submission* 18, p.2 (Mid North Coast Disability Committee).

[36] *Submission* 112, p.8 (Queensland Government).

[37] *Submission* 28, p.30 (National Carers Coalition); *Submission* 44, pp 20–21 (Ms R West); *Submission* 6, p.1 (South Gippsland Carers Group); *Submission* 8, p.17 (Gippsland Carers Association).

[38] Buckmaster, L & Pratt A, 'Not on my account! Cost-shifting in the Australian health care system', *Parliamentary Library Research Note*, No. 6, 2 September 2005.

> difficulties with managerial assessment, contrasting accounting practises and data collation and analysis.[39]

3.45 Submissions, particularly from the Commonwealth, State and Territory Governments, while acknowledging problems existing in the current system, emphasised the benefits of joint funding arrangements. They noted that the CSTDAs have been successful in ensuring that all jurisdictions have specific funding available for people with disabilities and that where jurisdictions are clear on their responsibilities and sufficient funding is made available there have been significant outcomes for people with disabilities.[40] For example the Western Australian Government commented:

> The CSTDA has allowed the Commonwealth, States and Territories to maintain a focus on disability and direct resources specifically to meeting the needs of Australians with a disability to an extent that was not occurring before the existence of these agreements. While that in itself should not be held as the only argument for the continuation of the multilateral agreements, it is strong evidence in support of specific collaborative funding arrangements for disability services.[41]

3.46 Similarly the National Ethnic Disability Alliance noted that 'Commonwealth and State/Territory joint responsibilities in funding and providing disability services should be maintained for better accountability and Commonwealth/State coordination'.[42]

3.47 ACROD also noted the serious weaknesses in the CSTDA but continued to support a joint arrangement. Dr Baker commented:

> …we support governments negotiating a fourth Commonwealth State/Territory Disability Agreement. We think that the original CSTDA was an improvement on the system it replaced, and there have been some subsequent improvements. Having said that, we believe that the fourth agreement ought to be substantially reformed…[43]

Competitive federalism

3.48 An issue which was not discussed in many submissions was that of competitive federalism. The decentralisation of responsibility for disability services to the State and Territory Governments provides them with flexibility to address local issues and increased opportunities for innovation in policy. It also provides a competitive environment where the best policies once introduced and tested by one

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[39] *Submission* 44, p.20 (Ms R West).

[40] *Submission* 93, p.8 (MS Australia).

[41] *Submission* 3a, p.5 (Western Australian Government).

[42] *Submission* 107, p.6 (National Ethnic Disability Alliance).

[43] *Committee Hansard* 13.10.06, p.34 (Dr K Baker, ACROD).

jurisdiction can be adopted by other jurisdictions. State and Territory Government policies in relation to disability services are comparable which creates a competitive pressure on underperforming jurisdictions to match the 'best practice'. NSW Minister for Disability Services the Hon John Della Bosca commented:

> I am a fan of competitive federalism. That might sound like a very old-fashioned idea but I think there is some merit in the idea of six different systems in a range of areas, provided there is a reasonable harmonisation…[44]

A federal dilemma

3.49 In 2005 the Productivity Commission conducted a Roundtable on 'Productive Reform of the Federal System' which focused on issues associated with the challenges of securing better policy outcomes from Australia's federal system of government and included some examination of options for systemic change in health reform.[45] Some of the discussion is readily applicable to consideration of the CSTDA joint funding arrangements.

3.50 A key feature of the current federal system in Australia is that the States have broad spending responsibilities but few revenue sources whilst the reverse is true at the Commonwealth level. The difference between the relative revenue and spending responsibilities of the Commonwealth and States is known as vertical fiscal imbalance.[46] In the CSTDA the State and Territory Governments contribute the majority of funds for specialist disability services other than employment and have administrative responsibility. However because of factors relating to vertical fiscal imbalance and recent budget surpluses the Commonwealth was perceived by some as having a greater financial capacity than the State and Territory Governments to fund specialist disability services and swiftly address unmet need.

3.51 A number of possible options for health reform were identified by Mr Andrew Podger. These options included: the States taking full responsibility for health and aged care services; the Commonwealth taking full financial responsibility for health care; the Commonwealth and States pooling their funds as regional purchasers; and a 'managed competition' model where Commonwealth and State funds are available for channelling through private health insurance funds by way of 'vouchers' which individuals may pass to the fund of their choice.[47]

3.52 Mr Podger's view was that it was feasible for the Commonwealth to take full financial responsibility and identified a number of the possible benefits of such a

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[44] *Committee Hansard* 3.10.06, p.48 (Minister Della Bosca).

[45] *Productivity Commission Roundtable on Productive Reform in the Federal System*, 2005.

[46] Webb R, ' Public Finance and Vertical Fiscal Imbalance' *Parliamentary Research Note* no.13 2002-03 p. 1.

[47] Podger A, 'Directions of health reform in Australia', *Productivity Commission Roundtable on Productive Reform in the Federal System*, 2005, p.147.

proposal. These included allowing a single Commonwealth minister and department to control the national management and delivery of services. This would increase accountability for services and operate to reduce cost-shifting and duplication. Such an approach would also address the problems created by vertical fiscal imbalance by having the revenue raiser as the primary purchaser of services. It would also reflect a trend towards increasing Commonwealth control over health care.

3.53 However, Mr Podger also noted costs and risks in a Commonwealth 'take over' of health services. It would require significant expense and a lengthy transition period for the Commonwealth to take over control of State and Territory personnel and facilities as well as to establish new administrative structures which allowed for regional and community flexibility and input. The proposal would also involve complex renegotiation of current tax revenue arrangements.

3.54 In 2006 the House of Representatives Standing Committee on Health and Ageing tabled *The Blame Game: Report on the inquiry into health funding* which also examined proposals for reforming federal arrangements in relation to health care.[48] A key recommendation from this report was that Australian governments develop and adopt a national health agenda. Part of the proposed national health agenda would be to identify policy and funding principles and initiatives to: 'rationalise the roles and responsibilities of governments, including the funding responsibilities, based on the most cost-effective service delivery arrangements irrespective of governments' historical roles and responsibilities'.[49]

Conclusion

3.55 The current and previous Agreements have demonstrated a commitment on the part of all Australian governments to ensure that resources are specifically allocated for the provision of specialist services to improve the lives of people with disability.

3.56 The Committee supports a fourth disability agreement between the Commonwealth, State and Territory Governments. The State and Territory Governments continue to have the service delivery expertise and can be more responsive to the needs of people with disability and carers within their jurisdictions.

3.57 However there is clearly a need for improvement in consistency, equity, coordination of specialist disability services as well as accountability, performance monitoring and reporting. In these areas the Commonwealth is best placed to perform a leadership role. The Commonwealth also possesses the capability through the Bilateral Agreements to achieve better results in these areas.

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[48] House of Representatives Standing Committee on Health and Ageing, *The Blame Game: Report on the inquiry into health funding*, December 2006.

[49] House of Representatives Standing Committee on Health and Ageing, *The Blame Game: Report on the inquiry into health funding*, December 2006, p.53.

3.58 The Committee notes that the ANAO audit of the administration of the CSTDA found evidence that the Bilateral Agreements had improved coordination with relevant State and Territory Government disability agencies and considered the Bilateral Agreements have the potential to be an effective coordination mechanism for the Commonwealth's lead agency to work with State and Territory agencies.

3.59 The Committee notes that Bilateral Agreements between the Commonwealth and State and Territory Governments for funding of disability services will often necessarily affect the provision of other disability services as well as other publicly funded services. Where possible Bilateral Agreements should not skew or distort the broader objectives of the CSTDA.

3.60 The Committee also notes that the Commonwealth may potentially have more capacity to control and co-ordinate disability services if it increased the proportion of Commonwealth funding to CSTDA services. ANAO also noted:

> The fact that the Australian Government only provides 20 per cent of the funding for services administered by the States and Territory governments limits its roles, and the amount of influence it has over the delivery of those services.[50]

3.61 The Committee recognises that the present funding arrangements assign the States and Territories the primary responsibility for funding specialist disability services and the Commonwealth responsibility for funding disability employment services, with some Commonwealth supplementation of the States and Territories' role. However these arrangements are problematic, and have generated considerable uncertainty within the disability community about where services can be found, what criteria for eligibility apply and which government bears responsibility for its proper funding. The next CSTDA must as a priority, remove this uncertainty and create transparent lines of responsibility.

3.62 Options for large-scale reform to the current CSTDA joint funding arrangements may offer more challenges than solutions. The Committee recognises that any reform is not without cost or risk and that any new arrangement or division of responsibilities will necessarily involve some service delivery problems. Any major change to the structure of joint funding arrangements under the CSTDA should be accomplished as part of a broader restructure of Commonwealth, State and Territory health and community care responsibilities.

3.63 However despite these concerns the Committee agrees the CSTDA could be utilised more broadly to improve the lives of people with disability. The Committee supports the AFDO's comment that:

> …the CSTDA is far from being a coordinated, high level strategic policy document. Despite its broad aim and the priority placed on access to

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[50] ANAO, *Administration of the Commonwealth States Territory Disability Agreement*, Audit Report No. 14 2005 -2006, p 30.

> generic services, the current CSTDA retains a narrow focus on service delivery, particularly disability-specific services, to people with disability aged under 65 years. The CSTDA is crisis driven, with the result that short-term, individually focussed interventions are prioritised over systemic reforms.[51]

3.64 A renewed national disability strategy could function to coordinate the objectives of the Commonwealth Disability Strategy and the disability policy frameworks which have been developed by many of the States and Territories, such as Victoria's State Disability Plan. By providing a coordinating framework for various policies, programs, legislation and standards the next CSTDA may enable effective responses to be developed to the complex issues which people with disabilities face.

Recommendation 3

3.65 That the next CSTDA should include –

- **A whole of government, whole of life approach to services for people with disabilities.**
- **A partnership between governments, service providers and the disability community to set policy priorities and improve outcomes for people with disability.**
- **A clear allocation of funding and administration responsibilities based on the most effective arrangements for the delivery of specialist disability services.**
- **A clear articulation of the services and support that people with disability will be able to access.**
- **A commitment to regular independent monitoring of the performance of governments and service providers.**
- **A transparent and clear mechanism to enable people with disability and their carers to identify and understand which level of government is responsible for the provision and funding of services.**

Recommendation 4

3.66 That in the life of the next CSTDA, signatories agree to develop a National Disability Strategy which would function as a high level strategic policy document, designed to address the complexity of needs of people with disability and their carers in all aspects of their lives.

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[51] *Submission* 90, p.6 (AFDO).

Assessment

Assessment and planning

3.67 The Committee was concerned at the apparent lack of connection between assessments being undertaken and the planning by governments for the needs of people with disability. Assessments would seem an appropriate method for governments and service providers to budget and plan services as well as to give people with disability and their carers a level of certainty. Mrs Franklin highlighted the approach taken by the United Kingdom to lifelong assessment and planning.

> When the child is born or diagnosed with a disability, you are assessed and they put a care package together. Then they reassess it when the child is going to school and they either take some of that care package off them or add to it, depending on the disability. Then at the end of primary school they are reassessed. Two years before they leave high school they are assessed, and what they look at there is accommodation and employment—all of that.[52]

3.68 This approach could be contrasted with the experience of many Australian families. Ms Allen commented:

> The maze to find services was an absolute nightmare and actually was the most energy-zapping situation that you can imagine. Rather than having that time to give to my child, I found myself fighting the bureaucracy almost every minute of the day. There was no plan for us and there was certainly no plan for Simon. We had to negotiate for everything that we got. We had to emphasise the negative the whole time. We had to make it sound actually as bad it was and it was very hard for people to actually realise what we were going through.[53]

Application procedures

3.69 Another assessment issue raised was the procedures involved in the applications for State and Territory disability services. While practices differ between jurisdictions these application and eligibility procedures often rely on people with disabilities or their carers filling out detailed forms setting out their circumstances and needs in order to be assessed for eligibility and access to disability services. These forms are then assessed on a competitive or criticality of needs basis to determine who has access to disability services.

3.70 These can be highly distressing for families members required to describe a loved one negatively, focusing on how caring for their needs is a burden to them.[54]

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[52] *Committee Hansard* 5.10.06, p.86 (CASA).

[53] *Committee Hansard* 5.10.06, p.20 (NCID).

[54] *Committee Hansard* 5.10.06, p.68 (Ms D Croft).

People with disability and their families are also forced to 'compete' for the available disability services against other equally deserving families. Ms Croft commented:

> I think there are a number of consequences of having a competitive or criticality of needs basis for service provision. One is that family carers are required to portray the needs of their family member with a disability in the worst possible light, as being a burden on them and their family, and I think that has enormous implications. There is a risk of devaluing people with disabilities. I think also it requires an enormous bureaucracy to supervise who gets funding on whatever level of critical need, so providing services on the basis of pitting people's needs against each other consumes resources and has an effect even in terms of simple human dignity. I hear so many parents expressing views about having to compete against people that they recognise are also experiencing great hardship. They feel guilty about that. But also it is a matter of who can demonstrate that their crisis is worse than someone else's crisis, which is not a dignified way in which services should be provided. It also means that we have lost sight of the rights and needs of people with disabilities and instead we are focusing solely on how healthy or strong their parents or their carers are…[55]

3.71 The Committee is also concerned that some assessment procedures for access to disability services appear reliant on written applications. These procedures disadvantage people with poor literacy or communication skills, often the people in the most need of assistance. An example given by Mrs Franklin from Committed about Securing Accommodation for People with Disabilities (CASA) highlighted this concern:

> I have been helping a family—a Vietnamese lady; she has a son with severe disabilities, her husband is dying of cancer and another son has had kidney transplants. Because she cannot articulate on a piece of paper and because of her cultural background—she does not like to ask for help—she keeps getting knocked back in the funding round. If a team had gone out and assessed the child with the disability and looked at the family in general she would have got funding a long time ago.[56]

3.72 The Committee was interested in the potential benefits of utilising information technology and the internet to reduce the burden that people with disability and their carers carry in relation to communicating their needs to services providers. An Adelaide based disability organisation 'Life is for Living Inc' are currently running a project 'What I'd Like You To Know About Me!'[57] The project created a CDROM resource kit for service providers that focused on capturing holistic and positive information about people with disabilities. The information collected by the resource

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[55] *Committee Hansard* 5.10.06, p.68-69 (Ms D Croft).

[56] *Committee Hansard* 5.10.06, p.82 (CASA).

[57] *Committee Hansard* 6.10.06, p.25 (Ms M Baker).

could then be printed and shared with others such as family and friends, teachers, therapists, health professionals and community members.[58]

> For example, "Who are the members of my family?" "When I go to hospital, I need this," "This is how I like to be cared for", and "These are my favourite toys." It is written from the perspective of the person with the disability. It empowers the family and the person with the disability to put their own story forward. It can be used by health services and other service providers to talk to the child when they are in hospital, for example.[59]

A National Framework

3.73 The ANAO audit of the administration of the CSTDA noted that:

> The States and Territories, and the Australian Government, have recognised that there: "is currently no one conceptual model adopted by jurisdictions that assesses eligibility, support needs and priority for service at both a systemic and individual level".
>
> This situation has resulted in a lack of national consistency in how individuals' needs for services are identified and in determining priority. The ANAO considers that, in this circumstance, there is a significant risk that services provided under the CSTDA may not be provided to those recipients in most need across Australia.[60]

3.74 Carers Australia also highlighted the need for national consistency in assessments of eligibility, support needs and service priority.

> 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.[61]

3.75 The National Disability Administrators Research and Development Program was undertaking a project *National Assessment and Resource Allocation Framework* with the purpose of developing 'a flexible, nationally-consistent system which ensures a fair, transparent, consistent and rationale-based allocation of resources that will also assist in understanding and managing demand for disability services.' The Committee understands this project has now been cancelled.

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[58] www.lifeisforliving.com.au

[59] *Committee Hansard* 6.10.06, p.25 (Ms M Baker).

[60] ANAO, *Administration of the Commonwealth State Territory Disability Agreement*, Audit Report No. 14 2005-06 p.38.

[61] *Submission* 52, p.9 (Carers Australia).

A Disability Assessment Team?

3.76 A key issue for the Committee was the importance of assessing the needs of people with disabilities. Without an accurate and comprehensive assessment of the care and support needs of each individual it seems impossible to determine which specialist disability services or other services they should be able to access. This basic information also appears crucial to a number of the other issues raised in the inquiry.

3.77 Accurate and comprehensive assessments of the needs of each individual with a disability could assist in:

- tailoring available services to meet an individual's specific needs rather than fitting people to services or programs;
- enabling governments to plan services and funding by clarifying the needs of people with disabilities in their jurisdiction;
- preventing cost-shifting between the levels of government by independently assessing the services a person should be able to access;
- informing people with disabilities about the services which they are eligible to access and facilitating access to those services;
- determining eligibility and priority through an equitable process to ensure resources are delivered to those in the most need as well as reducing the burden on family carers in making applications for services
- collecting additional data concerning unmet need in each jurisdiction as well as making governments accountable for inadequate funding or provision of specialist disability services; and
- recognising and addressing the special needs of people with dual and multiple diagnoses.

3.78 The approach of the Aged Care Assessment Teams (ACATs) involving face-to-face comprehensive functional assessments of individuals was generally supported during the inquiry. ACATs are multi-disciplinary and can include health professionals such as medical officers, social workers, nurses, occupational therapists and physiotherapists. The objective of the Aged Care Assessment Program is to 'comprehensively assess the needs of frail older people and facilitate access to available care services appropriate to their care needs.' Proposals were raised for a similar approach to assessments for people with disabilities and their access to services.

Recommendation 5

3.79 That the next CSTDA incorporate a nationally consistent assessment process to objectively and comprehensively determine the support and care needs of each person with a disability. These assessment processes should also assist people with disability by making determinations of eligibility for services and priority of need as well as facilitating access to appropriate services.

The burden of multiple assessments

3.80 The Committee was concerned to hear of the issues people with disabilities and their carers had with assessment procedures for access to disability services. A common complaint was the need to continually repeat information regarding disability care needs to service providers and care workers or to frequently attend assessments in order to access disability services. This was particularly burdensome for people with permanent lifelong disabilities and their carers. Ms Stagg explained to the Committee some of the challenges of caring for her daughter Michelle:

> All I want is a piece of paper that says, "Has anything changed?"—"No," tick, the doctor signs it and you go. That sort of stuff is frustrating all the time…Somebody who starts this from birth has to go through that again and again…I really do not know how you are going to get away from that, but there must be some way of facilitating people from day dot to help them through the system…[62]

3.81 Mrs Griffin repeated these concerns regarding assessment procedures in relation to her son Scott:

> One of the things that I find most frustrating is being sent forms continuously and having to restate that nothing has changed with Scott. The fact is that nothing is going to change. He is not going to suddenly get better. He has a genetic deletion that is there and will be there and is never going to change, so his needs are always going to be as they are, if not worse as he ages. It would be nice if some of that could be understood so that it was broader than a particular disease. It needs to be understood so that once a person is diagnosed with something like a genetic deletion that is never going to change you do not have to spend your whole time begging for equipment or begging for help. It should be on record that this child needs help ongoing, long-term, until the day he dies.[63]

3.82 This issue appeared to be the result of the complexity of the administration disability services as well as inefficient assessment procedures and information sharing by disability providers and agencies. This is an issue complicated by administrative requirements and by privacy laws designed to protect the private health information of all Australians. The Committee agrees that people with permanent lifelong disabilities and their carers should not be required to repeatedly 'prove' their disability in order to obtain disability services. Where possible they should be given the choice to consent to their assessment information being shared and utilised in the most administratively effective fashion.

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[62] *Committee Hansard* 6.10.06, p.22 (Ms D Stagg).

[63] *Committee Hansard* 3.10.06, p.19 (Mrs S Griffin).

Appropriate Assessment

3.83 The specialised assessment needs of people with chronic degenerative diseases such as Motor Neurone Disease and Multiple Sclerosis were also raised with the Committee. The degenerative nature of these conditions means the assessment of current and future need for disability services was problematic. Changes in their needs for disability services and equipment were often sudden and unpredictable. Long waiting periods for assessment and access to services was inappropriate for the changing nature of their conditions.

Recommendation 6

3.84 That the Commonwealth, State and Territory governments ensure that:

- **administrative burdens of assessment procedures are reduced for those with lifelong and permanent disabilities and their carers; and**
- **flexible assessment options are available to people with disabilities who have needs that may change rapidly.**

Indexation of CSTDA funding

3.85 A number of submissions raised the issue of indexation of CSTDA funding, particularly in relation to Commonwealth contributions.[64] Indexation (or price adjustment) is intended to change funding to take account of changes in the cost of services over time so that providers can continue to offer the same services.

3.86 Part 8(10) of the current CSTDA provides that indexation of Commonwealth funds to be transferred to the State and Territory Government are calculated each year by reference to the Commonwealth indexation parameter Wage Cost Index 2. The Commonwealth indexation of CSTDA funding based on Wage Cost Index 2 was 2.1 per cent for 2005/06 and 1.8 per cent for 2006/07. The decision about which indexation rate is applied to Commonwealth CSTDA funding is made by the Department of Finance and Administration. The State and Territory Government indexation of their CSTDA funding varied.

3.87 Table 3.2 outlines the indexation rates applied to CSTDA funding by each jurisdiction.

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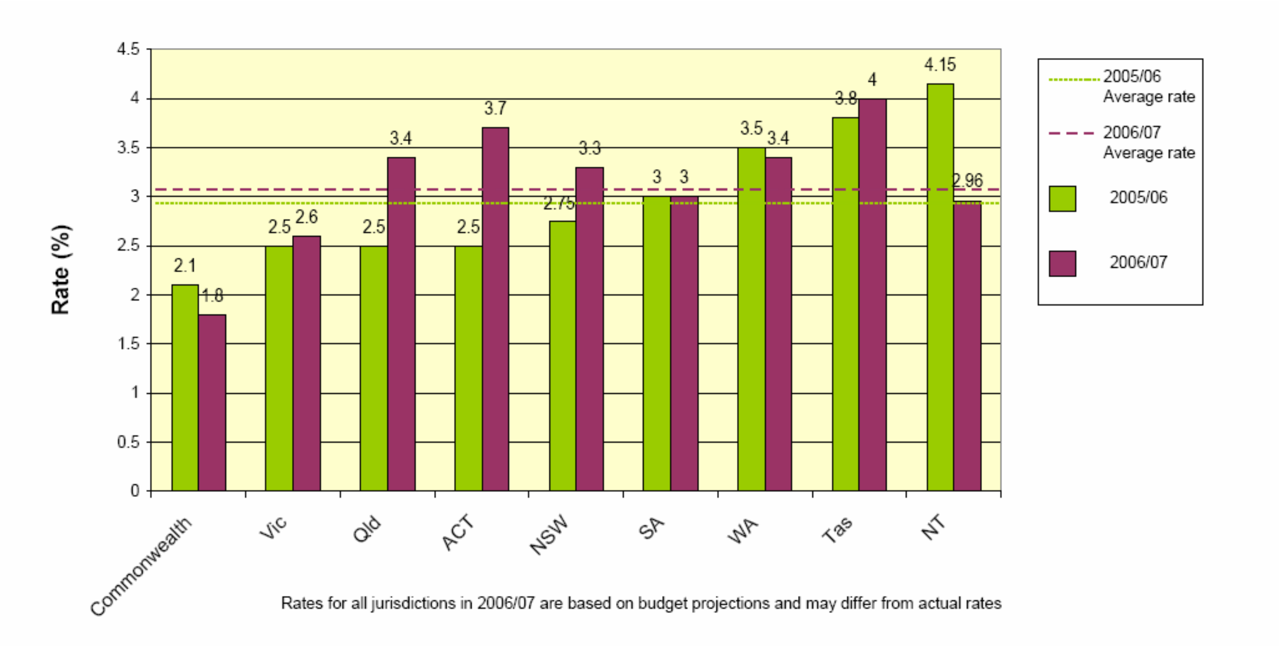
[64] *Submission* 3, p.17 (Western Australian Government); *Submission* 99, p.15-16 (Victorian Government); *Submission* 84, p.7 (NSW Government); *Committee Hansard*, 13.10.06, p.58 (ACT Government); *Submission* 112, p.3 (Queensland Government); *Submission* 60, p.15 (Disability Coalition WA); *Submission* 95, p.5 (NCOSS); *Submission 45,* p.7 (ACROD); *Submission* 72, p.9 (Australian Blindness Forum).

Table 3.2: CSTDA indexation rates by jurisdiction 2005/06 and 2006/07



Source: Western Australian Government, *Submission* 3, p.18.

3.88 Many submissions to the Committee argued that the Commonwealth's rate of indexation was unrealistic and insufficient to keep up with increased costs (particularly wages) in the disability sector. The consequences of indexation rates applied to CSTDA funding which did not reflect increases in costs in the provision of disability services were also highlighted. In particular an inadequate rate of indexation applied to CSTDA funding could gradually erode the real value of the base funding and affect the viability and sustainability of disability services.

3.89 NCOSS stated in their submission:

> Certainly, previous indexation rates have not compensated for increases in costs, including wages, activities and overheads, as well as external impacts such as insurance, workers compensation and fuel prices etc. This has resulted in a pattern of consistent underfunding with the net effect being diminished service capacity.[65]

3.90 Dr Baker from ACROD identified the problems that inadequate indexation of CSTDA funding could cause for disability service provider staffing:

> The cumulative effect of this gets worse and worse as time proceeds and makes it more and more difficult for disability service providers to recruit and retain staff. This has now reached quite critical levels within the sector…we need first of all to provide service providers with enough

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[65] *Submission* 95, p.5 (NCOSS).

> capacity to recruit, train and retain quality staff. That cannot be achieved while they are having to manage what is in effect an annual funding cut.[66]

3.91 Some State and Territory Governments argued that the level of indexation applied by the Commonwealth to CSTDA funding has operated to gradually shift the funding burden to them. The Queensland Government also highlighted the Commonwealth's application of different indexation rates in relation to other social program funding.

> The Home and Community Care Program, for example, has a range of indexation rates varying between 2.1 per cent and 3.85 per cent applied annually. The Supported Accommodation Assistance Program has an indexation rate of 2.2 per cent, while the Australian Healthcare Agreement also has varying indexation rates. Its general component is made up of two per cent wage-cost indexation and 2.84 per cent population growth. Seventy-five per cent of the general component comprises 1.7 per cent utilisation growth.[67]

3.92 However FaCSIA indicated that the Commonwealth was not merely seeking to address increased costs in the delivery of disability services in setting the indexation rate. Consideration of the Commonwealth's indexation in relation to CSTDA funding should also take into account additional funding initiatives made by government. Mr Stephen Hunter of FaCSIA commented:

> The government does not seek, through indexation, to cover all cost increases that might occur in the delivery of a service. If it were to do that there would be very few incentives to seek to contain some of the costs. What it seeks to do through indexation is to ensure that the forward estimates broadly reflect the price basis of the year in which the expense is to occur and the minimal realistic costs of delivering policy outcomes. So it does not try to compensate for actual movements in costs but rather to, in the broad, ensure that the forward estimates reflect the price basis of the units involved…I think when you look at the issue of indexation alongside the other additional funds that have been put forward in the context of the CSTDA, that is a relevant consideration. If, simply, you just compensate for all the cost increases that might occur, governments then to an extent rob themselves of the capacity to make specific initiatives which might go to achieve specific outcomes.[68]

3.93 The Department of Finance and Administration has also indicated that Wage Cost Index 2 has been used as the indexation rate for Commonwealth CSTDA funding as the relative weighting of wage and non-wage costs best reflects the balance between wage and non-wage costs in the services supplied under the CSTDA.[69]

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[66] *Committee Hansard* 13.10.06, p.36 (ACROD).

[67] *Committee Hansard* 17.11.06, p.2 (Queensland Government).

[68] *Committee Hansard* 13.10.06, p.85 (FaCSIA).

[69] Department of Finance and Administration, Additional information, 12.12.06.

3.94 However in 2002, the Social Policy Research Centre (SPRC) conducted a study for the National Disability Administrators which examined the issues of indexation and demand in relation to CSTDA funding. It suggested that Wage Cost Index 2 was not suitable for CSTDA indexation as the method of calculation was not appropriate for the disability sector:

> Wage Cost Index 2 is based primarily on the Industrial Relations Commission Safety Net Increase together with a small component based on general price inflation. This is so the index should not include any component of wage growth that is intended to be offset by efficiency gains. However, this implies assumptions about productivity growth that are not in accord with generally accepted economic principles. Economic theory suggests that wage growth in service industries and human services in particular, will run well ahead of productivity growth in that sector.[70]

3.95 This view was supported by the Queensland Government which commented:

> Indexation models adopted by the Commonwealth Government have been based upon the assumption that there will be efficiency dividends or productivity saving that result in reduced labour costs or efficiencies due to technology or telecommunications improvements. However research has found that industries such as human services are not able to make productivity gains in ways that are available to other industries. This is due to the fact that they are highly labour intensive, have limited opportunities for technology-based productivity gains, experience significant flow-on pressures for wage increases from allied sectors and are expected to meet prescribed service delivery standards.[71]

3.96 Dr Baker commented:

> There is an assumption built into the Commonwealth indexation formula which is just flawed. It may be appropriate for a manufacturing sector or a mining sector, where human resources can be replaced with technology and productivity can be achieved like that, but that is not true within the disability sector, where social interaction is the nature of the business. Disability support workers cannot be replaced by machines. The assumption within the Commonwealth indexation formula that any increase that is over and above the safety net increase can be traded off against productivity or efficiency increases is just not true.[72]

3.97 The Committee considers that the application of the efficiency dividend is generally inappropriate in relation to the indexation of funding for specialist disability services given the necessarily high proportion of total budget which must be spent on

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[70] Bradbury B, *Methods to Address Requirements for Changes in Funding Disability Services Brought About By External Change*, Social Policy Research Centre, Report No. 5/02, April 2002.

[71] *Submission* 112, p.5 (Queensland Government).

[72] *Committee Hansard* 13.10.06, p.36 (ACROD).

staff wages in delivering personal care. Recognising that limited efficiencies can be gained in the sector, the efficiency dividend effectively acts to cut the level of funding for disability services.

Recommendation 7

3.98 Given the reality that a large proportion of costs in disability services will always be wages and salaries of care providers, the Committee strongly recommends that the Commonwealth consider removing the efficiency dividend from the indexation formula for funds allocated through the CSTDA.

3.99 The SPRC study recommended an indexation rate based on actual movement in wages that reflects a more realistic level of productivity savings in the disability sector. It proposed a wage cost index be used based on the Australian Bureau of Statistics Wage Cost Index (ABS WCI) combined with a general Consumer Price Indicator (CPI) inflator to cover costs not related to wages. It noted that over recent years the ABS WCI had grown at twice the rate of the Wage Cost 2, currently applied to Commonwealth CSTDA funding.[73] The SPRC study also noted the need for indexation of CSTDA funding to address on-costs for service providers such superannuation and workers compensation insurance.

3.100 The Committee notes the annual September quarter 2006 ABS Wage Price Index seasonally adjusted increase for all employee jobs in Australia was 3.8 per cent.

Recommendation 8

3.101 That the Commonwealth set an indexation level in line with the actual costs of delivering services. This rate should be applied as a minimum indexation rate by State and Territory Governments.

Demand funding

3.102 A number of submissions argued that the current CSTDA lacks long-term strategic planning for increasing demand for specialist disability services. In general demand adjustments to funding seek to ensure that the relationship between the supply of services and the demand for services remain the same. For example to adjust funding to account for increases in the population or in prevalence of disability in the population which would increase demand for services.[74] Ms Felicity Maddison of the National Carers Coalition commented:

> …the whole CSTDA is crisis driven as to the rollout of support. Because of the lack of the bulk of funding that is available, funding is rationed and it is

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[73] Bradbury B, *Methods to Address Requirements for Changes in Funding Disability Services Brought About By External Change,* Social Policy Research Centre, Report No. 5/02, April 2002, p.3.

[74] Bradbury B, *Methods to Address Requirements for Changes in Funding Disability Services Brought About By External Change,* Social Policy Research Centre, Report No. 5/02, April 2002, p.1.

> coming out—it is being rolled out—on the basis of crisis intervention rather than in a well-constructed forward planning process. There is no evidence of long-term planning for the future and you are getting a lot of flavour-of-the-month-type initiatives coming through…[75]

3.103 In the current CSTDA demand adjustment and growth funding is dealt with in Part 8 (8):

> Commonwealth, States and Territories acknowledge demand management requires regular annual growth in funding levels to continually improve the level and quality of services and the efficiency of systems for specialist disability services. The States/Territories will provide annual funding growth at a level agreed between each State/Territory and the Commonwealth over the life of the Agreement for services they are directly responsible for administering under the Agreement.

3.104 The CSTDA arrangements do not require multi-year budgetary planning based on demand growth. Some submissions proposed population-based benchmark funding similar to that used for the funding of aged care services would be more appropriate for funding calculations for disability services.[76] ACROD commented:

> Aged Care uses a needs-based planning framework that seeks to achieve and maintain a national provision level of 108 residential places and Community Aged Care Packages (CACPs) for every 1,000 of the population aged 70 years and over. While there is some debate about the formula, its aim is to ensure that the growth in the number of aged care places is in line with growth in the aged population and that there is a balance of services, including services for people in rural and remote areas.
>
> The disability sector has nothing similar to guide the provision of residential and community care places to people with disability. We know that only 48 of every thousand persons in the comparable population (broadly, people under 65 years with a severe or profound core activity restriction) receive a CSTDA-funded disability accommodation support service.[77]

3.105 The Committee notes that the Disability Policy and Research Working Group (formerly the National Disability Administrators) is conducting research into Demand Management due for completion in June 2007.

Recommendation 9

3.106 That the next CSTDA incorporate appropriate benchmarks and annual targets in relation to identified unmet need for specialist disability services.

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[75] *Committee Hansard* 3.10.06, p.28 (National Carers Coalition).

[76] *Submission* 28, p.7 (National Carers Coalition); *Submission* 10, p.1 (Ms E Shields).

[77] *Submission* 45, p.12 (ACROD).

Growth Funding

3.107 Several State and Territory submissions noted that their CSTDA funding contributions for specialist disability services were growing at a faster rate than those from the Commonwealth. The Queensland Government noted that:

> The Queensland Government has made significant additional investments in disability services in recent years representing a commitment at the State level to respond to needs of people with a disability. A commensurable effort by the Commonwealth Government has not been realised.[78]

3.108 However, a larger proportion of new Commonwealth funding has gone into the disability employment services which it directly administers. Over the course of the current agreement annual Commonwealth funding of disability employment services has increased from $303 million to $486 million while funding to the States and Territories for special disability services has increased form $521 million to $616 million.[79]

3.109 ACROD suggested the following reasons for this trend:

> This reflects the Commonwealth's view that:
>
> - implementing the ambitious raft of disability employment service reforms required additional spending on those services;
> - States are insufficiently accountable for the expenditure of funds they receive from the Commonwealth;
> - State-administered services are principally the responsibility of the States; and
> - higher-than-expected GST revenue should reduce the States' call on Commonwealth specific-purpose transfers.[80]

3.110 The State and Territory Governments also expressed concern that increases in the level of CSTDA funding were not being reflected in requirements set in the Bilateral Agreements.

> The Australian Government applies a "matched funding" requirement as a part of most bilateral agreements, but there is no structure in place to acknowledge additional funding efforts made by the States and Territories.
>
> A further shortcoming of the Commonwealth’s introduction (as part of a regime of input controls) of a ‘matched commitment’ at the time of signing an agreement is that this does not recognise previous efforts of States and Territories. This can create a disincentive to states in making additional efforts in growth funding during an agreement as this additional effort

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[78] *Submission* 112, p.3 (Queensland Government).

[79] *Commonwealth State Territory Disability Agreement 2002-2007, Schedule A1.*

[80] *Submission* 45, p.9 (ACROD).

> becomes effectively locked-in to areas that may not be reflective of need in the State or Territory.[81]

Recommendation 10

3.111 That the next CSTDA ensure 'matched funding' commitments do not provide a disincentive for governments to provide additional funding for specialist disability services.

Equity of funding distribution

3.112 A number of State and Territory Governments argued the Commonwealth funding for specialist disability services was not distributed equally amongst the jurisdictions in relation to their proportion of people with disabilities.[82] For example the Victorian Government commented:

> Victoria receives less than its equitable share of Commonwealth funding, which results in an estimated shortfall of some $40 million over the life of the current CSTDA.[83]

3.113 The Western Australian Government provided a graph, reproduced as Table 3.3, to illustrate what it suggested was a lack of equity in the distribution of Commonwealth CSTDA funding in relation to potential population.[84] The Australian Institute of Health and Welfare (AIHW) estimates 'potential population' in each jurisdiction to broadly indicate the number of people with the potential to require specialist disability services at some time. The potential population for each jurisdiction is calculated from population disability survey estimates and is constructed for comparative purposes and to provide indications of relative need.[85]

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[81] *Submission* 3a, p.20 (Western Australian Government).

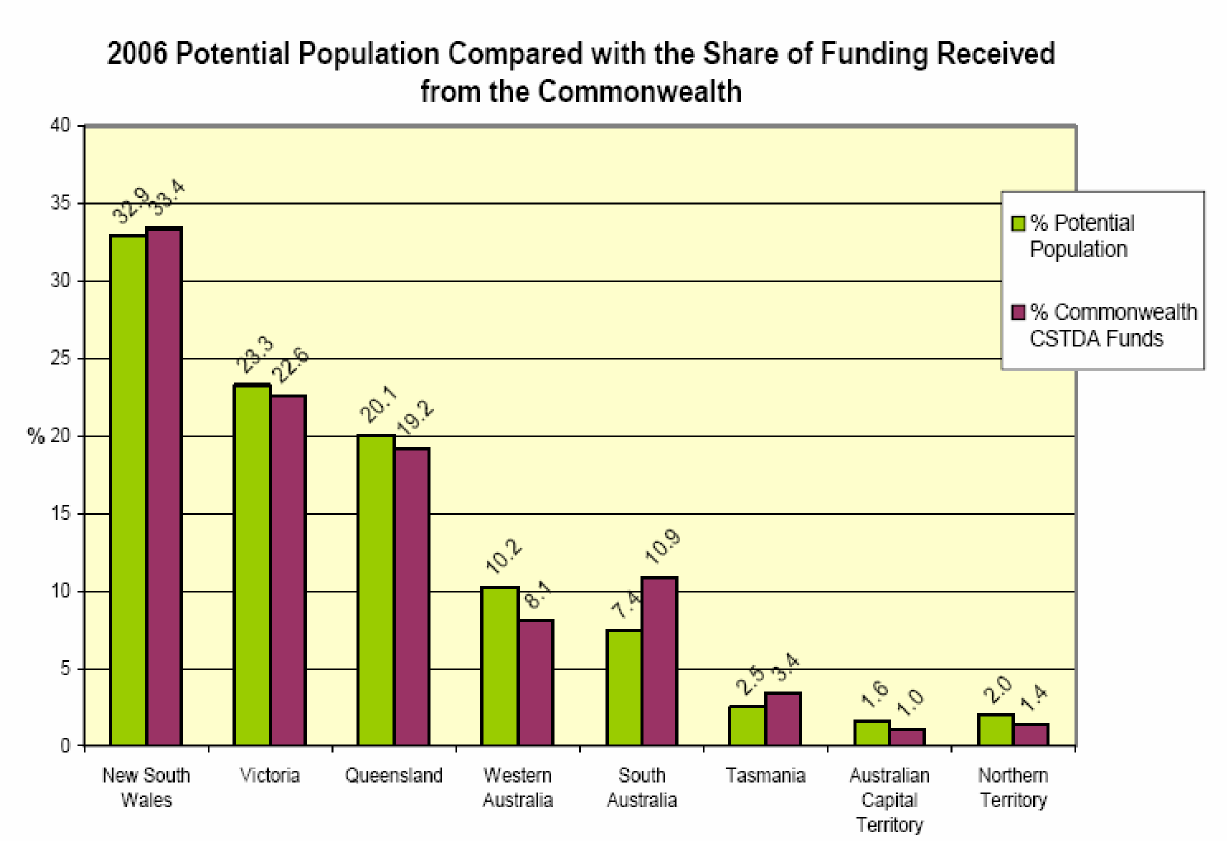
[82] *Submission* 3a, p.22 (Western Australian Government); *Submission* 99, p.16 (Victorian Government); *Submission* 60, p.15 (Disability Coalition WA).

[83] *Committee Hansard* 28.9.06, p.66 (Victorian Government).

[84] *Submission* 3a, p.23 (Western Australian Government).

[85] AIHW, *Disability and Disability Services in Australia – based on an extract of Australia's Welfare 2005,* Canberra 2006, p. 4.

Table 3.3: Funding equity in relation to potential population



Source: Western Australian Government, *Submission* 3a, p.23.

3.114 The current distribution of Commonwealth funding is based on historical arrangements present during the first CSDA. During the negotiations for the current CSTDA parties considered solutions for a more equitable distribution of Commonwealth funding. The Western Australian Government commented:

> …Ministers considered options for an accelerated equity formula. The Commonwealth Minister took the position that they would allocate their growth funds on whatever equity funding formula agreed to by States/Territories. Ultimately, agreement was not reached, and the overall distribution of funding to the States and Territories has remained inequitable. The Commonwealth was not prepared to provide additional funding to address the equity issue.[86]

3.115 The Northern Territory Government also identified funding equity issues in relation to other factors, such as the costs of service delivery:

> 29% of the Northern Territory population are Aboriginal…Australian Institute of Health of Welfare (AIHW) estimates indicate the Aboriginal people are 2.4 times as likely to have a severe or profound disability as non-Indigenous Australians…The Northern Territory also has the largest population of people living in extremely remote settings…The highly

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[86] *Submission* 3a, p.25 (Western Australian Government).

> dispersed nature of the population, particularly for those with the greatest need, substantially increases the cost of service delivery in the Northern Territory.[87]

Possible solutions

3.116 The Western Australian Government argued that certain principles should be adhered to in any solution to address inequity in the distribution of Commonwealth CSTDA funding:

> The core principle underlying a move towards equity must be to recognise that this is funding used to provide services to individuals and that no Australian with a disability should be disadvantaged on the sole basis of the jurisdiction they reside in.
>
> The second principle is that no state or territory should receive a lower proportion of funds than is appropriate for their population. In the case of South Australia and Tasmania this may mean that the level of funding they receive may be the level necessary and thus should not be reduced.[88]

These principles suggest a solution of the 'making the pie bigger', by providing an increased proportion new funding to States and Territories currently receiving less than the proportion indicated by their potential population. However there were also concerns raised about this approach. The Tasmanian Government noted there was a risk that jurisdictions may 'increase the number of clients that they provide a service for by simply allowing people into the system who have very low levels of support'.[89]

> We are not against anyone getting their fair share, but you can build that into future growth components and then simply try to equalise it over the next five years.[90]

3.117 An argument also discussed was that providing additional Commonwealth funding to States and Territories which are providing inadequate levels of disability services or which have historically provided inadequate funding could be perceived as rewarding underperformance. An alternative model raised also discussed which would match additional funding for disability services by State and Territory governments over a base funding level. This would reward jurisdictions which provided additional funds for specialist disability services. For example Dr Baker of ACROD commented:

> Ultimately I would not want to see any service user in any state disadvantaged by that process, but at present I think the situation is inequitable… it reinforces low performance by state governments because the Commonwealth is providing proportionately more funding to states where state government funding is low. I think the Commonwealth should

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[87] *Submission* 106, p.2 (Northern Territory Government).

[88] *Submission* 3a, p.25 (Western Australian Government).

[89] *Committee Hansard* 22.11.06, p.3 (Tasmanian Government).

[90] Committee Hansard 22.11.06, p.4 (Tasmanian Government).

> be doing the opposite. It should be, if anything, rewarding high-performing or high-funding states.[91]

3.118 The Committee's view is that there should be a balance in the next CSTDA between providing a base level of funding for specialist disability services and allowing governments a measure of flexibility to make agreements to provide additional funding for priority areas. The Committee is sympathetic to the principles outlined by the Western Australian Government as applied to based funding, however there should also be opportunities for governments to establish incentives for other jurisdictions to provide additional funding for specialist disability services, for example by seeking matched funding for specific initiatives of that government. Matched funding agreements have been an efficient mechanism to provide incentive for governments to commit additional funding to services.

Recommendation 11

3.119 That the Commonwealth have responsibility in the lead up to the next CSTDA for developing an equitable distribution formula of Commonwealth base funding which takes into account differences between States and Territories in terms of potential population and costs of service delivery.

Recommendation 12

3.120 That, in addition to that funding "platform", arrangements be put in place to allow specific services or programs to be initiated on the basis of cost-sharing or matched funding between the Commonwealth and particular State and Territory governments which commit additional funding for specialist disability services.

Performance monitoring and reporting

3.121 There are three main performance reporting arrangements under the CSTDA:

- the CSTDA National Minimum Data Set (NMDS) and associated data collection arrangements;
- annual reporting between governments on funding spent and progress and achievements in implementing strategies to address national policy priorities; and
- the CSTDA Annual Public Report commissioned by the National Disability Administrators listing the progress and achievements in implementing national policy priorities.[92]

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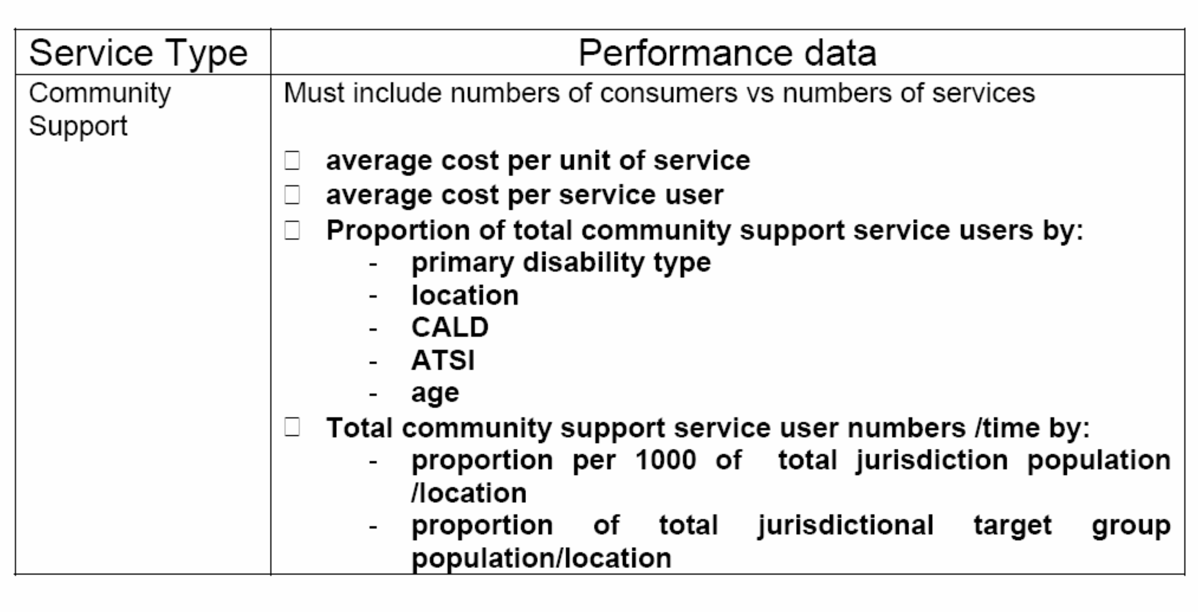
[91] *Committee Hansard* 13.10.06, p.41 (ACROD).

[92] National Disability Administrators, *Commonwealth State Territory Disability Agreement Annual Public Report 2004-05*, August 2006.

3.122 Schedule A3 of the CSTDA provides for the form of performance reporting against the major areas of disability services being provided – accommodation support, community support, community access, respite, open employment and supported employment – see Table 3.4 for an example of the performance data required. The performance indicators are largely similar for each area of disability services and consist of efficiency measures and equity measures.

Table 3.4: Example of CSTDA performance data requirements



Service Type	Performance data
Community Support	Must include numbers of consumers vs numbers of services ☐ **average cost per unit of service** ☐ **average cost per service user** ☐ **Proportion of total community support service users by:** - **primary disability type** - **location** - **CALD** - **ATSI** - **age** ☐ **Total community support service user numbers /time by:** - **proportion per 1000 of total jurisdiction population /location** - **proportion of total jurisdictional target group population/location**

Source: Commonwealth State Territory Disability Agreement 2002-2007, Schedule A3.

3.123 In 2005 the Australian National Audit Office (ANAO) undertook a performance audit of the (then) Department of Family and Community Services' role in the CSTDA. The audit report noted that the objective of the CSTDA to 'enhance the quality of life experience by people with disabilities through assisting them to live as valued and participating members of the community' was not reflected in the performance management framework.

> …the performance information framework contained in the CSTDA includes no indicators of the quality of life of people with disabilities, their participation in the community, their value in the community, or any related parameters, despite the objective directly aimed at enhancing quality of life. Therefore, the performance information framework contained in the Multilateral CSTDA does not require the collection of data that can clearly indicate whether, or to what extent, the CSTDA is meeting its objective.[93]

3.124 This criticism was repeated in a number of submissions the Committee received. For example, the Australian Federation of Disability Organisations commented on the limitations of the current performance management model.

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[93] ANAO, *Administration of the Commonwealth States Territory Disability Agreement*, Audit Report No. 14 2005 -2006, p.42.

> If you think about the way that the CSTDA is currently assessed, it is a real counting exercise: how many people have you seen? It is supposed to assess the objective of the CSTDA, which is: have we made the lives of people better? There is nothing about counting how many people who have access to services that tells you anything about whether people's lives are better.[94]

3.125 The ANAO audit made five recommendations focusing on improvements in performance measures and reporting requirements all of which were accepted by FaCSIA. However FaCSIA has stated that while there has been progress in implementing the ANAO's recommendations 'because states and territories are responsible for the delivery of specialist disability services other then employment, improvements in performance reporting will require input and agreement from state and territory governments.' FaCSIA have indicated that these issues will be part of the negotiations for next agreement.[95] The ANAO Report noted long-standing problems in reconciling State and Territory commitments under the CSTDA with State and Territory Budget appropriations and reporting in annual reports.[96] The challenges in relation to obtaining performance data comparable between the jurisdictions are well recognised.[97]

Input controls

3.126 State and Territory Governments raised concerns that the structure of the CSTDA was too focused on input controls reducing the flexibility of governments and service providers to address local issues.[98]

3.127 The current CSTDA defines the specialist disability services funded under the agreement into a number of categories, such as community support services. Services with a specialist clinical focus and non-specialist services are outside of the agreement.[99] Funds made available may only be utilised for the provision of specialist disability services covered under the Agreement or a Bilateral Agreement.[100] However other specialist disability services may also be included under the agreement where the Commonwealth and States/Territories agree.

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[94] *Committee Hansard* 6.10.06, p.7 (AFDO).

[95] *Submission* 96, p.12 (Australian Government).

[96] ANAO, *Administration of the Commonwealth State Territory Disability Agreement,* Audit Report 14 2005-2006, p.82.

[97] Monro D, 'The Role of Performance Measures in a Federal-State Context: The Examples of Housing and Disability Services' 62 (1) *Australian Journal of Public Administration*, March 2003 pp.70-79.

[98] *Committee Hansard* 22.11.06, p5 (Tasmanian Government); *Submission* 112, p.6 (Queensland Government); *Submission* 3, p.20 (Western Australian Government).

[99] *Commonwealth State Territory Disability Agreement 2002-2007,* Part 5.

[100] *Commonwealth State Territory Disability Agreement 2002-2007,* Part 8 (2).

3.128 The Queensland Government commented:

> The input control process requires the matching new funds to programs, resulting in a service system that is rigid and requires people to fit the programs instead of providing services that are needs based…Given the five-year term of the CSTDA, flexibility is needed to promote service improvement and innovation in relation to local priorities, and to promote the capacity to develop responses to emerging issues. The CSTDA was developed in such a way as to "rope" all funds into expenditure on six service types only. This is proving limiting to Queensland's ability to be more responsive and innovative.[101]

The burden of accountability

3.129 The Western Australian Government noted that performance monitoring and accountability regimes also need to appropriately balance the relative size of both parties' contributions.

> An acceptance of shared responsibilities by the States and Territories should not be taken by the Australian Government as an invitation to exercise disproportionate control over policy direction in the disability services sector. As this submission has shown, the proportion of the Australian Government contribution to the sector, particularly in Western Australia, has shrunk. Despite this, the Australian Government has sought ever higher levels of control over both administration and policy of the State’s and Territory’s disability services.[102]

3.130 The NSW Government highlighted that while the current CSTDA does not include incentives and targets, it does contain potential penalties for the State and Territory Governments whereby the Commonwealth Government can withhold payments if reporting requirements are not met.[103] The NSW Government commented:

> The move to include incentives, sanctions and targets in SPP Agreements needs to recognise the recommendations by the Australian Parliament’s Joint Committee of Public Accounts and Audit that financial accountability requirements for SPPs should be as streamlined as possible, to improve administrative efficiency and to avoid duplication between Commonwealth and State and Territory Auditors–General.[104]

Outcomes and quality based performance framework

3.131 The current CSTDA NMDS does not include measure or indicators of individual outcomes or quality of life. The Committee noted broad support of an

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[101] *Submission* 112, p.6 (Queensland Government).

[102] *Submission* 3a, p.30 (Western Australian Government).

[103] *Submission* 84, p.9 (New South Wales Government).

[104] *Submission* 84, p.9 (New South Wales Government).

increased role of outcomes and quality based performance measures in the next CSTDA.[105] These changes appear to be a priority for governments going into the negotiations for the next agreement. FaCSIA noted that:

> …despite advances in transparency and accountability under the current CSTDA, further work is needed to augment the current input controls and output reportings with an outcomes reporting framework. An outcome reporting framework will enable us to look at performance in a meaningful way and assess what outcomes are being achieved for people with a disability.[106]

3.132 There appear to be challenges in developing a realistic outcome and quality framework which gathers meaningful performance data and does not impose administrative burdens on service providers. [107] Nonetheless ACROD commented:

> Quality monitoring has focused more on processes and systems than on quality-of-life outcomes for service users. This should change...While measuring quality of life outcomes for service users poses challenges (and invites scepticism from some commentators), there are several existing designs which claim to do it well. Measurement systems should include subjective and objective dimensions, be administratively simple for governments and service providers and closely involve service users[108]

3.133 AIHW noted the methods for collecting data on measures or indicators of individual outcomes and quality of life were the subject of extensive work during the redevelopment of the CSTDA NMDS in 1999-2000. A proposed participation module was designed to collate information collected from service providers and users into a common framework for national comparison. The AIHW commented:

> Improved information about outcomes for service users would inform the objectives of the CSTDA itself. For example, it would be possible to explore the extent to which CSTDA service users participate in a broad range of life areas such as recreation, communication with family and friends, employment or education and how they (and their carers and advocates) rate their satisfaction with this level of participation.[109]

Recommendation 13

3.134 That realistic outcomes based performance reporting requirements be added to the CSTDA.

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[105] ANAO, *Administration of the Commonwealth State Territory Disability Agreement*, Audit Report 14 2005-2006, p.42.

[106] *Committee Hansard* 13.10.06, p.80 (FaCSIA).

[107] AIHW, *Disability and Disability Services in Australia – based on an extract of Australia's Welfare 2005*, Canberra 2006, p.46.

[108] ANAO, *Administration of the Commonwealth State Territory Disability Agreement*, Audit Report 14 2005-2006, pp.15-16.

[109] *Submission* 65a, p.4 (AIHW).

Recommendation 14

3.135 That the Commonwealth take the lead in developing consistent cross-jurisdictional performance monitoring and reporting of specialist disability services to promote greater coordination and accountability between jurisdictions.

CHAPTER 4

UNMET NEED

> The CSTDA has specified the shared responsibility of governments in making demand adjustments. It is the view of the Office [of the Public Advocate] 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.[1]

4.1 Unmet need for disability services has been an issue for many years. Service providers, support and advocacy groups and individuals can provide countless instances where a person with a disability either has had no access to the services they require or has access to services which meet their needs only to a limited extent. The areas where needs are not being met include accommodation services, respite services, in-home care and supply of equipment and aids. A range of studies provide estimates of the level of unmet need including Australian Bureau of Statistic (ABS) surveys and reports from the Australian Institute of Health and Welfare (AIHW). These are discussed below.

4.2 Unmet need became a priority for government under the second CSDA with the Commonwealth offering the States and Territories $150 million over the last two years of the Agreement to help the States and Territories address unmet need for services. The Commonwealth provided the additional funding on the proviso that the States and Territories contributed a similar amount. The States and Territories contributed $366 million over the two years. The Commonwealth continued the funding in the third Agreement.[2]

4.3 Under Bilateral Agreements with the Commonwealth in 2000, all jurisdictions were funded to 'help address unmet needs by providing additional services which enable people with disabilities who have ageing carers to remain supported within their families in their local communities'. The Bilateral Agreements also noted that the 'State's contribution will be used to assist in addressing other priority areas of unmet need'. These other priority areas were not specified in the Bilateral Agreements. The effectiveness of the unmet need funding was evaluated in 2002 by the AIHW. This is discussed below.

4.4 Even with this substantial additional funding, significant levels of unmet need remain. State and Territory Governments argue that they lack the capacity to provide

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[1] *Submission* 94, p.10 (Office of the Public Advocate, Victoria).

[2] *Submission* 96, p.8 (Australian Government).

further resources. The Commonwealth, while acknowledging there is still a level of unmet need, has stated that the 'data collected and made available by the States and Territories does not allow an accurate assessment of the level and nature of this need'.[3]

4.5 The Committee does not accept this buckpassing between jurisdictions and considers that a much greater and better-resourced effort is required to address unmet need by all jurisdictions.

Disability support services

4.6 Services provided under the CSTDA are targeted at people with a need for ongoing support in everyday activities and aim to 'maximise the opportunity for people with disabilities to participate socially and economically in the community'. The 2002-2007 Agreement specifies that a disability experienced by a CSTDA service user should be manifest before the age of 65 years. The AIHW noted that services do not generally place upper age restrictions on their clients.

4.7 National data on services provided under the CSTDA are collected through the CSTDA National Minimum Data Set (NMDS). The following provides a brief overview of the size and scope of the disabled population in Australia and the utilisation of services for 2004-05:

- approximately 4 per cent of the population (697,124 people) aged less than 65 years have the potential to require CSTDA-funded services at some time;
- 200,493 service users accessed CSTDA-funded services during 2004-05;
- 46 per cent of service users accessed community support, 32 per cent employment services, 22 per cent community access, 17 per cent accessed accommodation support services, 12 per cent accessed respite services;
- 41 per cent of CSTDA service users had an intellectual disability;
- 3.1 per cent of CSTDA service users were identified as being of Aboriginal or Torres Strait Islander origin;
- around 18 per cent of CSTDA service users reported that they received individualised funding with those in respite and employment services most likely to report that they received such funding;
- 29 per cent of users accessed services from two or more CSTDA-funded service groups; and
- 42 per cent of users indicated that they had an informal carer.[4]

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[3] *Submission* 96, p.10 (Australian Government).

[4] AIHW, *Disability support services 2004-05: National data on services provided under the Commonwealth State/Territory Disability Agreement*, August 2006.

Assessments of unmet need

4.8 In 1998 the ABS Survey of Disability, Ageing and Carers showed that 956,600 people with a profound or severe disability needed assistance with the core activities of self care, mobility and/or communication. The major proportion of these (97 per cent) received some assistance to meet their need for help with core activities with 57 per cent indicating that they had their need for assistance fully met, 40 per cent needed more help than they actually received and 3 per cent (24,400) received no help at all. For carers, the ABS indicated that 42 per cent of primary carers did not need any assistance, 25 per cent of primary carers did not get enough help and 9 per cent of primary carers who needed help did not receive any assistance.[5]

4.9 The AIHW has published a number of reports on the demand for disability services. In 1997, the AIHW reported on a study to provide estimates of unmet demand for accommodation and support, respite and day programs, the cost to government of meeting unmet demand and project growth in demand for specialist disability services.

4.10 The AIHW estimated that in 1996 there were 13,400 people aged 5-64 years who experienced an unmet need for accommodation, support and respite services. There was also an unmet demand by an estimated 12,000 people (or full-time-equivalent places) for day programs in 1996. The AIHW commented that these estimates for accommodation and support and respite were considered to be conservative because the estimates excluded certain groups including those in 'health establishments' (some 19,000 in 1993 in hospitals, nursing homes and other institutions) and children under 5 years of age and because growth factors were placing ongoing pressure on services, chiefly the ageing of clients and their carers. Day program estimates were also considered to be conservative for several reasons including that they excluded certain groups such as people with severe handicap who needed assistance sometimes rather than always and people who were employed part-time; it was assumed that there was no growth in total demand since 1993; and no additional services were offered to current program users.[6]

4.11 The AIHW concluded that projected demographic trends, particularly population ageing, would result in a substantial projected increase in the number of people in the CSDA target group for the period 1997-2003. The ageing of carers was seen as continuing to be an important issue, while the ongoing trends in de-institutionalisation would continue to place pressure on families and community-based services.[7]

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[5] ABS, *Survey of Disability, Ageing and Carers 1999.*

[6] AIHW, *Demand for disability support services in Australia: size, cost and growth*, 1997, p.viii.

[7] AIHW, *Demand for disability support services in Australia: size, cost and growth*, 1997, pp.xi-xii.

4.12 In 2001 the National Disability Administrators (NDA) commissioned the AIHW to update the 1997 report, to examine the effectiveness of the unmet need funding provided to States and Territories in the last two years of the second CSDA and to estimate any remaining shortfalls. The AIHW reported in 2002 and found that the unmet need funding had been effective in putting services on the ground.[8] Those services which focused on flexibility, the use of individual packages and local area coordination mechanisms were viewed positively.

4.13 However, the AIHW reported that quantifying or tracking the use of the additional services resulting from the unmet need funding was not easy. The AIHW found that jurisdictions differed in the application of the unmet need funding, the speed and method of the rollout, the information they could provide and the extent to which the unmet need funding and its application were identifiable in administrative systems and processes. Information requested by AIHW in its survey of jurisdictions could not be provided by all jurisdictions. In addition, the Bilateral Agreements were not accompanied by consistent agreements about acquittal and reporting to the Commonwealth and some of the reporting agreements had not yet been fulfilled.

4.14 The AIHW concluded that the full impact of the new funding would not be apparent in client outputs until 2002-03. As to unmet need in 2001, the AIHW estimated that:

- 12,500 people needed accommodation and respite services;
- 8,200 places for community access services were needed; and
- 5,400 people needed employment support.[9]

4.15 The AIHW stated that it had made these estimates on a conservative basis, with the aim of providing reliable 'lower bound' estimates. In addition, the estimates did not represent the sum total of unmet need for CSDA services as community support services were not included in the project brief. Other evidence also suggested further unmet need:

- some 5,300 older carers in the target group of the Bilateral Agreements had either never received respite and wanted it, or had received it in the previous three months and wanted more;
- most new services were provided to people with urgent needs;
- there appeared to be between 6 and 24 times more people seeking services and on jurisdiction registration or waiting lists in 2000-01 than were removed from these lists; and
- anecdotal evidence pointed to community knowledge of waiting lists was possibly dampening the numbers of applications.

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[8] AIHW, *Unmet need for disability services: Effectiveness of funding and remaining shortfalls,* July 2002.

[9] AIHW, *Unmet need for disability services,* p.xxi.

4.16 The AIHW again identified a range of issues which suggested that the overall service system for people with disabilities was under pressure. These issues included the ageing of the CSDA broad target group; the number of people with disability aged under 65 years living in residential aged care; the high numbers of people with disabilities using services for the homeless; transport needs are not part of disability services; and systems for the provision of equipment appear to be nationally fragmented.

4.17 In addition to the AIHW's comments on the conservative nature of its estimates other witnesses pointed to shortcomings in the estimation of unmet need. ACROD noted that the AIHW study did not consider under-met need or needs being inappropriately met.[10] The National Council on Intellectual Disability argued that the full extent of unmet need will never be known as most States and Territories do not keep waiting lists or needs registers and 'therefore it becomes impossible to determine how many people need support and what they need support for'.[11]

4.18 Witnesses also noted that a people funded under a range of insurance and compensation schemes for injuries or disabilities arising from motor vehicles or work accidents and people with disabilities receiving funding through the Department of Veterans' Affairs sit outside the CSTDA arrangements. In addition, people with disabilities who receive damages obtained through the courts under public liability actions are funded independently of any Commonwealth, State or CSTDA funding arrangements. Ms Raelene West commented that the failure to include these disability services within the structure of the CSTDAs has 'distorted the view of how disability service delivery is truly funded (or not funded) across Australia, failing to provide an adequate picture as to many inequities in funding that exist across the entire disability sector, not just within the CSTDA arrangements'.[12]

4.19 In 2005, the AIHW was commissioned to update its analysis of unmet need. The AIHW indicated that the final report was due at the end of February 2007.[13]

Disability services data

> …we do not have reliable data about the level of need. We know it is massive and that it is growing, but we simply cannot identify accurately enough to project what we need to do in the future.[14]

4.20 At the core of any analysis is the reliability of the data used. In the context of disability services, the difficulties of obtaining reliable and comparable data from eight jurisdictions have been acknowledged and improvements have been undertaken.

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[10] *Submission* 45, p.6 (ACROD).

[11] *Submission* 50, p.8 (National Council on Intellectual Disability).

[12] *Submission* 44, p.24 (Ms R West).

[13] *Committee Hansard* 13.10.06, p.51 (AIHW).

[14] *Committee Hansard* 28.9.06, p.4 (YPINHNA).

CSDA Minimum Data Set

4.21 Following the signing of the first CSDA, the AIHW was requested to assist in the development of an agreed Minium Data Set (MDS) for CSDA-funded services. The AIHW noted that while the need for relatable data on disability had been recognised for some time, there were major difficulties in bringing the data together including the use of varying definitions and terminology.

4.22 The MDS was developed as an agreed set of data items and for each data item an agreed definition to be applied across all CSDA-funded services. From 1994, the CSDA Minimum Dataset provided funding bodies, funded agencies (service providers), service users and other stakeholders with information about services delivered under the CSDA and the people receiving those services. The information was collected on one snapshot day in the year.

CSTDA National Minimum Data Set

4.23 In 1999, the NDA and the AIHW undertook a review and redevelopment of the CSDA MDS collection. The redeveloped collection, referred to as the CSTDA National Minimum Data Set (NMDS), was fully implemented nationally in October 2002. The first collection period for the CSTDA NMDS was for the six months commencing on 1 January 2003.

4.24 The CSTDA NMDS has an agreed set of data items of national significance and an agreed framework for collection. Data items relate to equity, efficiency and effectiveness of services and is collected throughout the year from funded agencies about all service users. Not all agencies provide the same level of data: accommodation and community support services provide all data items relating to service users whereas recreation or holiday program providers provide only minimal information. Services such as advocacy and print services are not required to provide service user details.

4.25 Items on informal carers were introduced in the CSTDA NMDS. This is in recognition of the mutual support among people with a disability, informal carers and formal services, and the fact that program goals are recognising, in particular, the importance of ageing carers.

4.26 In specifying revised core data items for ongoing collection by all service providers funded under the CSTDA, the CSTDA NMDS:

- aims to meet critical data needs across the disability field, and to be consistent with other major data developments, such as the HACC MDS;
- integrates data collation with the operation of agencies and funding departments;
- uses statistical linkage keys to enable data from various sources to be related and collated without duplication; and

- uses statistical linkage keys to account for double counting of service users.[15]

Improvements in datasets

4.27 The AIHW noted that disability data has improved and pointed to a number of major developments:

- the National Aboriginal and Torres Strait Islander Survey 2002 provided information on Indigenous disability;
- the first full year of the redeveloped CSTDA NMDS collection provided a new benchmark collection on disability services for future reference;
- a disability question was included in the 2006 Australian Census;
- the AIHW is continuing to work on the implementation of the International Classifications of Functioning, Disability and Health (ICF); and
- there is increasing adoption of national data standards, based on the ICF, in administrative data collection.

4.28 The AIHW commented that these developments will provide improved infrastructure for disability identification in generic services, enabling access to, and outcomes from, these services to be monitored. Some of the initiatives will be challenging, 'particularly when they involve bringing a newer and more holistic conceptualisation of disability into the sphere of health surveys and information systems and into the plethora of assessment scales now used in human services fields in Australia'. The AIHW concluded that:

> The long-term vision is that, with more consistent approaches to disability data across the spectrum of human services, the resulting 'joined up' data will support whole-of-government approaches to the provision of services relevant to people with a disability.[16]

4.29 In response to the Committee's invitation to indicate further areas of improvement in data collection, the AIHW stated that:

> …we do not have an incredibly good handle on what goes on within some states. There seems to be a differential across states and territories in terms of how well needs are met and how well even reporting is done. I think it would be good to be able to ensure that, when we put the national together, we are getting a true picture of what is happening within each of the jurisdictions. We are pretty reliant on what is provided to us at a jurisdictional level.[17]

4.30 The *Report on Government Services 2006* addressed the issue of data collection in the jurisdictions. It indicated that the implementation of the CSTDA

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[15] *Report on Government Services 2006*, p.13.13.

[16] AIHW, *Australia's Welfare 2005*, pp.209-210.

[17] *Committee Hansard* 13.10.06, p.53 (AIHW).

NMDS 'has led to some data quality issues'. In particular, the proportion of service users and service outlets that provided data and the 'not stated' rates of particular data items vary across jurisdictions.[18] The Department of Families, Community Services and Indigenous Affairs (FaCSIA) also noted inconsistencies in the way that service data is collected across jurisdictions as some jurisdictions were unwilling to commit to the level of data collection proposed prior to the last agreement. There is not a common assessment platform across jurisdictions, which means the nature of the data collected by services at the point of assessment also differs.[19]

4.31 The NSW Government noted that data collection response rates were poor in NSW. The Government indicated that it was now assisting service providers to return data and to improve the quality of the data including the use of continuous electronic collection rather than a yearly census.[20]

4.32 ACROD commented on the need to improve data sets to guide and service planning in order to make meaningful comparisons across jurisdictions. For example, 2003-04 data suggest that community access expenditure per client varies from $18,002 in NSW to $2,004 in Western Australia. ACROD commented that at least some of this difference reflects variations in the response rates between the States, the inclusion of disparate service models in the community access category and varying hours of service per client.

4.33 ACROD concluded that the CSTDA should provide a planning framework for the provision of disability services across Australia, one that takes into account demographic changes, future service needs, the changing expectations of service users and carers, the capacity of service providers and other relevant factors. However, this planning framework will require an improvement in the quantity and quality of data collected.[21]

4.34 Other shortcomings identified in the data collected included that it was based on a 'one size fits all' mentality and collected data primarily around personal care. As a result the specific needs of people who are blind or vision impaired around mobility, transport and access to print are not collected at all. Further, data is only collected from funded services and not from organisations such as the Royal Society for the Blind which provide services which are vital to independence.[22]

4.35 MS Australia noted that reporting has improved and pointed to the protocols such as Quarterly Data Collection. However, currently the data collection system used by CSTDA departments cannot discriminate between new entrants and existing clients

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[18] *Report on Government Services 2006*, p.13.12.

[19] *Committee Hansard* 13.10.06, p.83 (FACSIA).

[20] *Committee Hansard* 3.10.06, p.46 (NSW Government).

[21] *Submission* 45, p.11 (ACROD).

[22] *Committee Hansard* 6.10.06, pp.43-44 (RSBSA).

so there is no measure on how quickly waiting lists can be cleared, or what happens to people while they wait. MS Australia also argued that the data collection is aimed at addressing the Commonwealth's need for accountability and that it does not measure the quality of the service interaction or report any outcomes. MS Australia called for outcome measures, including, but not limited to, counting the number of people serviced. MS Australia concluded:

> Decent planning cannot occur without good data, and the lack of data is a major barrier to progress in the sector. There clearly needs to be a better way of working out the future resourcing of disability services than what individual Ministers can squeeze out of treasury year by year by year.
>
> The next CSTDA should have mechanisms to measure the jurisdictions performance on a number of outcome measures, including, but not limited to counting the number of people serviced, numbers needing particular services and an actuarial measure of the future demand and costs of the suite of services from early intervention through to aged care.[23]

4.36 The Office of the Public Advocate Victoria also voiced concern about the narrowness of the datasets:

> 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.[24]

4.37 The Office of the Public Advocate argued that it was meaningless to talk about numbers of service users when what is really needed is an outcome based measure of how successful is the delivery of services. While outcomes are more difficult to measure, there has been progress in some areas, for example in relation to support accommodation for people with intellectual disability where outcome based reporting is achieved by having personal plans for residents.[25] The Public Advocate concluded that:

> 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.[26]

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[23] *Submission* 93, p.12 (MS Australia).

[24] *Submission* 94, p.7 (Office of the Public Advocate); see also *Committee Hansard* 28.9.06, p.56 (Office of the Public Advocate).

[25] *Committee Hansard* 28.9.06, p.59 (Office of the Public Advocate).

[26] *Submission* 94, p.7 (Office of the Public Advocate).

4.38 The NSW Government commented that if there is an outcomes based CSTDA then comparative data would be required. However, a broader view of effort and investment in disability could be taken to consider broader outcome indicators, such as the number of people who are employed, the number of people who are participating in various activities and the percentage of families who are able to stay together. The NSW Government commented that 'maybe there is a debate to be had about whether we want the CSTDA performance indicators to report only on the activity covered by the agreement or whether we want to take a broader look at what is happening for people with a disability and how we measure the success of that' and concluded:

> They are two different directions. Whether they could come together in an agreement like this I am not sure, but I understand and have some sympathy with the view that we need to take a broader look at what the outcomes are rather than just having some accountability for the outputs that the money is buying within the agreement.[27]

4.39 The Tasmanian Government also raised some concern about the cost of providing outcome data:

> There is also a need to get the balance between providing really good outcome data and the cost. Everyone agrees that we do need good evaluation data but we have to balance that against what that is going to cost and whether that money could be used for other purposes. Keeping it to a minimal set of outcomes is another important point; we need to ensure that we do not get swamped by the whole accountability agenda.[28]

4.40 The AIHW indicated that data on outcomes for individuals was to be included in the existing minimum dataset but was abandoned. AIHW stated that although it is difficult, there are guidelines in AIHW documentation of how information about outcomes could be collected consistently. As to why the collection of this data was abandoned, AIHW commented that practice varies across jurisdictions, and as improvements on the data sources were about to be undertaken, to also include this additional information on comparable outcome information might have seemed a very expensive task and burdensome to data providers.[29]

4.41 FaCSIA indicated that the there was a need to augment the current input control and output reporting with an outcomes reporting framework.[30] This could be undertaken at the service provider level or through a survey. FaCSIA concluded:

> The issue with looking at the collection at the service provider level…is the difficulty services face already in providing and collecting data. That is a set of discussions we need to have with the states and territories – and with

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[27] *Committee Hansard* 3.10.06, p.48 (NSW Government).

[28] *Committee Hansard* 22.11.06, p.5 (Tasmanian Government).

[29] *Committee Hansard* 13.10.06, p.53 (AIHW).

[30] *Committee Hansard* 13.1.0.06, p.80 (FaCSIA).

> the [AIHW], to get their advice on the best way to move forward. But the minister does think it is important to more clearly measure whether or not the services we are purchasing are getting the outcomes we expect that they should get for people.[31]

Conclusion

4.42 The Committee notes the significant improvements that have been made in the data collection for disability services. However, there are still gaps and inconsistencies in the datasets. The collection of accurate data and the timely remittance of that data involve administrative time and costs for service providers and the Committee welcomes the initiatives undertaken by the State and Territory Governments to assist service providers to remit accurate data.

4.43 The Committee is also supportive of further research being undertaken on the datasets which are currently available as this would provide much more information to assist planning of disability services. As the AIHW pointed out there is potential for further detailed analysis, however additional funds are required for this work to be undertaken. The need for data on outcomes was a major concern raised by witnesses. The Committee also considers that it is a fundamental flaw in the datasets for disability services to not be able to identify if the aims of one of the major programs of government are being achieved.

Recommendation 15

4.44 That additional funding be made available under the next CSTDA to:

- **enable further analysis using the CSTDA data collections, to better inform policy makers and the public about the effectiveness of disability services; and**
- **enable jurisdictions and service providers to improve CSTDA NMDS data.**

Recommendation 16

4.45 That the Commonwealth ensure that outcomes data is included in the CSTDA National Minimum Dataset.

Continuing unmet need

> In my experience of people with disabilities who access CSTDA funds there is a feeling of hopelessness in the sector which is leading to a great underestimate of the degree of the unmet need and I reiterate that the national minimum data set really only measures the services delivered and ignores what is needed.[32]

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[31] *Committee Hansard* 13.1.0.06, p.83 (FaCSIA).

[32] *Committee Hansard* 13.10.06, p.26 (WWDA).

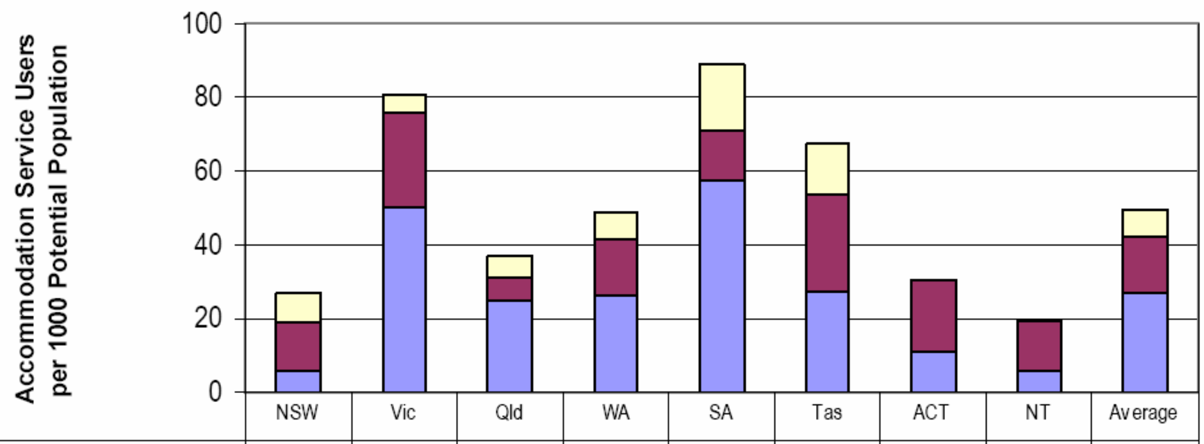
4.46 As noted above, the AIHW 2001 study identified a high level of unmet need. While governments have responded to increasing demand for specialist disability services, witnesses pointed to evidence of a growing gap between demand for disability services and the supply of those services. That gap is yet to be identified as the results of the current AIHW have not yet been released. However, evidence provided to the Committee goes some way to identifying the magnitude of the unmet need in the service areas covered by the CSTDA.

Accommodation support services

4.47 State and Territory Governments administer accommodation support services that provide support to people with a disability in accommodation settings (hostels, institutions and group homes) and the community (attendant care, personal care and in-home support). In total, 33,787 people received accommodation support services during 2004-05. More than half (56 per cent) received community based support to live in the community within their own or family home. A further 31 per cent were provided with accommodation in group homes and 14 per cent were provided with accommodation in institutions or hostels. Nationally, 4.8 per cent of the estimated potential population were using CSTDA funded accommodation support services in 2004-05.[33]

4.48 Figure 4.1 shows the use of accommodation support services across jurisdictions in 2004-05.

Figure 4.1: Service users of accommodation support services, per 1000 potential population, by service type category, by State/Territory, 2004-05



	NSW	Vic	Qld	WA	SA	Tas	ACT	NT	Average
□ Institutions & Hostels	8	5	6	7	18	14	-	-	7
■ Group Homes	13	26	6	16	13	26	20	14	15
■ Community Based Support	6	50	24	26	58	28	11	6	27
Total Accommodation	26	79	36	48	87	65	30	19	48

Source: National Disability Administrators, *CSTDA Annual Public Report 2004-05*, p.60.

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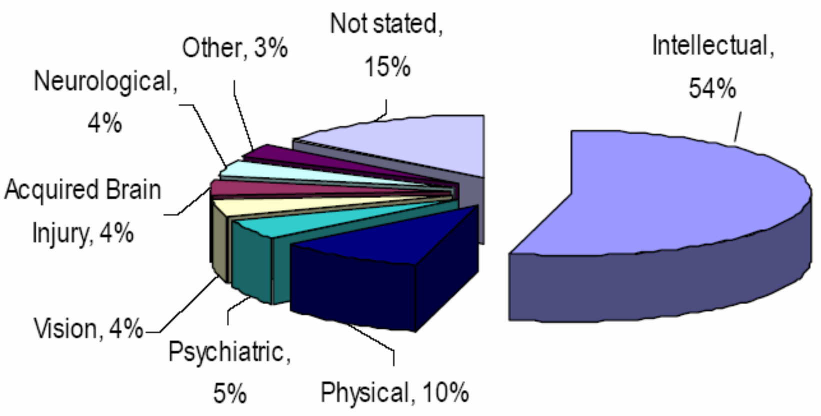
[33] *CSTDA Annual Public Report 2004-05*, p.60.

4.49 The average cost to government per accommodation support service user varies across categories, reflecting the different nature of services. The national average CSTDA expenditure for the year 2004-05:

- institutions and hostels: $82,389 per service user;
- group homes: $92,949 per service user; and
- community based support: $17,674 per service user.[34]

4.50 Figure 4.2 shows that the majority of accommodation support service users reported an intellectual disability as the primary disability.

Figure 4.2: Service users of accommodation support services, by primary disability group, 2004-05



- People reporting an intellectual disability as their primary disability (54%) represented the largest group using accommodation support services, followed by people with physical (10%) disabilities.
- For 15% of service users, their primary disability was not stated.

Source: AIHW 2006.

Service users of accommodation support were generally older than those using other CSTDA-funded service types. Over half (54%) of accommodation support service users were aged 40 years and over, including 13% aged 60 years and over. Only 7% were under 20 years of age.

Source: National Disability Administrators, *CSTDA Annual Public Report 2004-05,* p.61.

Identification of unmet need for accommodation services

4.51 While accommodation support services have been identified as the area of greatest unmet need, the estimation of the level of that need is complex. In its 2002 report, the AIHW reported that there were 12,500 people needing accommodation and respite services. However, many witnesses stated that this did not reveal the true level of unmet need as a number of significant factors were contributing to the underestimation of the need for accommodation services. **First**, many witnesses commented that significant numbers of people with disabilities whose unmet needs should be addressed by CSTDA funds do not apply or register for support and

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[34] *CSTDA Annual Public Report 2004-05,* p.69.

services because they know that it is unlikely that they will ever get into a priority position on a waiting list.[35]

4.52 **Secondly**, in some jurisdictions waiting lists are not kept so that there is no way of identifying the level of unmet need or indeed levels of under-met need. However, evidence was received about some waiting lists which provides a glimpse of the level of unmet need:

- in Victoria, the waiting list for shared accommodation and in-home and community support was almost 4,500 people;[36]
- in Victoria, there had been a 76 per cent increase in the number of people classified as urgent on the waiting list for support accommodation;[37]
- in Victoria, one in six people waiting for supported accommodation are cared for by family members aged 75 years and over;[38]
- in 2006, the South Australian Intellectual Disability Services Council had a waiting list for urgent accommodation for 2,200 people with intellectual disabilities;[39]
- in Western Australia, in relation to Accommodation Support Funding, unmet demand for 2005-06 was 276 unfunded applicants with a notional cost to meet unmet demand of $14.9 million.[40]

4.53 **Thirdly**, some people with disability are not included in unmet need calculations because they are regarded as being accommodated. However, witnesses pointed to the many types of unsuitable accommodation that may be used because essential support services for community integration are insufficient to meet the needs of people with disabilities. Types of inappropriate environments include hostels and boarding houses where services are few and people with a disability are more vulnerable to abuse and exploitation.[41] People with disabilities living in public housing fare little better:

> People with disabilities living in public housing experience isolation, harassment from neighbours, and often sheer fear of being assaulted and taunted. Many have no access to any other services, their flats decay, many feel too embarrassed to ask for help. These are the forgotten, but

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[35] *Submission* 40, p.5 (MNDA Vic); *Submission* 68, p.8 (DACSSA).

[36] *Submission* 45, p.6 (ACROD).

[37] Coalition for disability rights, *Call to political parties 2006 Victorian State Election*, p.5.

[38] Coalition for disability rights, *Call to political parties 2006 Victorian State Election*, p.10.

[39] *Submission* 68, p.7 (Disability Advocacy and Complaints Service of SA).

[40] *Submission* 3, p.21 (Western Australian Government).

[41] *Submission* 15, p.5 (WWDA).

> accommodated people with intellectual disabilities, for example, or recovering from mental health problems.[42]

4.54 The Committee also heard evidence of other groups of disabled people who may be seen as being accommodated but for whom the accommodation did not meet all their needs. Mr Patrick Eadington, a young person with cerebral palsy, informed the Committee that he lives in a unit designed for people with disabilities but he is socially isolated and has no on-going assistance. While there are group homes available these are mainly for people with intellectual disabilities and other people who cannot maintain an independent lifestyle, such as people with a degenerative disease. Mr Eadington stated that his personal preference is to be accommodated with other people with a similar disability but at the present time this is not an option even though there are a large number of people who are in a similar position to himself:

> You will find a huge amount of people with physical disabilities, particularly people who are 30-plus. Because you find the older they get the more support they need; not that they want support, but they accept that they need support. You will find a big backlog.[43]

4.55 The Young People in Nursing Homes National Alliance (YPINHNA) noted that younger people with disabilities living in the aged care system are not included in the AIHW's analysis of unmet need. However, while they are accommodated they live in inappropriate settings which do not provide adequate services to allow them lives of dignity and independence. YPINHNA noted that 70 per cent of those who receive CSTDA services have an intellectual disability while over 80 per cent of young people in aged care facilities have an acquired disability such as ABI, stroke or progressive neurological conditions. Supported accommodation is very limited for this group with only approximately 1.5 per cent of total expenditure on shared disability supported accommodation in Victoria being directed specifically for housing services for this group. YPINHNA went on to state that while it is administratively attractive to absorb this group into the disability system, 'this cannot be done because the services required simply do not exist'.[44]

4.56 MS Australia commented that the growth in the number of young people in aged care facilities 'is a direct expression of the incapacity of the disability system to absorb additional demand – particularly those people with high and urgent support needs'.[45]

4.57 **Fourthly**, the Committee heard evidence of the needs of particular groups for accommodation services that are not being met currently. WWDA voiced concerns for women with disabilities who have poor access to housing and are considered to be of

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[42] *Submission* 68, p.14 (Disability Advocacy and Complaints Service of SA).

[43] *Committee Hansard* 22.11.06, p.21 (Mr P Eadington).

[44] *Submission* 98, p.6 (YPINHNA); see also *Submission* 75, pp.1-2 (Inability Possibility).

[45] *Submission* 93, p.17 (MS Australia).

the highest risk for homelessness with data pointing to lower levels of CSTDA service usage by women. Women with disabilities are also at great risk of violence and are often forced to live in situations in which they are vulnerable to violence.[46]

4.58 People aged between 50 and 60 years also appear to have poorly serviced accommodation needs. Brightwater commented that there were restricted accommodation options for this group with a disability and that 'it is questionable whether age should be the main determining factor when assessing eligibility to participate in Disability accommodation funding rounds'.[47]

4.59 Young people in the acute hospital system with high support needs and complex care issues are another group which are often poorly identified. Families receive confusing information from outside agencies about the entitlements of these young people and which agency has major responsibility for their ultimate living option. The limited accommodation options that are available to these young people result in them being placed low on the priority list for disability funding.[48]

4.60 The Committee also received evidence on the accommodation needs of people with acquired brain injury (ABI). People with ABI who have high support needs have few choices in accommodation, due to the limited options. Some will end up in group homes, while others will be placed in a hostel. Often these facilities have been designed for a different cohort of people with a disability, for example people with an intellectual disability or mental illness. Staff of such facilities are generally unable to respond appropriately to the complex issues surrounding ABI. As a consequence, people with ABI are refused access because of the perceived complexity of their support requirements.[49]

4.61 Accommodation services also encompass support for those living at home or in the community. Evidence to the Committee indicated that these services are being spread very thinly, with few people accessing the level of services they require to maintain an independent lifestyle with the quality and dignity that they wish. MS Australia commented:

> We have noticed that the size of available care packages coming out of disability programs in some states (particularly Victoria) are getting progressively smaller as the demand on limited growth funds intensifies. Clearly, as in HACC, it appears that the position has been taken to spread available resources as thinly as possible over the largest group of people as a way of managing demand. While this meets the needs of some people,

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[46] *Submission* 15, p.8 (WWDA).

[47] *Submission* 22, p.3 (Brightwater Care Group).

[48] *Submission* 22, p.3 (Brightwater Care Group).

[49] *Submission* 80, p.8 (BIA).

> those who have high needs and progressive conditions have few, if any options.[50]

The Committee heard that the lack of attendant care services had led some people with disabilities to choose between having a meal or having a shower.[51]

The Human Face of Unmet Need

T. suffered brain damage through illness when he was 18 months old and was left with a severe intellectual disability. He is now 35 years old and lives with his parents who are 71 and 64 years old.

T.'s parents shower, shave, toilet and dress him each morning. He cannot go out without having someone with him and cannot be left alone at home even for 5 minutes. T.'s world revolves around his job with a local Supported Employment Service which he attends during the week from 9.30am to 3.00pm. He enjoys listening to music, watching television programmes and travelling on public transport.

T.'s parents are growing older and realise they will have difficulty in coping in the near future. T. has been on the waiting list for Supported Accommodation since 1998 (7 years). In 2001 he moved up to High priority classification and in 2003 he moved up to Urgent priority.

His parents know that T. will have a long transition period to his new home and want to be around to help and support him through what they know will be a difficult period for him.

Source: Submission 33, p.6 (CIDA (Vic))

4.62 Evidence was also provided indicating the difficulties faced by some groups, particularly those with a degenerative disease, in accessing adequate services in a timely way. People with a degenerative disability have intensive specialised care needs over a relatively short period of time: for example, approximately three years for people with Motor Neurone Disease, five or more years for people with Multiple Sclerosis. Some people with degenerative disability remain at home and access support packages. However, the degenerative nature of their condition means that accurate assessment of current and future care needs, while crucial, is a real challenge. People with degenerative conditions must 'line-up' to get access to services.

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[50] *Submission* 93, p.19 (MS Australia).

[51] *Submission* 15, p.8 (WWDA).

Client 44 – Is a sole parent of adolescent boys. Her MS has deteriorated significantly and she immediately requires assistance with personal care and meal preparation. In attempting to carry out these tasks she is experiencing falls and extremely high fatigue levels, which are putting her health and safety at risk. She requires assistance with showering, dressing/undressing, transfers and is having to rely increasingly on emergency services due to urinary and bowel accidents. Client 44 currently receives 13.5hrs per week for assistance with personal care and 7.5hrs for household tasks. She requires an additional 1.5 hrs per day with personal care in the evening, 2 hrs per week assistance with meal preparations and 2 hrs per week with household management. Client 44 has reported incidences of verbal abuse from her sons, which she attributes to their inability to come to terms with her condition and its deterioration. This client is at immediate risk of family breakdown and institutionalisation if the above supports are not put in place.

Source: Submission 88, p.9 (MS Australia of SA and NT)

4.63 Allowance for professional support is usually not factored into estimated cost of care, and is often calculated only at a care worker rate.[52] MS Australia reported that a number of HACC Linkages services in Victoria refuse to take people with progressive neurological conditions into their programs because they are expected to have escalating needs that will clog the program and put stress on their budgets and waiting lists.[53]

4.64 In some jurisdictions age impacts on the amount of in-home services provided. For example in Victoria, 'Home First' packages which can provide support up to 34 hours per week are open only to those under the age of 65 years.[54]

4.65 People with ABI are another group with specialist support needs who face difficulties in obtaining services. They require practical assistance to complete rehabilitation, develop social networks, obtain employment, and participate in their communities. Brain Injury Australia commented that given the complexity and diversity of the services that may be required (an average of over four different types, according to one recent study), it is unlikely that a single service provider can meet all the needs of a person with ABI. Brain Injury Australia supported cohesive, cross program strategies to ensure appropriate care and support is provided to those with ABI.[55]

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[52] *Submission* 22, p.2 (Brightwater Care Group); see also *Submission* 31, p.3 (MNDAA).

[53] *Submission* 93, p.11 (MS Australia).

[54] *Submission* 40, p.p.4 (MNDA Vic).

[55] *Submission* 80, p.8 (BIA).

Mother in mid 50s, caring for three members of her family. 15 year old son with severe intellectual and physical disabilities, needing PEG feeding every three hours, positioning in his wheelchair, bathing. He is unable to communicate and at night needs changing and repositioning in his bed. 21 year old son has kidney disease, he has had a kidney transplant but still needs dialysis three times pre week, and he is severely depressed and has tried to commit suicide once. Dad is undergoing treatment for cancer, and is so depressed will not come out of his bedroom. Mother applied for some in home support to allow her to spend time with he husband and other son. She was refused funding.

Source: Submission 66, p.2 (Committed about Securing Accommodation for People with Disabilities)

Options for accommodation services

4.66 The Western Australian Government argued that the Commonwealth was failing to assist with unmet need for accommodation services:

> The Australian Government has consistently refused to take any responsibility for funding of accommodation services, even when there are clear links between their funding priorities and the capacity of the states to meet the needs of carers and people with a disability. At the same time the Australian Government demands greater efforts on all fronts and the States and Territories are left with the dilemma of not being able to deliver the required level of services in areas that are important in the long term (such as early intervention) in order to meet basic but critical needs such as accommodation for people with high support needs.[56]

4.67 The Western Australian Government went on to comment that under the first CSDA there was agreement that funding and administrative responsibilities would be shared between both levels of government. It was understood that while the States had administrative responsibility for accommodation services, the Commonwealth would continue to make a solid contribution towards meeting the cost of State-administered services, particularly accommodation. The Government concluded 'it is of concern that increasingly the Australian Government appears to see accommodation, with its huge demand factors, as being solely a State funding responsibility'.[57]

4.68 Western Australia indicated that it had increased disability funding in 2006-07 by 11.7 per cent which would enable more people to receive disability services, including an additional 113 to receive accommodation support. The Western Australian Government concluded that 'the shortfall in Australian Government funding, compounded by Western Australia’s historical low equity share, means that people with disabilities continue to miss out on much-needed support, including accommodation'.[58]

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[56] *Submission* 3, pp.14-15 (Western Australian Government).

[57] *Submission* 3, p.21 (Western Australian Government).

[58] *Submission* 3, p.22 (Western Australian Government).

4.69 The Victorian Government commented that a commitment is needed from all levels of Government to pursue options for affordable housing. The Commonwealth needs to ensure that welfare payments in relation to rent assistance are sufficient to gain access to housing in the contemporary market as demand for low cost and affordable housing continues to grow.

4.70 The Victorian Government argued that central to managing unmet need is the provision of alternative accommodation options. Strategies should include options beyond traditional models of supported accommodation such as group homes and require tailored packages of support linked with housing options, the provision of early intervention and support for carers, and targeted strategies to promote skills development and participation of people with a disability to heighten independence. The capacity for group homes to support people with a disability using a more individualised approach and a greater emphasis on transition by encouraging more independence in the community needs to be explored, as do innovative service options.[59]

4.71 However the Commonwealth noted that accommodation is an area of State and Territory responsibility under the CSTDA. It also noted that 'poor data provided by the states and territories and delays in establishing new or expanded services with the additional funds provided to address unmet need, has meant that it is now difficult to determine whether the additional funding has effectively addressed the unmet need identified in the 2002 AIHW report'.[60] In its submission the Commonwealth also highlighted it also provides contributions to accommodation services through the Commonwealth State Housing Agreement and the Supported Accommodation Assistance Program. Approximately one quarter of people accessing these programs had disabilities.[61]

Respite services

> Long-term carers find that 'surviving' is a matter of taking time out for themselves. Part of this may just be taking time for a cuppa during each day but often longer breaks are needed. Respite care is an essential part of the overall support that families may need.[62]

4.72 The AIHW has estimated a potential population of 215,511 people who will require respite services at some time.[63] Evidence indicates that there are very high levels of unmet need in respite services. Many carers are unable to access the hours of respite they need and services are constantly juggling resources to try to meet client requirements.

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[59] *Submission* 99, p.12 (Victorian Government).

[60] Submission 96, p. 14 (Australian Government).

[61] Submission 96a, p. 10-11 (Australian Government).

[62] *Submission* 87, p.10 (Brain Injury Association of Tasmania).

[63] *CSTDA Annual Public Report 2004-05*, p.58.

4.73 Interchange Respite Care identified the main concerns with respite services as:

- services are difficult to access and the service system landscape seems to be fragmented and complex;
- availability of respite support is decreasing;
- service support needs to be flexible and responsive to meet individual needs; and
- many families and carers believe their future respite needs will only continue to increase.[64]

4.74 The shortage of respite places is exacerbated by other shortages in the disability sector, particularly long-term supported accommodation. Witnesses commented that in many respite services bed blocking occurs because there are no alternative long-term accommodation options available for people with disabilities. Such practices exacerbate the already desperate situations for some families who are only seeking some short-term respite but cannot do so because of the lack of places:

> We receive some respite which helps but respite has issues too, there is simply not enough! The beds are continually blocked and will continue to be so as more and more families go into crisis. This (respite) is where they put the children of those families. You must understand that by blocking the beds, families get less respite and consequently they too may go into crisis.[65]

4.75 The Western Australian Government welcomed the additional funding under the Older Carers Bilateral Agreement but stated that this agreement 'is implicit acknowledgment of the continued unmet need in disability services'. The Government, and other witnesses, argued that additional funds are required for long-term accommodation support. Respite care is also used to hide need in other areas including day programs and vacation care programs. Older carers are in great need and that 'for this group in particular, offering additional respite gave no sense of security or confidence that their loved one would be well cared for when they were no longer able to do so themselves'.[66]

4.76 Interchange Respite Care commented that 'respite has been seen and used by governments and bureaucrats as bandaid solutions and forced some families into situations of permanent care roles which they ultimately do not wish to pursue'.[67] A witness provided the following case:

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[64] *Submission* 91, p.1 (Interchange Respite Care).

[65] *Submission* 104, p.1 (Ms L and Mr I Allen).

[66] *Submission* 3, p.14 (Western Australian Government); see also *Submission* 50, p.9 (NCID).

[67] *Submission* 91, p.1 (Interchange Respite Care).

> I have a friend who developed breast cancer; she is a sole parent Carer. When she was hospitalised for surgery, her mother was supposed to care for her 16 year old son. Her mother, wise to the ways of government, unbeknown to my friend, sent her son off to respite care, saying she could not cope. When my friend came home from hospital, she was too sick to bring him home. She came to realise, with the support of her mother, that her son was happy and that this was her opportunity – it might never come again, so she decided to refuse to bring him home. He stayed in respite care for 8 months, finally the government realised she could not be manipulated into taking him back and found him a permanent placement.[68]

4.77 The Committee also heard evidence about the lack of respite options for people with specific disabilities such as ABI. The Brain Injury Association of Tasmania commented that there is a significant and pressing need for respite models which are affordable, age appropriate and are staffed with support workers that are educated regarding the needs and best practice service delivery models for people with ABI. These respite services should be available in a community based and/or home based setting and should focus on offering flexible, needs based services which are part of a planned, individualised support program.[69]

4.78 For people with degenerative conditions such as MS, respite is often limited to time in an aged care facility. Young people are generally reluctant to take up these options, don't enjoy the experience if they do go and facilities find it difficult to provide the type of care they need.[70] Hopes Inc noted that often facilities only have one respite bed and this may be in a dementia unit: 'to be totally surrounded by people with varying stages of dementia and to be physically unable to move out of the locked unit, is incredibly stressful for a younger person used to family support in their own home'.[71]

4.79 The overwhelming evidence received by the Committee indicates that the provision of adequate respite care is fundamental to enabling people with disabilities to continue to be cared for within families. Significant levels of unmet need for respite services were identified with the result that many families are unable access adequate respite unless they face a crisis situation. In part, the lack of respite services is due to problems in the provision of other services most notably accommodation services. Witnesses pointed to reduced access to respite facilities arising from the lack of accommodation options for people with disabilities whose families are no longer able to care for them. This, in turn, decreases the number of respite beds available and so places greater pressure on families seeking short-term respite options.

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[68] *Submission* 28, p.12 (National Carers Coalition).

[69] *Submission* 87, p.10 (Brain Injury Association of Tasmania).

[70] *Submission* 88, p.13 (MS Australia of SA and NT).

[71] *Submission* 103, p.2 (Hopes Inc).

Assistive technology

4.80 Assistive technology (aids and equipment) is not included in the CSTDA. However, its importance to people with a disability cannot be underestimated: assistive technology can provide individuals with greater personal independence; improve quality of life; assist with social inclusion; and reduce the demand for costly personal assistance. Investment in aids and equipment assist people to remain at home thereby diverting from more costly disability or aged care support options. Aids and equipment can reduce the need for out of home placements through avoiding hospital admissions (for example because of pressure sores from poor equipment) and can enhance the longer-term capacity of carers (for example the use of hoists). YPINH National Alliance commented that delays in accessing much needed equipment leads to diminution of health and independence and a consequent increase in the health and support costs borne by government. It is a false economy when Australians with disability cannot access the equipment they need.[72]

Client M4 is a single man aged 42 years living alone in cluster style accommodation. This Client describes his living experience as being 'solitary confinement'. The client reports carer attendance to his needs morning and evening and his mother helping with his meal in the middle of the day. Client says he spends his day watching TV as he cannot independently get around his home and cannot access his computer/music etc independently. This is due to the client no longer being able to manage a manual wheelchair. Client asks that he be allocated an electric wheelchair as this will allow him to move around his flat. He indicated he had been on the waiting list for this equipment for at least 18 months. The client says he does not see anyone else day after day and does not have the opportunity for any meaningful activity. He has little or no contact with the young people in the other flats that make up the complex of 7 units.

Source: Submission 88, p.10 (MS Australia of SA & NT).

4.81 The AIHW reported that some research suggests that aids and equipment alone may be a more efficacious form of assistance than personal assistance in reducing difficulty associated with performing tasks of daily living.[73] Nearly half of all people with disabilities use assistive technology but there continues to be high unmet need.

4.82 Both the Commonwealth (through the Departments of Health and Ageing, Veterans' Affairs and Employment and Workplace Relations) and the State and Territory Governments administer schemes which provide cost-free or low-cost aids and equipment to people with disabilities. A range of non-government organisations and health insurance organisations also provide access to assistive equipment.

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[72] *Submission* 98, p.15 (YPINHNA).

[73] AIHW, *Disability: the use of aids and the role of the environment*, August 2003.

4.83 Access to assistive technology varies with the provider and across jurisdictions. The Independent Living Centre WA commented that the criteria for funding eligibility vary from State to State which leads to confusion and inequity:

> What you find when you start to look into it is that each state has totally different, separate, individual programs that they are running that are state funded. We have great variation in access to funding from state to state. The amount of funding – the ratio per capita – varies from state to state…[74]

4.84 In addition, narrow definitions of assistive technology in all States serve to restrict access to those most in need. There are multiple barriers to embracing assistive technology in addition to the funding and policy obstacles. These include the volume of change facing organisations, lack of consumer pressure, organisational fragmentation and technology phobia present amongst many members of the disability sector.[75]

4.85 Current schemes fall short in meeting demand and timely provision of appropriate equipment. Waiting times for equipment can be long. MS Australia commented that there are people with MS who have experienced long periods of hospitalisation for skin breakdown (pressure sores) because their equipment needs could not be met. In many situations the prescribed pressure mattress or wheelchair could not be fully funded through the Government schemes, and the additional resources could not be secured, so the person has tried to get by with inadequate or no equipment.

4.86 Funding limits for equipment like mattresses or wheelchairs can be as little as 50 per cent of the purchase price, leaving the individual and the family to find the difference. In most cases the $4,000-6,000 required is simply not there. This is also a common reason for young people being admitted to nursing homes, because either their disability is worsened by the lack of correct equipment, or the effort required by families to care for a person with a severe disability without the right equipment is overwhelming.[76]

4.87 Other schemes are fragmented by Commonwealth-State divisions and under-supply. MS Australia noted that there are 40 separate equipment programs in Australia, which is overwhelming. State and Territory Governments, Workers Compensation and CTP schemes, hospitals, aged care providers, HACC, disability brokerage programs, Veterans' Affairs, the Workplace Modifications Scheme and School Education integration programs all are discrete purchasers of equipment. An example is the Continence Aids Assistance Scheme, which the Federal Department of Health and Ageing funds for people 16 to 65 years but not for people over 65 years unless they are in paid employment.[77] Once a person turns 65 they are no longer

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[74] *Committee Hansard* 5.10.06, p.46 (Independent Living Centres of WA).

[75] *Submission* 38, p.1 (ILC WA).

[76] *Submission* 93,, p.21 (MS Australia).

[77] *Submission* 45, p.13 (ACROD).

eligible for this program and must find an alternative source of support. MS Australia commented 'this is one area of split responsibilities that is difficult to defend from any standpoint'.[78]

> …one patient with a permanent tracheostomy was declined DVA funding for suction equipment and was then denied home modifications to make way for his existing equipment because he has a DVA card. Most alternative public funding options will exclude access to those holding DVA cards, hence this patient had no alternative funding source.
>
> *Source:* Submission 70, p.4 (APA).

4.88 In its 2003 study of aids and equipment AIHW found there to be 'a limited range of equipment, problems with cost, availability and shortage of referral services in remote areas of Australia, and a decline in equipment supply from traditional dispensing units such as hospitals. Systems for the provision of equipment appear to be nationally fragmented.'

4.89 Other reports reinforce the AIHW's findings: a 2002 NSW report into the equipment needs of children found that the processes of equipment provision are slow and inefficient and that children do without prescribed items for long periods. Because of the high costs associated with some equipment, families often need to seek external support to purchase items.[79]

4.90 In 2006, the AIHW published a review of therapy and equipment needs of people with cerebral palsy and like disabilities.[80] The AIHW reported significant levels of unmet need, with long waiting times particularly for those living in non-metropolitan or lower socioeconomic areas and for adults. Equipment schemes were fragmented and complex with excess paperwork, restrictive conditions of use and supply adding to inefficiencies. The AIHW provided some examples of waiting times for equipment for people with cerebral palsy:

- in Western Australia, the cost of equipment on the Community Aids and Equipment program in June 2006 was $255,000;
- in May 2006, The Spastic Centre was waiting for funding for 378 equipment items; and

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[78] *Submission* 93, p.22 (MS Australia).

[79] Dowling L, *Children who live with equipment: Report to the Department of Ageing and Disability and Home Care,* Issues Paper February 2002, cited in *Submission* 45, p.13 (ACROD).

[80] AIHW, *Therapy and equipment needs of people with cerebral palsy and like disabilities in Australia,* Disability series, December 2006.

- in August 2006, there were 241 outstanding requests for funding from the Independent Living Equipment Program made by clients of the Novita Children's Services South Australia worth about $661,000 in total.[81]

4.91 The AIHW estimated that the annual national cost of meeting unmet need for equipment for people with cerebral palsy and like disabilities ranged from $3.5 million to $4.4 million.[82]

4.92 People with a disability also face problems of retaining specialised equipment and accessing new equipment if they move between States. Mr Ben Lawson gave this example:

> …my powered wheelchair is provided by Queensland Health through a scheme called 'Medical Aids Subsidy Scheme' (MASS). My wheelchair with its specialised modifications is worth approximately $10 000. However, if I were to move to another Australian State I would have to hand back the chair and its modifications to Queensland Health. Apart from the obvious question of what I would do without a wheelchair in the interim, I would then reapply in that state and hope that my application was considered speedily.[83]

4.93 Access problems also arise when people with disabilities move into the aged care sector. The Motor Neurone Disease Association of Australia noted that while residential aged care facilities are required to provide appropriate aids and equipment, most residential services do not have the funds to provide equipment that is necessary for people living with motor neurone disease. This is also the case for other groups of people with a disability living in aged care such as those with acquired brain injury and multiple sclerosis.[84] Access to specialised equipment is further diminished in some jurisdictions as State government aids and equipment programs specifically exclude people living in aged care facilities. In addition, aged care facilities only provide basic care which does not address the aspirations of young people with a degenerative disability.[85]

4.94 The Victorian Government noted that there are a range of factors influencing demand for aids and equipment, including population ageing. Moves to support more people with a disability or people who are ageing at home or in the community also have an impact on demand. A heightened awareness of health and safety issues has led to increased requests for expensive equipment such as hoists and beds.

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[81] AIHW, *Therapy and equipment needs of people with cerebral palsy and like disabilities in Australia,* Disability series, December 2006 p.127.

[82] AIHW, *Therapy and equipment needs of people with cerebral palsy and like disabilities in Australia,* Disability series, December 2006 pp.xii-xiii.

[83] *Submission* 81, pp.3-4 (Mr B Lawson).

[84] *Submission* 31, p.2 (MNDA).

[85] *Submission* 40, p.4 (MNDA Vic).

4.95 The impact of changing technology and increasing costs is making the purchase of aids and equipment prohibitive to many people with a disability and their families due to affordability. The Victorian Government suggested that the Commonwealth should consider offering financial assistance by way of tax relief to people with a disability and their families to assist with the affordability of some aids, equipment and essential home modifications. Such a move would recognise the high costs incurred by people with a disability due to their impairment.[86]

4.96 MS Australia also commented that the CSTDA signatories are major purchases of equipment but there is no mechanism across programs (and in some cases within programs) to improve purchasing power and to improve pricing. MS Australia went on to state that this lack of attention to purchasing also means that there is little or no expectation of service level agreements with suppliers or customers.

4.97 MS Australia pointed to the system used by the Department of Veterans' Affairs as a model that goes close to what is required in disability services. The Department's equipment brokers delivery good price and service outcomes through purchasing agreements and referral processes.[87]

The Victorian Aids and Equipment Program (VAEP) is a Victorian Government program which aims to assist children and adults to access subsidised aids, equipment and home modifications to enhance their safety and independence, support their family and carers and prevent premature admission to institutional care or high cost services.

Unfortunately, if a client lives in any sort of supported accommodation (ie a Residential Aged Care Facility) they are not eligible for equipment through VAEP and supported accommodation funding does not cover equipment purchase.

Patients being discharged from hospital to nursing homes are not eligible for equipment. I have had two patients recently in their 50's and needing high level care who need motorised wheel chairs or custom made chairs to re-enter the community. Both patients have the family and community support necessary to re-enter the community but they can’t do so because of lack of equipment. If they lived in the community they would be eligible for equipment.

Source: Submission 70, p.4 (APA).

4.98 There was widespread support for the development of a national strategy for the provision of aids and equipment. The Independent Living Centre commented:

> A national approach to access, support, and funding of AT is a vital step to inclusion and participation across Australia and an essential response to the rapid the rate of growth and change occurring in AT. It is important to the future of Australians with a disability, and those yet to have a disability, that AT be included in the next CSTDA.

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[86] *Submission* 99, p.12 (Victorian Government).

[87] *Submission* 93, pp.20-24 (MS Australia).

> AT is a vital component in the development of a national policy and service framework. The correct coordination, disbursement and application of AT is an economically sound strategy which can enrich the quality of life of people with a disability, meaning more people return to work, live safely in their own homes and actively participate in their community. In the current climate of workforce shortages AT has a significant role to play, reducing the volume of personal care services required by those with a disability and the frail aged and keeping people in the workforce.[88]

4.99 Witnesses pointed to the work undertaken by Ernst and Young on equipment needs for the 1996 evaluation of the Commonwealth State Disability Agreement. It was recommended that a National Equipment Strategy be developed to improve the range and timeliness of equipment provision and lower the cost of maintenance and repairs. The evaluation report recommended that work be done around equipment services so that it is strategically integrated with the rest of the specialist disability services system, its is accessible to all people with disabilities who need equipment and is provided for in ways which are customised appropriately.[89]

4.100 The evaluation report stated that just bringing equipment into the CSTDA is not enough:

> What this would mean in any case cannot be resolved without giving attention to the policy issue of just what is and should be the strategic role and place of cost effective equipment services within an integrated disability service system. It is important to emphasise that 'it is a policy issue in the first place, not a program management one, as it has been taken to be'.

4.101 ACROD concluded that the need for such a strategy is now pressing with the CSTDA providing an appropriate multi-lateral framework under which to coordinate such a strategy.[90]

4.102 The Australian Physiotherapists Association (APA) argued that a national strategy should include:

- responsive and timely provision of aids and equipment for all people with disabilities that meet both their short and long term needs;
- strategies to build national purchasing power in the equipment market, while retaining local individualised clinical assessment and provision;
- more inclusive and nationally consistent eligibility criteria;
- an end to arbitrary access barriers such as age; and

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[88] *Submission* 38, p.1 (ILC WA).

[89] Ernst and Young, *Commonwealth/State Disability Agreement Evaluation, Supporting Paper 5 – The Equipment Study*, AGPS, 1996.

[90] *Submission* 45, p.13 (ACROD).

- equitable access for people waiting for, and accommodated in, residential aged care facilities; people living in rural and remote areas; people with hearing and/or visual impairment; and for Indigenous Australians.[91]

Recommendation 17

4.103 That the Commonwealth, State and Territory governments implement a national equipment strategy as part of the next CSTDA.

Early intervention

4.104 Witnesses commented on the importance of early intervention. ACROD stated that early intervention means both providing assistance before a problem escalates into a crisis and providing support and therapy early in life to enable a child or young person to develop well and fulfil their potential.[92]

4.105 Early intervention assists children and young people to grow, learn and achieve, and it can prevent the development of secondary disabilities. All family members benefit from the improvements in the life of the child or young person. However, concerns were raised that many children and young people with disability lack adequate access to programs that would encourage their optimum development.

4.106 Mr Bob Buckley raised the particular needs for early intervention for young children with autism. Early diagnosis and specialised early intervention are proven methods for minimising the level of disability children with autism spectrum disorder carry into adulthood. However, there are waiting lists of up to two years for diagnosis in the public system while private assessment cost about $1,500.[93]

4.107 Research points to the need for a minimum of 20 hours per week of effective early intervention for children with autism. However, Mr Buckley noted that 'in Australia there are no government-funded programs providing the recommended amounts of intervention'. Mr Buckley also pointed to shortcomings in the services governments and their agents provide as they do not offer an appropriate level of language and communication intervention, social skills development and skill development in other key areas. The programs also lack appropriate professional supervision and monitoring of program outcomes. These programs are not evidence-based; in fact they are programs of a type that is known to be inappropriate and ineffective for children with autism. Mr Buckley concluded:

> The existing process leaves many parents without appropriate information. And it denies equality of opportunity to many children who are severely disabled by their autism. It means they do not have the opportunity to

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[91] *Submission* 70, p. 3 (Australian Physiotherapists Association).

[92] *Submission* 45, p.14 (ACROD).

[93] *Submission* 74, p.32 (Autism Aspergers Advocacy Australia).

> develop skills that are critical to their success in education, and subsequently in employment and community participation.[94]

Recommendation 18

4.108 That the next CSTDA include a commitment of additional funding for early intervention.

Employment services

4.109 The 2002 AIHW report on unmet need estimated 5,400 people needing employment support.[95] In 2000-01, a total of 60,352 people with disability accessed specialist employment services while in 2004-05, a total of 68,370 people with disability accessed these services – an overall increase of 8,018 or 13.3 per cent. Over this time period, funding for specialist employment services increased from $241 million to $352 million.[96]

4.110 The Commonwealth commented that in considering unmet need for specialist disability employment services, it should be noted that service capability is just as important as the number of places available. The Commonwealth's reforms to specialist disability employment services 'have had a small but observable impact in broadening the focus of specialist employment services from a traditional focus on intellectual disability to supporting people with a much wider range of disabilities'. For example, service users with autism increased from 1.7 per cent in 2001-02 to 2.3 per cent in 2004-05 in open employment services and over the same period the proportion of service users with specific learning difficulties and attention deficit disorder rose from 9.2 per cent to 10.3 per cent. Supported employment services have shown similar increases.

4.111 People with intellectual disabilities are increasingly choosing open employment over supported employment services. In 2004-05, there were 12,325 people with intellectual disabilities using open employment services (26.8 per cent of all clients) and 14,097 service users with intellectual disabilities accessing supported employment services (73.4 per cent of all supported employment clients). This is significant change since 1997 when people with intellectual disability made up 48.3 per cent of open employment users and 77.9 per cent of supported employment clients.

4.112 The Commonwealth commented that the introduction of individualised, case based funding for supported employment has resulted in a marked shift towards a client group with much higher support needs. In the three years from 2002 (the year before case based funding places began to be released) to 2004, supported

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[94] *Submission* 49, p.10 (Mr B Buckley).

[95] AIHW, *Unmet need for disability services*, p.xxi.

[96] *Submission* 96, p.15 (Australian Government).

employment service users were increasingly likely to have a profound core activity restriction. Over that period:

- the number of supported employment clients with a profound core activity restriction increased by 28.6 per cent nationally;
- the number of supported employment clients with a severe core activity restriction increased by 15.3 per cent nationally; and
- the number of supported employment clients with a core activity restriction of 'moderate to none' has fallen by 13 per cent nationally.

4.113 Additional evidence that case based funding has been effective in directing supported employment services increasingly towards those with higher support needs can be found in data from the annual Disability Services Census. Those data show that the proportion of supported employment clients who receive care has increased from 66.4 per cent in 2002 to 73.7 per cent in 2004.

4.114 The Commonwealth concluded that the ongoing commitment of the Government to improving employment outcomes for people with disability is demonstrated in the 2005-06 Budget announcement of an additional 21,000 demand driven (uncapped) places in the Disability Employment Network, which have become available since July 2006.[97]

4.115 The Western Australian Government did not support the view that Commonwealth employment programs showed a shift towards clients with higher support needs. The Western Australian Government pointed to the following data to support its claims:

- direct staff hours have remained constant while the number of people accessing the program has increased by 30 per cent;
- indirect staff hours have fallen by 14 per cent;
- there has been a major change in the proportion of people with intellectual disabilities from 62 per cent in 1998 down to 41 per cent in 2004;
- there has been a significant increase in the proportion of people with low support needs from 11.5 per cent in 1998 to 23.5 per cent in 2004;
- in the period 1998-2004 there has also been a significant change in the number of hours people with disabilities are working, with more program participants working less than two days per week;
- the proportion of Western Australians with a disability employed for 15 hours or less has increased from 18 per cent to 29 per cent; and
- the proportion of Western Australians with a disability employed for 30 hours or more each week fell from 53 per cent to 43 per cent.[98]

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[97] *Submission* 96, p.15 (Australian Government).

[98] *Submission* 3, pp.10-11 (Western Australian Government).

4.116 The Western Australian Government commented that the introduction of the *Commonwealth Disability Services Act 1986* had been the impetus for stringent Commonwealth driven reforms to employment support for people with disabilities. In addition, since 1997 the Commonwealth reforms have 'significantly redefined the scope of the Disability Employment Program, that is, who is eligible, and what is considered to be an employment outcome'. States andTerritories were not consulted about this process and 'represents a fundamental shift in the interpretation of responsibilities on which the first Commonwealth/State Disability Agreement was negotiated'.

4.117 MS Australia also commented on the introduction of very strict rules of eligibility, type of service and financial incentives for providers when the Disability Open Employment Program moved to DEWR in 2005. MS Australia stated that 'while we would support the increased opportunities to work, much of the system is out of step with the other aims of the CSTDA of individualised service, linking to other sectors and choice'.[99]

4.118 The Western Australian Government also noted that at the same time these changes were being implemented, sheltered workshops were redefined as 'Business Services' and required to adopt a 'duality of focus', such that they would continue to be a human service provider, but were required to operate commercially viable businesses. As a consequence, 'people with low productivity were sacked from services and new people sought to fill vacancies had to be productive'.[100]

4.119 The Western Australian Government concluded that it continued to be concerned about the impact of changes and reforms to the Commonwealth employment program, including:

- reduced access to assistance for people with high support needs, with particular concern expressed about school leavers;
- increased care responsibilities/pressure on families; and
- the cost-shifting implications for States and Territories.[101]

4.120 The Western Australian Government also commented that progress in the employment area has been hampered by changes to Commonwealth administrative arrangements whereby business services remain under FaCSIA and job network services (formerly known as open employment services) moved to DEWR. This has added an additional layer of complexity to communications and, as with aged care, DEWR was required to take on work plan commitments from the general bilateral agreement.[102]

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[99] *Submission* 93, p.16 (MS Australia).

[100] *Submission* 3, pp.11-12 (Western Australian Government).

[101] *Submission* 3, p.12 (Western Australian Government).

[102] *Submission* 3, p.13 (Western Australian Government).

4.121 Other areas of concern included the transition of people with a disability from school to work and the impact of the Welfare to Work reforms. The Western Australian Government commented that the jointly funded Post School Options (PSO) programs were one way for school leavers with high support needs to succeed in a range of individually supported jobs and in open employment. With these other options available to them, very few school leavers chose sheltered workshops. However, the introduction of Centrelink has impacted on the Western Australian PSO program and program demarcations 'once again became barriers, particularly for school leavers with high support needs'.

4.122 The Victorian Government supported greater coordination of programs to improve the employment options for school leavers:

> …there are opportunities for the Commonwealth and the state to work together in a more coordinated way to increase employment opportunities for school leavers. The state operates a post-school planning and transition program for school leavers. The Commonwealth operates employment services and, whilst there is cooperation now, an agreed strategy with clear outcome targets could be developed between the jurisdictions to achieve higher workforce participation for school leavers.[103]

4.123 Jobsupport Inc (an open employment service) also commented that the current CSTDA interface arrangements between Commonwealth funded Disability Employment Network services and State funded Post School Options services are an obstacle preventing people with a significant intellectual disability who want to work from working. Commonwealth funded capped Disability Employment Network places are not always available because the program is capped. Post School Options service users and their families don't want to be without any service and some are reluctant to attempt open employment because it can be difficult to re-enter Post School Options if the open employment attempt is unsuccessful.

4.124 Jobsupport noted the significant savings to government of increased workforce participation by people with disability. Research by Econtech demonstrated that if approximately 8 per cent (just over 2,000) of the Post School Options users across Australia moved from Post Schools Options to Open Employment recurrent budget savings of $21 million would be made. Jobsupport concluded that:

> We simply want to highlight the fact that an opportunity exists to let people in State Post School Options services who want to work do so, while at the same time saving the taxpayer money. All that is needed is a more flexible interface between the Commonwealth and State Governments including the removal of the cap on Capped Disability Employment Network services.[104]

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[103] *Committee Hansard* 28.9.06, p.66 (Victorian Government).

[104] *Submission* 85, p.2 (Jobsupport Inc).

4.125 Many witnesses raised concerns about the impact of the Welfare to Work changes introduced by the Commonwealth in 2005.[105]

4.126 MS Australia noted that Welfare to Work is designed to achieve increased employment outcomes for those who are not working, and has not considered the impact on this system on those who are, but who need support. It has mostly ignored the need for job retention services, and is almost totally geared for finding new jobs for people who are not working at all. In fact there are exclusions to Disability Employment Services being able to work with those clients who are working – so the opportunity for a person in this risk group to seek job retention support is close to zero.[106]

4.127 Women with Disabilities Australia placed particular emphasis on the needs of disabled women in gaining employment. WWDA commented that 'with one of the lowest rates of labour force success and one of the highest rates of poverty, women with disabilities clearly stand out as a group in need of greater opportunities for employment'. However, little assistance has been provided to women. Commonwealth funded open employment services assisted over 35,000 people with disabilities to find employment and maintain jobs but 65 per cent of those assisted were men. Only 9 per cent of women with disabilities are in full-time employment compared to 21 per cent of men with disabilities. More women with disabilities are employed part-time (11 per cent) than men (6 per cent) and 'in any type of employment women with disabilities are already more likely to be in low paid, part time, short term casual jobs'. WWDA concluded that 'it is clear that the CSTDA has had little effect on the situation of women with disabilities in relation to employment'.[107]

4.128 The NCID commented that the Commonwealth does not provide employment support to all people with intellectual disability who want to work which forces many people with intellectual disability onto State/Territory funded alternatives to employment services or to be at home with parents. However, people with a significant intellectual disability can obtain and keep a job which benefits not only the person with an intellectual disability but their families as well. The NCID considered that the major obstacles are a lack of commitment from the Commonwealth to provide flexible funding and uncapped funding.

4.129 NCID noted that for job seekers with disability who are not seen to be able to work at award wages for more than 15 hours per week (without support) funding is capped to a limited number of 'places'. The consequence of this is that some State and Territory Governments have begun to provide pre-employment and employment support to job seekers with a disability, funding which the Commonwealth should be picking up while the States and Territories fund alternatives to employment programs.

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[105] *Submission* 15, p.7 (WWDA).

[106] *Committee Hansard* 93, p.15 (MS Australia).

[107] *Submission* 15, pp.6-7 (WWDA).

4.130 NCID concluded that job seekers with disability need flexible funding that can be used to gain pre-employment skills and to engage the employment support provider of their choice. For example, at the moment there are significant vacancies within the supported employment network, and given that employment support is now provided on a case based model, school leavers should be offered not a place in a service but the funding to approach a service provider of their choice. There is a clear need for Governments to provide funding (with clear assessment and accountability criteria) and not to be involved in choosing service models for people with disability.[108]

Recommendation 19

4.131 That the Commonwealth increase the number of places in the Disability Employment Network for people on the Disability Support Pension who do not have mutual obligation requirements.

Transport

4.132 The problems that people with disability face in accessing transport were raised in evidence. Not only is there a shortage of suitable transport, the cost of accessing that transport is often prohibitive. This is particularly the case for people with disability living in rural areas. Brain Injury Association of Tasmania provided the Committee with a glimpse of the difficulties of accessing suitable transport for people with a disability in rural areas:

> [In] Launceston, Burnie, Hobart there are some wheelchair accessible taxis, but this is an expensive service, often limited by availability. For others, there are few or no accessible transport services in their local community. This results in an inability (or at least, a reduction) in the person's capacity to participate in therapeutic services, and ultimately contributes to social isolation.[109]

4.133 Those people who live in areas where air travel is the only means of accessing necessary rehabilitation and support face additional financial burdens. BIA of Tasmania also commented that people with ABI have expressed feeling vulnerable when accessing public transport. Often taxi drivers do not know how to safely secure wheelchairs into vehicles and people with ABI experience difficulties in reading and interpreting public bus timetables.

4.134 ACROD emphasised the importance of transport not only to improving the social inclusion of people with disability but also to their ability to participate in the workforce. ACROD argued that as the ability to get to work is crucial to workforce participation, the Commonwealth's Welfare to Work Reform will rest on accessibility of transport. ACROD stated that 'the Australian Government could recognise that, and engage state governments and realise that getting people into sustainable jobs also

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[108] *Submission* 50, p.10 (NCID).

[109] *Submission* 87, p.13 (Brain Injury Association of Tasmania).

required getting accessible transport, good access to education and training, proper health management and proper in-home support—many of which are state responsibilities—then perhaps there could be a more cooperative approach'.[110]

4.135 Many witnesses noted that the CSTDA does not cover transport issues. AFDO stated that exclusion of transport 'restricts the relevance and power of the CSTDA as a strategic planning document'.[111] FaCSIA commented that there are connections to a range of service systems beyond those that are covered in the current CSTDA agreement. The rationale for the set of services that are covered in the current agreement 'stems from its historical origin, which was to relate it to a transfer of a particular set of services…it is a question of whether or not that remains a sensible set of services to cover under the agreement'.[112]

Recommendation 20

4.136 That the importance of access to appropriate transport and Patient Assisted Travel Schemes for people with disabilities be reflected in the terms of the next CSTDA.

Continuing pressures on demand for services

4.137 Witnesses also identified a number of issues which are now, or will be in the near future, placing increased pressure on the need for accommodation services. Of most significance is the number of older people with a disability still living at home with ageing carers. Many witnesses pointed to the growing need to provide suitable accommodation for people with disability in the care of ageing carers. The Gippsland Carers Association noted that in Victoria there were some 13,900 people aged over 30 years living with a parent as a primary carer and 55,600 people nation wide.[113] The National Council on Intellectual Disability also pointed to the over 5,000 people with severe and profound disability living with parents who are aged over 65 years as evidence of the level of unmet need.[114] The AIHW indicated that 6,472 carers aged over 65 years were caring for CSTDA-funded service users in 2003-04.[115]

4.138 As carer parents age, it becomes a constant concern about what will happen to their disabled children. The Client Guardian Forum noted that often children with a disability remain in the family home even though the parent/s can no longer support their adult children. This leads to a fall in the quality of life for both the person with a

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[110] *Committee Hansard* 13.10.06, p.39 (ACROD).

[111] *Submission* 90, p.9 (AFDO).

[112] *Committee Hansard* 13.10.06, p.84 (FaCSIA).

[113] *Submission* 8, p.3 (Gippsland Carers Association).

[114] *Submission* 50, p.9 (National Council on Intellectual Disability).

[115] AIHW, *Australia's Welfare 2005*. p.242.

disability and the parents. They remain at home until a crisis point is reached or the parents die.[116]

4.139 At the same time, more people with a disability are living longer, particularly those with an intellectual disability. Dr Jennifer Torr indicated that healthy older people with a disability are being placed into nursing homes when their family carers can no longer care for them, irrespective of whether they have an aged related disorder or not:

> It is not an uncommon scenario for older people with ID to seek services for the first time when their ageing parents can no longer provide care through their own ageing, illness or death. Anecdotally this seems to be a particular problem in rural areas where people with ID have been supported by family and community rather than specific CSTDA services.[117]

4.140 The Victorian Government also noted that the impact of technological advances and increased medical survival rates, particularly in the areas of premature births and traumatic incidents, has led to increased demand for support from people who have complex medical and disability-related support needs. Disability Services in Victoria is increasingly required to provide appropriate support responses for people with acquired brain injury, spinal injury and neurological conditions who would otherwise remain in acute health beds or nursing home placements without adequate interventions.[118]

4.141 It was argued that there was a need for increased supported accommodation options in order to relieve the stress and burden on aged, frail and ill carers.[119]

4.142 The incidence of some diseases is also growing: MS Australia reported that the incidence of MS is expected to grow by 7 per cent over the next five years.[120]

Conclusion

4.143 The Committee was acutely aware during this inquiry that evidence of sub-optimal organisation and provision of disability services underscores an immense personal, social and economic burden affecting hundreds of thousands of Australians. Although enormous improvements in services levels in the last few decades can be measured, it is difficult not to be aware that there remain substantial disparities between the outcomes and living standards of disabled Australians, even allowing for their disability, and those of others in this country. The fact is inescapable that physical or intellectual disability today equates almost ineluctably with lesser

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[116] *Submission 51*, p.3 (Client Guardian Forum).

[117] *Submission 48*, p.5 (Dr J Torr).

[118] *Submission 99*, p.11 (Victorian Government).

[119] *Submission 6*, p.1 (South Gippsland Carers Group).

[120] *Submission 93*, p.19 (MS Australia).

opportunities, services, social inclusion and quality of life that the rest of the community takes for granted.

4.144 The evidence of carers, who undertake so much of the caring, brought home this reality to the Committee. Many cases were cited of families and loved ones shouldering enormous responsibilities over decades caring for a person with a disability, with government or community assistance relieving that burden only slightly or not at all. The Committee acknowledges that families will always have a substantial responsibility towards the care of their disabled members, and that it may never be either desirable or economically feasible to shift that responsibility onto the community as a whole. At the same time, the Committee recognises that the weight of that responsibility on countless families is a crushing and unreasonable one, and that much greater community assistance in that task is urgently called for.

4.145 This report contains several recommendations for improvements in the coordination and delivery of disability services. The Committee warmly recommends that Commonwealth, State and Territory governments embrace these changes; however, the stark reality is that such change cannot adequately address the very substantial need within our community. Only large and sustained increases in resourcing to programmes and services will do this.

4.146 The disability system in Australia is replete with examples of inflexible access criteria, silo-ed services, bureaucratic application and assessment processes, poor linkages with companion services and obscured entry points to programs. It is tempting to view these phenomena as coping mechanisms for a system which simply doesn’t have enough resources to satisfy the demands placed on it. The consequent rationing of services throws an added burden on carers: that of expending precious time and energy chasing help that simply won’t be there.

4.147 While the Committee has recommended that the responsibility for funding specialist disability services other than employment should primarily rest with the State and Territory governments under the CSTDA, both levels of government continue to have an obligation to provide services that address unmet need.

4.148 How large an increase is required to fully satisfy need is impossible to quantify at this time. The National Carers Coalition estimated that $10.9 billion was required annually to properly provide accommodation choices to disabled Australians;[121] however, other witnesses were unable to place a figure on the cost.

4.149 However, the following comments from MS Australia sum up many issues associated with unmet need and responsibilities of addressing them:

> The first point is to try to measure [unmet need] a lot more deeply, and that may also lead to a more intelligent agreement, because at the moment…both jurisdictions blame each other for not doing enough…The

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[121] *Committee Hansard* 3.10.06, p.34 (National Carers Coalition).

> amount of money that is needed to meet that demand at the fullest extent is exponential, but we do not know whether we need to go to the fullest extent…there are a lot of families who want to keep caring, so it is much more about looking at sharing the care between governments, families and communities. It is not just that it is a transfer of responsibility from families to government, but it is going to be like that. If it keeps being ignored, people are going to say: 'I've done my share. I've had enough. I'm out of here.' Whereas, if there is a more measured response early, people will stay in longer.[122]

Recommendation 21

4.150 That Commonwealth, State and Territory governments jointly commit as part of the fourth CSTDA to substantial additional funding to address identified unmet need for specialist disability services, particularly for accommodation services and support.

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[122] *Committee Hansard* 28.9.06, p.11 (MS Australia).

CHAPTER 5

THE AGEING/DISABILITY INTERFACE

Introduction

5.1 This chapter will focus on the interface between disability services provided under the CSTDA and aged care services.

5.2 Australia's demographic trend is towards an ageing population. By 2044-45 one-quarter of Australians will be aged 65 years or more, approximately double the present proportion. This is expected to have broad implications for social and economic policy and government spending. Aged care has been recognised as the most demographically sensitive area of government spending and the number of people requiring aged care services is expected to increase.[1] There will also be significant implications for people with disabilities. People with disabilities, because of improvements in care and support, are living longer and increasingly also require aged care services. People with disabilities can also need aged care services earlier in life as a consequence of living with a disability or due to shorter than average life expectancy.

5.3 There are also workforce and social implications for disability services as the proportion of population aged over 65 increases. The available workforce in the health, community services and disability areas is likely to decrease while demand for services will increase. Informal carers will also be under increasing pressure as they age and will be caring for a greater number of older people as well as people with disabilities.

5.4 Given these trends the interface between disability services funded under the CSTDA and aged care services will be important. In 2005 the Senate Community Affairs References Committee Report, *Quality and Equity in Aged Care*, recommended that the Commonwealth 'address the need for improved service linkages between aged care and disability services'.[2] While disability services and aged care services can often provide similar types of services to clients, disability services are generally not well equipped to manage the conditions and symptoms of ageing, and aged care services are generally not able to meet the specific support needs of people with disability.

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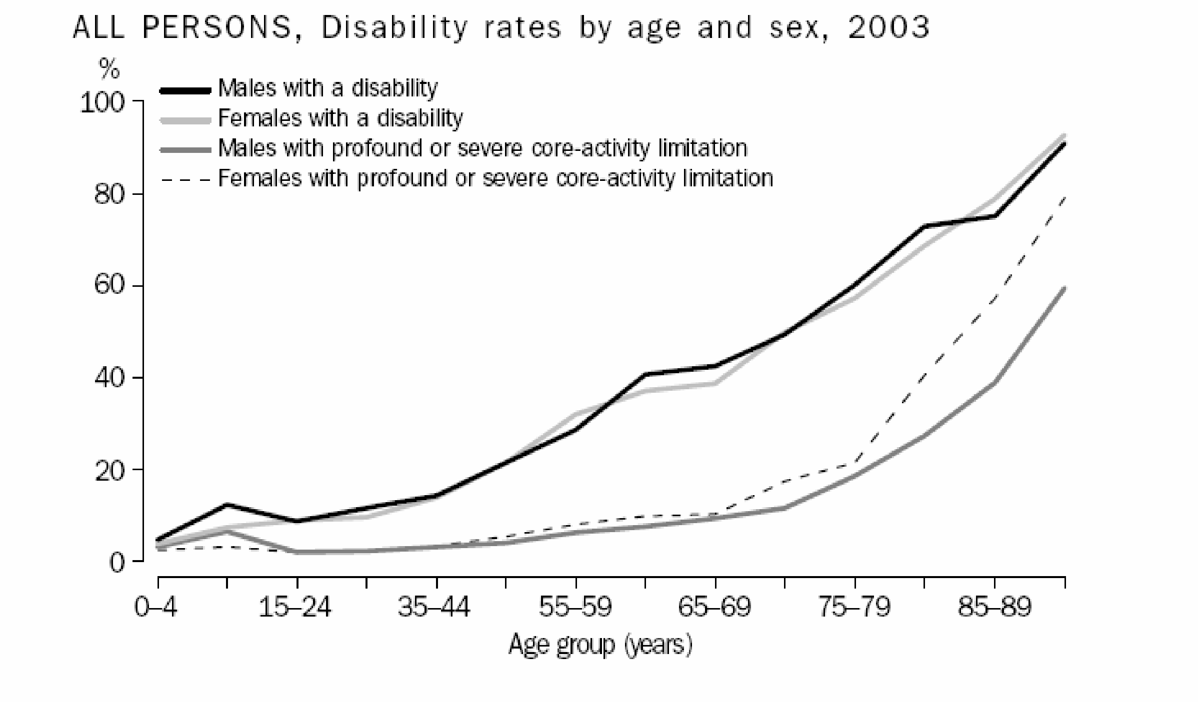
[1] Intergenerational Report 2002-2003, *Budget Paper No. 5*, p. 9; Productivity Commission, *Economic implications of an ageing Australia* (2005).

[2] Senate Community Affairs References Committee, *Quality and Equity in Aged Care,* Recommendation 44, p.167, June 2005.

Disability and ageing

5.5 The relationship between disability and ageing is complex. While the prevalence of disability increases steadily from around 35 years of age, the needs of people with disabilities and the types of disabilities acquired vary as they age.[3] The most frequently reported primary disability for users of CSTDA funded services in all age groups from 5–14 years to 45–64 years was intellectual disability. In contrast the most commonly reported disability for users aged 65 years and over was physical.[4] People over 65 with a disability needed more frequent assistance and with more core activities than younger people. This appears particularly true for people with intellectual disabilities as they get older.[5]

Figure 5.1



Source: ABS, Disability Ageing and Carers, 2003, p. 5.

People with a disability who are ageing

5.6 The exact number of people with disabilities who also require aged care services is not certain. Dr J Torr commented:

> One thing to recognise is that we are not talking about a huge population. Even though there are projections for the rapid increase of that population,

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[3] AIHW, *Disability and Disability Services in Australia – based on an extract of Australia's Welfare 2005*, Canberra 2006, p.7.

[4] AIHW, *Disability Support Services 2004-05*, p. 22.

[5] AIHW, *Disability and Disability Services in Australia – based on an extract of Australia's Welfare 2005*, Canberra 2006, p.7.

> it is still going to be a small population compared with, say, the general population and the explosion in the number of people with dementia.[6]

5.7 The AIHW report, *Disability support services 2004-05*, reported there were 2,819 persons aged over 65 in CSTDA funded supported accommodation. While not all these people would require or seek access to additional support for needs associated with ageing, people with disability can require ageing related support before they reach 65. In the AIHW report there are 11,229 people listed in supported accommodation aged 45 to 65.[7]

5.8 The AIHW report *Disability and Ageing* identified a number of groups at risk of falling within the 'grey areas' of the disability and aged care services interface and potentially not being able to access appropriate services.

- People with an early onset disability often have fewer basic living skills and so need higher levels of assistance in these areas as they age.
- People ageing with a disability acquired during adulthood usually have basic living skills. Their need for assistance generally arises from increasing physical frailty and diminishing levels of functional skills.
- Some people ageing with an intellectual disability may acquire dementia relatively early in life, at around age 50. They may become frail and need health and medical care more than help with other activities. These people may be more appropriately assisted by aged care services, because of their early ageing and deteriorating health.
- People retiring from Commonwealth-funded employment services may need replacement services.
- People accessing CSTDA accommodation support may require more flexible 'retirement' services, enabling them to 'age in place' or to make a smooth transition to appropriate residential aged care.[8]

5.9 The AIHW noted that because of their changing needs, or changes in their eligibility for certain services, it may be appropriate or necessary for people ageing with a disability to transfer between service types – for instance from specialist disability to generic aged care services. This transition is most likely to affect people with an early onset disability in their later years.[9]

5.10 People with a lifelong disability who are ageing have different needs from older people who have not aged with a lifelong disability. Associate Professor Christine Bigby in her submission to the Committee stated:

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[6] *Committee Hansard*, 28.9.06, p.49 (Dr J Torr).

[7] AIHW, *Disability Support Services 2004-05*, p. 26; *Submission* 32B, p.1 (Aged and Community Services Australia).

[8] AIHW, *Disability and Ageing*, p. xxi.

[9] AIHW, *Disability and Ageing*, 2000, p. xix.

> Although a diverse group, people ageing with a life long disability share some common characteristics associated with their pattern of ageing and the impact of their life experiences of being a person with a disability that suggest they should be regarded as a distinct special group of older people, who cannot simply merge into the general aged population. For example, some groups of people with life long disability age relatively early, experience additional health needs or impairments associated either with ageing per se or with their original impairment. For some their age related health needs are a complex combination of disability and age related changes.[10]

5.11 People with a disability who are ageing are not a homogenous group and there is no single factor such as age, the age disability is acquired or the type of acquired disability which will reliably indicate their needs as they age. This is important as it highlights the importance of tailoring services to the needs of each person and the need for services and programs to work across jurisdictional boundaries to meet these individual needs and circumstances.[11]

Jurisdictional overlap and inefficiency

5.12 The disability services provided under the CSTDA and aged care services can differ in a number of ways. These include the focus of their programs, the types of services offered, the main target groups and the expertise of personnel providing the services. While aged care services focus more on health needs, broad personal care and self-maintenance, disability support services emphasise non-health needs and can address a broader range of needs, including employment.[12]

5.13 The difficult nature of the interface between CSTDA and aged care services was discussed in the AIHW's evaluation of the Innovative Aged Care Interface Pilot.

> Community aged care programs act on the disability sector by blocking access to community-based aged care specific services for CSTDA consumers in supported accommodation. Correspondingly, the disability sector acts on the aged care sector by steering disability services clients who are ageing and younger clients with complex needs that cannot be managed at home towards residential aged care. A number of complex issues lie hidden in this simplistic appraisal of the situation.
>
> There is considerable overlap between the type of basic living support that supported accommodation providers deliver to CSTDA consumers and the types of assistance delivered to older people through community aged care programs. Older people with disabilities and people with disabilities who age prematurely typically experience an increase in support needs that is associated with ageing. Much of the additional need that emerges falls into

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[10] *Submission* 19, p. 3 (Assoc. Prof. C Bigby); see also *Submission* 3a, p. 28 (WA Government).

[11] AIHW, *Disability and Ageing*, p.xxi.

[12] AIHW, *Disability and Ageing*, p.xxi.

> the areas of personal assistance, domestic assistance and social support—all types of assistance which is presumed to be provided by the person's supported accommodation service. An important question is what level of service a supported accommodation service is funded to deliver and whether the level of funding is designed to meet the lifelong needs of each resident.[13]

5.14 Many of the interface problems appear to stem from the access and eligibility requirements of disability services and aged care services. The CSTDA does not impose explicit age-based restrictions on eligibility for services, however the current CSTDA defines 'people with disabilities' as those with disabilities which manifest before the age of 65 and in practice services are generally directed to people under 65 years of age.[14]

5.15 ACROD commented:

> The needs that arise from ageing do not displace the needs associated with a long-term disability: they are additional. Yet the existing funding arrangements and policy rules mostly deny a person simultaneous access to services from the aged care and disability service systems.[15]

Aged care services

5.16 The main aged care services funded by government in Australia are residential services, community care services, respite services and assessment services. These include the Home and Community Care (HACC) program, the Aged Care Assessment Program, Community Aged Care Packages (CACPs), the Extended Aged Care at Home (EACH) program and the National Respite for Carers Program (NRCP).

5.17 Several other programs address the special needs of aged care including various programs for people with dementia and their carers, the Veterans' Home Care (VHC), the Veterans' Home Nursing Program, the Day Therapy Centre Program, the Continence Aids Assistance Scheme, and flexible aged care services through Multipurpose Services and services under the National Aboriginal and Torres Strait Islander Aged Care Strategy.[16]

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[13] AIHW, *National evaluation of the Aged Care Innovation Pool Disability Aged Care Interface Pilot: final report* (2006) p.36.

[14] Hales C, Ross L & Ryan C, *National Evaluation of the Aged Care Innovative Pool Disability Aged Care Interface Pilot*, Australian Institute of Health and Welfare, 2006, p.30.

[15] *Submission* 45, p.18 (ACROD).

[16] AIHW, *Australia's Welfare 2005*, pp.159-197.

Home and Community Care (HACC) Program

5.18 Home and Community Care (HACC) Program provides services for older people, people with disability, and their carers. HACC services include community nursing, domestic assistance, personal care, meals on wheels and day-centre based meals, home modification and maintenance, transport and community-based respite care (mostly day care).[17] The HACC program is aimed at reducing inappropriate or premature admission to residential care by providing basic maintenance and support services to frail older people and people with a disability.

5.19 Commonwealth, State and Territory governments jointly fund the HACC program, with the Commonwealth contributing approximately 60.8 per cent and State and Territory governments funding the remainder. Total national expenditure on the Home and Community Care (HACC) program was $1.3 billion in 2004-05.[18] In 2004-05, HACC services provided care and assistance to over 744,000 people, 36,800 more than in 2003-04. People with disability are estimated to comprise over 24 per cent of the total number of HACC clients but consume an estimated 30 per cent of the funding. This is because proportionally people with disabilities access higher levels of services.[19]

5.20 Nominally HACC services are delivered on the basis of a person’s need for assistance and not on the basis of age. An estimated 68.2 per cent of HACC clients in 2004-05 were aged 70 years or over. However CSTDA clients who reside in supported accommodation facilities are normally excluded from accessing HACC services. People with disabilities (including CSTDA service users) who live in private residences, or another form of accommodation besides disability-funded supported accommodation, form part of the HACC target population and may be eligible to receive HACC services.[20]

5.21 Access to HACC services is governed by the HACC National Program Guidelines (2002), which provides:

> The HACC Program does not generally provide services to residents of aged care homes or to recipients of disability program accommodation support service, when the aged care home/service provider is receiving government funding for that purpose. Nor does it generally serve residents of a retirement village or special accommodation/group home when a resident’s contract includes these services…

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[17] *Submission* 96, p.18 (Australian Government).

[18] Steering Committee for the Review of Government Service Provision, *Report on Government Services 2006*, Productivity Commission, p.12.8.

[19] *Submission 96*, p.17 (Australian Government).

[20] Hales C, Ross L & Ryan C, *National Evaluation of the Aged Care Innovative Pool Disability Aged Care Interface Pilot*, Australian Institute of Health and Welfare, 2006 p.37.

> The excluded services, also known as 'out of scope', are classed as such because funding is already provided for them through other government programs.
>
> Excluded services are: accommodation (including rehousing, supported accommodation, and aged care homes or a related service)…[21]

5.22 In general all services provided by supported accommodation services under State and Territory government disability programs are regarded as ‘a related service’. This eligibility barrier exists so that HACC services would not be provided where services would be funded under another government program such as the CSTDA, or in other words to prevent 'double dipping' (the receipt of substitutable services from multiple program sources of funding).[22]

5.23 A number of submissions and witnesses raised the issue of the bureaucratic boundaries between the disability and HACC services and the problems caused. For example Associate Professor Christine Bigby stated:

> What is happening is that people are living in shared supported accommodation funded by disability services, and the Commonwealth funded aged care services or HACC services are saying, "We can't provide top-up support, we can’t provide expertise, we can't provide in-home nursing, because otherwise that would be double dipping".[23]

5.24 Ms Raelene West commented:

> Continuing to be problematic is the interface between the CSTDA and HACC funding arrangements…The shortfall in disability services resources however has seen many people with disabilities being forced to utilise HACC services to make up the need for services they require to live independently within the community. In many cases, as the Young People in Nursing Homes campaign has shown, many people with disabilities are being forced into institutional facilities because of limited or no other accommodation options available. The use of HACC funding to provide disability services therefore provides a messy interface between Commonwealth HACC funding and State/Territory funded disability services.[24]

Aged Care Assessment Program

5.25 The objective of the Aged Care Assessment Program is to assess the needs of frail older people and their eligibility to access available care services appropriate to their care needs. This is largely through Aged Care Assessment Teams (ACATs). In

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[21] *National Program Guidelines for the Home and Community Care Program 2002*, pp.9 -10.

[22] Hales C, Ross L & Ryan C, *National Evaluation of the Aged Care Innovative Pool Disability Aged Care Interface Pilot*, Australian Institute of Health and Welfare, 2006 p.35-36.

[23] *Committee Hansard* 28.9.06, p.44 (Assoc. Prof. Bigby).

[24] *Submission* 44, p. 19 (Ms R West).

general ACATs have access to a range of skills and expertise and are able to comprehensively assess older people taking account of the restorative, physical, medical, psychological, cultural and social dimensions of their care needs. ACATs involve clients, their carers, and service providers in the assessment and care planning process. A key feature of the ACAT process is face-to-face assessment. While ACATs can refer to a variety of services, including HACC services, their assessment is mandatory for access to Commonwealth funded residential aged care (permanent or respite) as well as some community and flexible care.

5.26 The Committee received evidence that ACATs were not sensitive to requirements of people with disability who also required care for needs associated with ageing. For example Dr Jennifer Torr commented:

> The average age for someone with Down syndrome to develop Alzheimer's disease is around 50. In a shared supported accommodation house, if the carers in that house approach the aged-care assessment services or teams, they are routinely told that the person is under 65. If you ring up and say you want to receive services, the first thing they do is get the person’s name, address and date of birth. If they are under 65, they say, 'They’re under 65.' You say, 'Yes, but they’ve got Down syndrome.' The reply is, 'We don’t see people with intellectual disabilities.' That is fair enough. It is not the role of the aged-care assessment teams to do assessments for someone who is under 65 with an intellectual disability. However, this is for someone who has an age related disorder, Alzheimer’s disease, which is a progressive and currently terminal condition. When that is pointed out to them the next thing they say is, ‘But we don’t put young people into nursing homes.[25]

Community Aged Care Packages

5.27 Community Aged Care Packages (CACPs) provide an alternative home-based service for elderly people who an ACAT assesses as eligible for care similar to low level residential care. The program provides individually tailored packages of care services that are planned and managed by an approved provider.

5.28 CSTDA clients in supported accommodation are also not normally eligible to receive a CACP. Provisions that allow younger people with disabilities to be considered for a CACP do not apply in the case of those who live in supported accommodation settings.[26] An older person with a disability who resides in supported accommodation would also not be able to access assistance through a CACP. The guidelines provide that people who live in supported accommodation facilities and receive funding through government programs to provide services similar to CACPs, or where lease arrangements include the provision of similar services, are not eligible to receive CACPs. While it appears some scope exists for CACPs to co-exist with

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[25] *Committee Hansard*, 28.9.06, p.45 (Dr J Torr).

[26] AIHW, *Disability and Disability Services in Australia – based on an extract of Australia's Welfare 2005,* Canberra 2006, p.35.

disability services, the 'governing principle is that people are not receiving the same services from different sources at the same time'.[27]

Extended Aged Care at Home (EACH) program

5.29 The EACH program provides tailored and managed packages of care, including nursing care or personal assistance, targeted at the frail aged and who have care needs equivalent to a high level of residential care. The Aged Care Assessment and Approval Guidelines note that it should be 'extremely rare' for an ACAT to approve a younger person for an EACH package. The guidelines state that:

> These packages are intended to be provided to frail older Australians. Disability programs managed by state and territory governments are the main providers of services to assist younger people with disabilities to remain at home.[28]

Residential aged care

5.30 Residential aged care is intended for frail older people whose overall care support needs cannot be adequately met in the general community, even with HACC services, CACPs or EACH packages. Residential aged care comprises accommodation plus care services within the accommodation setting (for example, nursing care, personal care, meals and laundry). A person approved for residential aged care by an Aged Care Assessment Team is approved for either residential respite care or low level or high level permanent residential care.

5.31 A person with a disability who would not be classed as an aged person may still be eligible for residential aged care if there are no other care facilities more appropriate to meet the person's needs. In the past residential aged care has been the main type of aged care service to be accessed by people with disabilities who live in CSTDA-funded accommodation facilities because this group is not ordinarily entitled to access community aged care programs funded by the Commonwealth. For a person with a disability, transferring to a residential aged care service can mean losing their existing specialist disability services.[29]

5.32 There were also indications that some younger people with a disability were being disadvantaged by recent policy decisions to divert them from accessing residential aged care. Dr Flett of the Brightwater Care Group commented:

> …the gate-keeping, if you like, for entry into nursing homes and hostels now is being quite scrupulously applied—for very good reasons—to preserve aged care beds for aged people, but it means that where a person might have been able to enter a nursing home in the past they cannot now.

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[27] DOHA, *Aged Care Assessment and Approval Guidelines*, September 2006 p.60.

[28] DOHA, *Aged Care Assessment and Approval Guidelines*, September 2006 p.8.

[29] Hales C, Ross L & Ryan C, *National Evaluation of the Aged Care Innovative Pool Disability Aged Care Interface Pilot*, Australian Institute of Health and Welfare, 2006 p.37.

> And so they are sitting in hospitals or in other services for a much longer time, because the queue is a whole lot longer.[30]

Young people in aged care

5.33 In June 2004 there were 6,240 clients aged under 65 years in permanent residential aged care, representing 4.3 per cent of all residents. Of these clients, 987 (16 per cent) were aged under 50 years.[31] There has been recent concern about the significant number of young people with disability in residential aged care. Such an environment is generally considered inappropriate for younger people (with the average age of residents being 84 years on entry to care) and is a 'last resort'. In the *Quality and equity in aged care* report this Committee found the situation of younger people in residential aged care facilities 'unacceptable in most instances' and it recommended that individual situations be assessed and alternative accommodation be provided.[32]

5.34 In February 2006, the Council of Australian Governments (COAG) announced joint funding of $244 million over five years for a programme aimed at reducing the number of younger people with disability in residential aged care. This program will initially target people aged under 50 years and people will only be moved to alternative, more appropriate services if they wish to do so.

Impacts of the aged care/disability interface

5.35 A number of submissions regarding the aged care/ disability interface outlined problems relating to the availability of aged care services when people reach the age of 65. Other submissions highlighted what they perceived as an unfair difference in the availability of aged care services for people who were disabled. Dr Morkham of the YPINH Alliance commented:

> We have a very fragmented system at the moment. It is divided according to age, not need. The quite extraordinary situation exists where you are considered young and disabled until you are 65, whereupon your disability magically disappears and you are simply old. This means that you lose some of the valuable disability supports and services, if you can get them, that you may need to continue beyond 65.[33]

5.36 The lack of clarity of the interface between disability and aged care services also appears to be creating additional burdens for service providers. Ms Armstrong of Endeavour commented:

> We are currently finding that one of our levels of frustration is our ability to work with all levels of government to successfully pilot our way through

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[30] *Committee Hansard* 5.10.06 p.35 (Brightwater Care Group).

[31] AIHW, *Australia's Welfare*, p.243.

[32] Senate Community Affairs Committee, *Quality and equity in aged care*, p.127.

[33] *Committee Hansard*, 28.9.06, p.4 (Dr B Morkham, YPINH Alliance).

> the ageing issue and to develop seamless transitions between the different services required by people, regardless of the jurisdiction and funding body. The organisation strongly supports the principle of ageing in place. It is one of the key challenges that we are facing. Cross-jurisdictional issues between Commonwealth and state funding and program bodies impact upon Endeavour's ability to successfully and adequately acquire funding and supports, as well as to undertake transitional planning for service users wanting to retire from Commonwealth business services, where they live in state funded, non-vocational services.[34]

5.37 There were also concerns expressed regarding the lack of uniformity and consistency of assessment procedures for access to disability services and aged care services. Carers Australia commented:

> 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.[35]

Innovative Pool Aged Care Disability Interface Pilot

5.38 The Disability Aged Care Interface Pilot was established under the Aged Care Innovative Pool, an initiative of the Department of Health and Ageing. Through the Pilot, a pool of flexible care places was made available outside the annual Aged Care Approvals Rounds to trial new approaches to aged care for specific population groups. This Pilot was aimed at people with aged care needs who live in supported accommodation facilities funded under the CSTDA and who were at risk of entering residential aged care. The objective was to test whether these people have aged care needs distinct from their disability needs and whether the provision of aged care services in addition to disability services could reduce inappropriate admissions to residential aged care.[36] The Pilot delivered additional services, tailored to individual needs, which are aged care specific, to assist clients remain in their current CSTDA funded living situations for as long as possible. Nine Pilot projects commenced operation between November 2003 and December 2004. The Department of Health and Ageing has agreed to continue to fund clients already in the pilots, but not to admit new entrants or to expand the pilots into a program.

5.39 An AIHW evaluation of the Pilot identified a number of benefits for the individuals involved and the service delivery systems. It indicated that 'additional assistance delivered with an aged care focus has significantly improved the quality of

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[34] *Committee Hansard*, 17.11.06, p.35 (Ms P Armstrong, Endeavour).

[35] *Submission* 52, p. 8 (Carers Australia).

[36] *Submission* 96, p 19 (Australian Government).

life of individual clients and that these improvements are likely to have long-term benefits for individuals and service systems'. The evaluation participants received was a median of approximately 6 additional hours of assistance in addition to aged care planning and ancillary services.[37] Comprehensive and collaborative joint assessments involving aged care providers and disability sector providers resulted in very few inappropriate referrals.

5.40 However, the AIHW evaluation also identified issues with the provision of aged care services to people with disabilities, including difficulties in assessing what were aged care specific needs and what was to be considered expenditure on aged care.

> Perhaps the greatest conundrum for evaluation is the contrast between seven projects operating separate aged care and disability budgets and two, Ageing In Place and MS Changing Needs, that operate with aged care services fully integrated into the disability accommodation service using pooled aged care and disability budgets. To some extent the latter two projects were able to provide a more seamless service, but there were indications that pooled funding and full integration made the reporting of aged care specific expenditure more difficult…
>
> From a system-wide perspective the top-up model of aged care funding seems to be an incomplete solution to the problem of limited choice in community-based aged care for people with disabilities in supported accommodation. It helps in individual cases by patching over systemic problems at the interface of disability and aged care programs and at the interfaces between different types of specialist disability services. There is a risk that some groups will fall through gaps in services modelled on separate aged care and disability funding. The high degree of overlap between the types of assistance delivered by Pilot projects and those funded under the CSTDA means that criteria are required to establish how aged care funding is to be used. The Pilot has shown that individual care planning will tend to address areas of need that are implicated in an individual's risk of entry to residential aged care and that these areas are closely related to features of the disability support system.
>
> The evaluation concludes that eligibility criteria based on interpretations of aged care specific need or age-related need, which have been demonstrated to vary, may lead to program management rules such as those which currently prevent access to HACC-funded services for the target group. Using subjective eligibility criteria, the only way to avoid questions of 'double dipping' and 'cost shifting' is for program managers to trust the processes that determine eligibility for aged care. There is also the unresolved issue of people with disabilities aged over a certain age, say 60 or 65 years, who live in supported accommodation and whose risk of admission to residential aged care is assessed as mainly disability related.

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[37] Cathy Hales, Lydia Ross & Claire Ryan, *National Evaluation of the Aged Care Innovative Pool Disability Aged Care Interface Pilot*, Australian Institute of Health and Welfare, 2006.

> The needs of these older Australians are not addressed by the evaluated model.[38]

Support for the Pilot

5.41 A number of submissions expressed support for the Pilot and various 'top-up' or blended funding arrangements as a possible solution to problems with the disability/aged care interface. Associate Professor Bigby commented on the success of the Pilots:

> They demonstrated that there can be partnerships between disability workers in the disability system and in the aged care system. With a fraction of extra funds you can resource the people who are in the shared supported accommodation—the staff—to respond appropriately and to add to their knowledge and their ability to respond to people's age related health care needs in particular. They demonstrated that you can share staff, you can resource staff or you can employ specialist staff—that the agencies can work together. They were very successful in improving the quality of life of all the residents in those houses where people were ageing, and they demonstrated that people could be retained and age in place. They also showed that the amount of top-up that was necessary was significantly less, I think, than a full package.
>
> …they are people with a disability who are being compensated for that disability and they are also people who are ageing and are entitled to support from the aged care system. I do not think they are double dipping, but they certainly do not need twice as much. You need to look at it that way. In terms of the shared arrangement between the Commonwealth and the state, the state pays the same and the Commonwealth pays a fraction of what it would pay if the costs were transferred completely. And that is what is happening at the moment: there is a cost shift going on between the states and the Commonwealth.[39]

5.42 ACROD argued in their submission that:

> The principle of 'top up' funding (with clients of disability service programs entitled to attract Commonwealth Aged Care funding) should be more widely applied in recognition of the fact that the needs that arise from ageing are additional to those associated with a long-term disability.[40]

5.43 This argument was repeated by Aged and Community Services Australia, which did not regard the concerns in relation to distinguishing disability and aged care needs as significant:

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[38] Hales C, Ross L & Ryan C, *National Evaluation of the Aged Care Innovative Pool Disability Aged Care Interface Pilot*, Australian Institute of Health and Welfare, 2006 pp.219-221.

[39] *Committee Hansard*, 28.9.06, p.48 (Assoc. Prof. C Bigby).

[40] *Submission* 45, p.19 (ACROD).

> This principle of blended funding, enabling services and support for those care needs related to disability and those to ageing, needs to be able to be applied throughout the system…
>
> However, the Department of Health & Ageing, while committing to continued funding for existing clients, will not continue the program or make these services available as a mainstream, rather than pilot, program. The main issue appears to be the need to determine which supports are required as a result of the disability a person may have and which, and how much, relate to the persons ageing. This is a prime example of concerns about cost shifting between jurisdictions getting in the way of effective service delivery to clients. A practical way of determining, or approximating, this needs to be developed or it will be used as a reason for not being able to combine funds and create service responses which genuinely meet the needs of this population.[41]

5.44 However, the Commonwealth saw the need for more work in determining the most appropriate model to address the ageing needs of people with disability:

> Preliminary results of the evaluation of these pilots by the Australian Institute of Health and Welfare indicate that identifying ageing related care needs of people already receiving disability services is complex. Although the pilots enabled some useful insights, further work is needed to inform any consideration by governments of how best to meet their needs.[42]

Ageing in place

5.45 An important component of aged care services is the principle of 'ageing in place'. The concept of ageing in place was a key part of the *Aged Care Act 1997* which increased the opportunities for people to remain in their home (however defined) regardless of their increasing care needs.[43] Ageing in place as a policy was designed to enable residents to remain in the same environment as their care needs increased, in facilities which could offer appropriate accommodation and care. The advantages of ageing in place for the elderly are significant and include less disruption to their lives and continuity of care in a familiar environment.

5.46 Broad support was expressed for the right of people with disabilities to 'age in place' where they choose to do so.[44] However, a part of the difficulty of the jurisdictional overlap and inefficiency in the interface between aged care and disability services is the commitment to allow people to age in place. If people with disability are to be allowed to age in place then their aged care needs must be assessed and then aged care services must provided to them as they age.

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[41] *Submission* 32, p.2 (Aged and Community Services Australia).

[42] *Submission* 96, p.19 (Australian Government).

[43] *Submission* 32a, p.2 (Aged and Community Services Australia).

[44] *Submission* 96, p.19 (Australian Government); *Committee Hansard*, 17.11.06, p.35 (Ms P Armstrong, Endeavour); *Submission* 45, p.19 (ACROD); *Submission* 48, p.9 (Dr J Torr).

5.47 The Queensland Government proposed a clear division to provide clarity regarding which level of government is responsible for people over 65 years of age with a disability.

> The Queensland Government considers that the Commonwealth Government should take responsibility for those aged over 65 years, including those who have a disability, while the Queensland Government should maintain responsibility for those aged less than 65 years. To have clear policies in this area would help to reduce the complexity surrounding the provision of services to this cohort.[45]

5.48 However the Commonwealth noted this could be contrary to the principle of allowing people with a disability the choice to age in place:

> As a growing number of people with disability are living longer, the principle of 'ageing in place' should apply to the disability community, just as it does to the general community, so that people with disability are encouraged to age in place and, where they choose to do so, are able to access appropriate support services.
>
> Suggestions have been made that the Australian Government should take responsibility for older people with disability and that all their care needs should be regarded as aged care needs.
>
> Such suggestions would be at odds with 'ageing in place' and conflict with responsibilities under the current CSTDA. In addition, as with older people generally, not all people with disability who are ageing will require aged care services (noting that the average age at entry into residential aged care is 84 years). Continuity of their specialist disability support services as they age will be essential.[46]

5.49 The Committee considers that people with disabilities should have the option of ageing in place if they so desire. Funding arrangements and eligibility criteria should not disallow people with disabilities in supported accommodation from receiving aged care services. At the same time, the Committee recognises that for some people with disabilities, an aged care facility may offer the most appropriate accommodation setting given their particular circumstances. In such cases, access to residential aged care services should be made available even if the person is not over 65 years of age

Recommendation 22

5.50 That funding arrangements and eligibility requirements should be made to allow supplemental aged care services to be made available to people with disabilities who are ageing, allowing them to age in place. Administrative funding arrangements should not impede access to aged care services for people with a disability who are ageing.

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[45] *Submission* 112, p. 7 (Queensland Government).

[46] *Submission* 96, p. 19 (Australian Government).

Interface with health care

5.51 People with disabilities have very diverse health needs and like the rest of the population require access to health services. People with disabilities experience poorer health outcomes compared to the general population and can have significantly lower life expectancy as a result. The Victorian Government commented:

> Higher incidences of conditions such as epilepsy, mental health disorders, vision and hearing impairments, gastrointestinal conditions, obesity, osteoporosis and dental disease are reported frequently. Additionally these health conditions are either poorly recognised or inadequately managed by health professionals. Many of these diseases and conditions are preventable or through earlier identification and intervention the impact can be significantly decreased thereby reducing more costly interventions.[47]

5.52 Strengthening 'access to generic services for people with disabilities' was one of the strategic policy priorities in the current CSTDA. Access to health care was identified as an issue for people with a disability. Associate Professor Bigby commented:

> There is also an assumption that, under the CSTDA, people with disabilities have access to healthcare services. They are not funded through the CSTDA, but it is assumed that, like everybody else, they have access to good-quality medical services. It is very clear from the research both here and overseas that people with disabilities, people with intellectual disabilities in particular, have difficulty accessing high-quality medical care. Our generic system is not attuned to dealing with people with complex needs associated with disability. There are almost no specialist services for adults and older people with lifelong disabilities that address their particular healthcare needs.[48]

5.53 Problems with access to generic health services were also identified by the Disability Advocacy and Complaints Service of South Australia:

> Women in wheelchairs still cannot be transferred onto examination tables, many private practitioners and allied health services such as chiropractors, do not provide wheelchair access. Private psychiatrists refuse to treat people with intellectual disabilities and paranoid schizophrenia.[49]

5.54 The role of disability service providers and health care was highlighted by Dr Torr:

> However state disability services do have a role to play in health care of people with intellectual disabilities. As the providers of supported accommodation and general care disability service providers have a role to play in managing lifestyle risk factors. Disability workers are expected to

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[47] *Submission* 99, p.20 (Victorian Government).

[48] *Committee Hansard* 28.9.06, p.44 (Assoc. Prof. C Bigby).

[49] *Submission* 68, p.12 (Disability Advocacy and Complaints Service of South Australia).

> be able to identify when someone needs to access a health service, arrange access, coordinate care, attend appointments, manage health information and to follow through on recommendations. All of this is required of people who are not health professionals.[50]

5.55 There is growing interest in the issue of health services for people with disabilities, their health outcomes, access to services and the quality of those services. Concerns which have been identified often relate to the training and expertise of health professionals. These concerns include: problems in communication between health professionals and people with disabilities; health professionals' inadequate knowledge of health conditions of people with disabilities, including patterns of dual diagnoses such as mental health and intellectual disability; 'diagnostic overshadowing' when a person's symptoms or condition is wrongly attributed to their disability rather than a separate medical condition; and the need for health professions to ensure sexually active people with disabilities are respected and given the 'appropriate information and support to protect themselves'.

5.56 Other issues for people with disability and health services include: the adequacy of medical records; the need for Medicare schedules to recognise that some people with disabilities require longer consultations to ensure the required communication takes place; the need for Auslan services; affordability of equipment; medication labelling and instructions (a variety of formats are needed); and the need for trials of new drugs to include a wider range of people, including people with disabilities.[51]

Recommendation 23

5.57 Access to generic services should continue to be a priority for the next CSTDA, particularly access to health care services.

Ageing informal carers

The importance of informal care

5.58 Family members shoulder the main responsibility of meeting the needs of people with disabilities, providing unpaid care and assistance on a regular and sustained basis. Of the 200,493 CSTDA service users during 2004-05, 84,964 (42 per cent) reported the existence of an informal carer. Of these 57,712 (68 per cent) reported that this carer was their mother. The next most commonly reported carer relationships were father (6.5 per cent), other female relative (6.3 per cent), wife/female partner (4.6 per cent) and husband/male partner (4.3 per cent).[52]

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[50] *Submission* 48, p.6 (Dr J Torr).

[51] AIHW, *Australia's Welfare*, 2005, p.244.

[52] ABS, *Disability, Ageing and Carers: Summary of Findings*, 4430.0, 2003, p.10.

5.59 Trends towards deinstitutionalisation and non-institutionalisation mean that greater numbers of people with disabilities now live in the community, frequently with their families. In 2003, nearly 454,000 people aged 65 years and over provided assistance to people with a disability. Around one-quarter of these care providers (113,200) were a primary carer, that is, they provided the most assistance to the care recipient. Overall, people aged 65 and over accounted for 24 per cent of primary carers of people with a disability.[53] 37 per cent of primary carers spent on average 40 hours or more per week providing care and 18 per cent spent 20 to 39 hours per week.[54]

5.60 The Committee's report *Quality and equity in aged care* recognised the tragic challenges facing ageing carers.

> Many ageing carers have provided care for family members for years, if not decades. This length of caring takes its toll on ageing carers: physically, financially, socially and emotionally. At a time when others have enjoyed a long retirement, carers face the anxiety of what will happen to their children once they require aged care.[55]

5.61 Evidence provided to the Committee again highlighted the problems facing ageing carers, particularly parents who were caring for children with disabilities. For example Ms Catherine Edwards, who cares for her son, commented:

> Most people look forward to a day they can retire; go on holidays and generally slow down a bit. When can carers look forward to retirement?
>
> With no security, my motivation is practically zilch and like many others in similar situations, I see myself reaching crisis point sooner than I technically would expect. I would dearly like to see my son settled into supported accommodation where I can assist in the transition making it easier for him, the staff and my family.[56]
>
> He will be in his 30s when I am in my 60s. How will I manage? It is not a luxury. It is not about families trying to renege on responsibilities. It is about quality of life, not just for the person with a disability but for the whole family. It is about choice for families. It is about being able to choose when the time is right for the whole family to say, "We can't do this anymore." This country needs a really good system of supported accommodation for adults with a disability.

5.62 Submissions also made clear that the ageing population was placing increasing pressures on carers. Carers Australia commented:

> 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

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[53] AIHW, *Australia's Welfare*, p.147.

[54] ABS, *Disability, Ageing and Carers: Summary of Findings*, 4430.0, 2003, p. 10.

[55] Senate Community Affairs Committee, *Quality and Equity in Aged Care*, p 83.

[56] *Submission* 92, p.1 (Ms C Edwards).

> time. Many carers who have cared for a child with a disability for a long time now require their own age care services.[57]

Transitional arrangements for ageing carers

5.63 An ageing population means that an increasing number of unpaid carers will require aged care services themselves and will no longer be able to act as carers. The people with disability for whom they care will need to be transitioned to alternative paid care. The uncertainty surrounding the issue of future care was a critical issue for informal carers and people with disabilities.

5.64 The AIHW study of unmet need in 2002 noted that disability services packages and residential arrangements are most valued when they allow a carer to begin withdrawing from the primary care role and assure carers regarding future care arrangements. It noted that the fundamental questions facing ageing carers are 'When can I retire?' and 'What will happen when I die?' [58] It was suggested to the Committee that a wider range of options was needed to support unpaid ageing family carers including in the transition arrangements involved with relinquishing care. This would assist in providing unpaid family carers with greater certainty in planning for the future. Ms Estelle Shields commented:

> I would also like to see a recommended age, possibly 30 or 35 for the disabled person or 65 for the primary carers, whereupon the family was offered (but not compelled to accept) an appropriate residential setting for their family member.[59]

5.65 Ms Deidre Croft made a similar argument highlighting the need to address the uncertainty for family carers:

> Basically they want to have an assurance that, when they indicate that they can no longer provide the care that is required for their son or daughter, there will be an alternative available…
>
> One of the concerns that I have, particularly with regard to people with a lifelong disability, is that the assumption is that parents will make a lifelong commitment. If you do not have an end point, you cannot pitch yourself or pace yourself over a time frame. So parent carers want some assurance that this is the extent of the commitment. Given that we define ‘youth’ these days normally as up to 25 years of age, I think that at 25 years of age an adult with a disability, even if it is an intellectual disability, should have the opportunity to leave the family home…
>
> If a family carer knew: "When my son or daughter turns 20 I have given my life, I have done my all; I do not have to break my back anymore," I think that would sustain people. It would give them a sense of hope that they can

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[57] *Submission* 52, p.8 (Carers Australia).

[58] AIHW, *Unmet need for disability services: effectiveness of funding and remaining shortfalls*, Disability Data Briefing Number 22, September 2002, p.6.

[59] *Submission* 10, p.1 (Ms E Shields).

> go the distance, whereas now people have no hope, they look at an indefinite future.[60]

Respite for ageing carers

5.66 In the 2004-05 Budget, the Commonwealth announced that it would provide $72.5 million over four years from 2004-05 to 2007-08, to increase access to respite care for older parents caring for their sons and daughters with a disability. Under this measure, parents aged 70 years and over who provide primary care for a son or daughter with a disability will be entitled to up to four weeks respite care a year. Parent carers aged between 65 and 69 who themselves need to be hospitalised will be entitled to up to two weeks respite care a year.

5.67 This increased level of access to respite care is subject to state and territory governments matching the Australian Government's offer and managing combined funds to directly assist older parent carers. As part of the announcement, the Minister for Family and Community Services indicated that this Budget measure would be implemented via bilateral agreements between Australian Government and state and territory governments under the Commonwealth State Territory Disability Agreement.

5.68 A number of submissions argued that while they welcomed the additional respite care being made available it did little to address the need for long-term accommodation. Additional respite did not address the concerns of family carers that their loved one would be well cared for when they were no longer able to do so themselves.

Recommendation 24

5.69 That Commonwealth, State and Territory governments, as part of their commitment to life long planning for people with disabilities, ensure:

- **that transitional arrangement options are available for people with disabilities who are cared for by ageing family members; and**
- **that there are adequate options for people with a disability and their carers to plan for their futures.**

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[60] *Committee Hansard* 5.10.06, p. 69 - 71 (Ms D Croft).

CHAPTER 6

ALTERNATIVE FUNDING ARRANGEMENTS FOR DISABILITY SERVICES

6.1 This chapter will examine alternative funding arrangements for disability services. In particular, it will examine individualised funding and insurance models.

Individualised funding

6.2 With the deinstitutionalisation movement of the 1960s, people with a disability were encouraged to live independently. However, 'professionals still provided top-down support and people with a disability still had little power and influence'. This was followed by moves towards individualised planning and involved interdisciplinary coordination, accountability, integration and consumer participation. This came to be criticised as it retained the pivotal role of the professional, had a bureaucratic style for life planning and emphasised quality program delivery over quality lifestyles. There followed a move to 'person-centred-planning' which focussed on the person and their wishes and aspirations.[1]

6.3 Some witnesses argued that the current system of the provision of disability services is based on the financial support of service providers by government rather than financial support of users of disability services to purchase services. The Australian Federation of Disability Organisations (AFDO) commented that the current service delivery models:

- are inflexible and unnecessarily restrictive in what is defined as a legitimate support service;
- do not allow people with disability to take risks, make mistakes or simply to change their minds;
- physically restrict people through the lack of portability of funding; and
- take decision making power away from people with disability and put it in the hands of service providers or carers.[2]

6.4 Many witnesses supported the increased use of individualised funding to people with disability to enable them to purchase and control the services they require. Individualised funding can be undertaken in a wide range of ways including direct payments, indirect payments, and funding held by trusts. What all these types of

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[1] Laragy C, 'Individualised funding in disability services' in T Eardley and B Bradbury eds, *Competing Visions: Refereed Proceedings of the National Social Policy Conference 2001*, SPRC Report 1/02, Social Policy Research Centre, University of New South Wales, Sydney, pp 263-278.

[2] *Submission* 90, p.13 (AFDO).

individualised funding have in common is the principle that the funding is put under the control of the individual. It enables the recipient to decide which services they require, how they will be delivered and when they will be delivered, that is the individual's needs shape the service system, rather than the service system shaping the life of the person with a disability. The implementation of individualised funding in other countries has been through service brokers, personal agents, fiscal intermediaries and vouchering mechanisms. These assist with budgeting, selecting services, managing payments and accountability.[3]

6.5 Some supporters argued that direct payments allow a person with a disability to purchase their supports according to their needs and lifestyle requirements. The services purchased could include personal support, domestic services and social services. For example the NSW Council for Intellectual Disability thought that a system of self managed funds including Direct Payments is likely to lead to the most effective outcomes for people with disabilities and be more flexible to adapt to people's changing needs.[4]

6.6 Similarly Queensland Advocacy Inc (QAI) commented that 'direct payments elevate a person with a disability from a welfare and service recipient to a potential employer and purchaser of community based services'. Direct payments would provide personal control to purchase only those support services that are convenient and appropriate for their personal needs and support their personal goals and requirements. This would also enhance self-determination and overcome the problems people with a disability face when moving between and within jurisdictions.[5]

6.7 Supporters of this arrangement argued that there were significant financial benefits in this method of funding disability service:

- Administrative costs would be lessened.
- Increased competition would lead to lower costs for the provision of some services: some governments place emphasis on specialist disability support services for the provision of tasks which may be more economically delivered by mainstream services for example, house cleaning; This would 'open up' an otherwise closed market and provide employment opportunities within communities.[6]

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[3] Laragy C, 'Individualised funding in disability services' in T Eardley and B Bradbury eds, *Competing Visions: Refereed Proceedings of the National Social Policy Conference 2001,* SPRC Report 1/02, Social Policy Research Centre, University of New South Wales, Sydney p.264.

[4] *Submission* 46, p.6 (NSW Council for Intellectual Disability).

[5] *Submission* 26, p.2 (QAI).

[6] *Submission* 26, p.1 (QAI).

Implementing a direct payment system

6.8 QAI suggested that the mechanisms already exist to deliver direct payments to people with a disability:

- Many people with disability and their families are currently in the Centrelink system either through Disability Support Pension, Carer's Payment or Carer's Allowance and can be easily added if they are not.
- Some service provision can be allocated a Medicare Benefit number that allows people to purchase support services through the Medicare system.
- Currently any person with a disability cannot access support services without a formal diagnosis from an appropriate medical specialist. Medical specialists could also assess the levels of support needed in the process of diagnosis which in turn indicates level of funding for a person's need. A central national data base that recorded this information would provide ease of coordination, as well as providing a more accurate picture of disability nationally for current and future needs.[7]

6.9 Other witnesses noted that the Commonwealth has already started a move to individual funding with the Case Based Funding program for employment support.[8]

6.10 Disability Advocacy and Complaints Service of SA pointed to a model espoused by People Power which called for the consolidation of all existing Commonwealth and State disability funding programs (with the exception of respite care) in a person-based funding entitlement (the Disability Funding Entitlement). The Entitlement would be allocated to the nominated agent (a community organisation, a health fund, a consumer co-operative, a for-profit financial agent, a GP or lawyer) or family member. Disability Agents would be permitted to contract with providers and practitioners in developing price and service quality arrangements and would be free to develop packages of care, innovations in care planning and information management, home-care supports, accommodation options and arrangements, and employment services for their people. People with a disability would be free to select their preferred agent, and to transfer from one to another annually.

6.11 The Disability Funding Entitlement would be adjusted for factors such as age, sex, disability and health status, and life-cycle-stage in order to ensure that agents will compete to attract the support of people with all kinds and severities of disability. Every child or adult who is diagnosed with a disability is eligible for the Disability Funding Entitlement from the time of diagnosis until death or until the disability has ceased to disable.

6.12 It was also suggested that a Respite Entitlement be established. The Respite Entitlement would be assigned directly to family carers or their agents as a respite

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[7] *Submission* 26, p.3 (QAI).

[8] *Submission* 50, p.11 (National Council on Intellectual Disability).

service voucher, adjusted with a severity-of-disability and difficulty-in-caring rating. The Respite Entitlement may be used to purchase in-home respite or centre-based respite according to the preference of the carer.

6.13 Other elements of the proposed system included an independent Disability Support Information Service to provide comparative online price and service quality data on Disability Agents, disability services, respite services, accommodation services, health services and practitioners and a Supported Accommodation Authority to research, design, purchase, and build innovative supported accommodation options.[9]

Accountability

6.14 One aspect to be considered in any individualised funding arrangement is the extent and form of accountability that will be required from people with a disability in relation to the use of public funding. AFDO commented that 'like the CSTDA, accountability by people with disability should be outcome focussed, in line with the goal of improving the quality of life of people with disability and enabling them to enjoy full citizenship'.[10]

Limitations of individualised funding

6.15 While individualised funding was supported by many, some shortcomings have been identified:

- individualised funding systems are not simple and can be more complex for individuals and their families to navigate;
- people with disability should be able to choose the level of self-sufficiency they need and are comfortable with, from traditional agency based services to self-management;
- individualising funding does not by itself lead to a person having increased control over their life or to a better quality of life – brokers can simply replace case managers as controlling forces and deciding how funds are spent;
- the removal of professional and service staff can lead to people with disability becoming increasingly isolated and more vulnerable to exploitation by family members and carers; and
- governments tend to abrogate their responsibility for individual support and service development once payments are devolved.

6.16 AFDO also noted that research has also identified the risk that people with disability, their carers and families, who are often already under immense pressure, can be asked to take on even greater responsibility under individualised funding

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[9] *Submission* 68, p.23 (Disability Advocacy and Complaints Service of SA).

[10] *Submission* 90, p.13 (AFDO).

models. Not only do they become directly responsible for the results of poor decision making, research suggests that apparent cost savings and efficiencies in the model may be gained at the literal expense of individuals and families, who absorb the cost of managerial tasks that were once undertaken by others.[11]

6.17 Both Canada and the United Kingdom have adopted individualised funding arrangements.

Vouchers

6.18 Vouchers were also raised as an alternative funding arrangement for disability services. Like individualised funding, arguments in support of a voucher system for disability services highlight that people with disabilities should be empowered to choose their services and where funding will go. This would encourage competition and better services from disability services providers. The providers with better quality disability services would attract more clients and other providers would have to reform. However, there were concerns raised about the practicality of a voucher system. NCOSS commented:

> …a voucher is useless if there are no services available to be delivered to the person in need and the services are not flexible enough to meet the person's needs. I fear for people in rural, regional and remote New South Wales, where everyone is walking around with a voucher but there are no services. Vouchers are just a different way of rationing limited resources. There are a lot of benefits in terms of the individualised stuff—and I know that a lot of people argue in terms of self-determination, and that is certainly attractive—but at the end of the day if it is still the same pie it will just get sliced a different way.[12]

6.19 Similarly Mr Craig Rowley of Multiple Sclerosis Society of Queensland commented:

> Just commenting on the voucher system, the DSQ lifestyle packages are, in effect, a voucher system. People are allocated a certain amount of money which is fixed and then they go to service providers and choose the provider they like, and if they do not like them down the track they can change provider. That is all in theory. In practice, it is much tougher. The problem with the system is an assumption that that person has the capability to do that. The reality is that people with a disability, particularly a severe disability, are by definition functioning at a much lower capability than other people in the community. It is only people with very stable disabilities, perhaps people with paraplegia, who can use those systems very effectively.[13]

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[11] *Submission* 90, p.13 (AFDO).

[12] *Committee Hansard* 3.10.06 p.38 (NCOSS).

[13] *Committee Hansard* 17.11.06, p.60 (MS Society of Qld).

6.20 Moving to a system based on individualised funding arrangements could lead to efficiencies and improvements in the provision of programs and services by increasing competition in service provision and reducing administrative costs, however the introduction of such a system poses some challenges for people with disabilities, their families and carers (and also for governments). Individualised funding systems can become more complex to navigate, and decision support tools and services would need to be provided. Ideally, people with disabilities should be able to choose the level of self-sufficiency they are comfortable with, and the introduction of such a system should not result in people with disabilities, their families and carers being put under more stress and required to absorb the costs of additional managerial tasks.

Insurance options

6.21 Several countries have instigated insurance systems for long term care. For example, in Germany, public long term care insurance commenced in 1995 and is comprehensive and mandatory, covering about 88 per cent of the population. Premiums are paid by employees and employers. There are uniform eligibility and benefit criteria and covers both institutional and home based care. Family caregivers receive cash payments. In 2000, Japan overhauled an ad hoc system for funding care provision. This tax-funded system pays a flat rate 90 per cent of costs of all care homes and home care. The remainder comes from a private 'co-payment' regardless of means. Unlike Germany, Japan does not offer public support for family care, which was previously the dominant form of long-term care, because the Government wants to relieve what is sometimes an excessive burden on families, and especially on women, by changing the prevailing culture. The reform has succeeded in increasing the amount of formal home care services.

6.22 Both of these systems have succeeded in establishing a coherent and transparent funding system. Neither has resolved fully the issue of how to pay for mounting demand, and both governments are curbing costs by adjusting the terms of their schemes.[14]

6.23 In New Zealand, a nationalised, no-fault disability service system has operated since 1974. The New Zealand system, irrespective of fault, provides ongoing support services to those acquiring permanent personal injury.[15]

6.24 In Australia, some people with disability are funded through transport insurance and workers compensation mechanisms. It was suggested that these schemes could be extended to include catastrophic injury more generally. Witnesses pointed to the Victorian Transport Accident Commission Scheme which is a no-fault insurance system for people who are injured in a traffic accident. People with

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[14] Joseph Rowntree Foundation, *Paying for Long Term Care: Moving forward*, www.jrf.org.uk/knowledge/findings/foundations/0186.asp

[15] *Submission 44*, p.26 (Ms R West).

disability have access to the services and supports that they actually need. By contrast, 'it is very unlikely that somebody who is noncompensable will be able to feel comfortable that they have what they need and that might not be taken away from them again at some point'.[16]

6.25 YPINHNA commented:

> …we believe that something like a social insurance levy, similar to the Medicare levy in intent and scope, is needed for long-term care and support. It is clear that younger people who need to access such a scheme are a small proportion of the overall demand…So if one of these levies were put in place you would have time to build capacity before people age and before the rise in disability that accompanies age.[17]

6.26 Ms Raelene West favoured a system modelled on the New Zealand system but inclusive of a capped common law system and commented that such a system would serve to provide an effective model for a nationalised no-fault disability services support scheme. This scheme could incorporate the various funding sources (motor vehicle, workcover, Veteran's Affairs) into a pool of funding and provide funding for services on a parallel pathway as generic services. A common law component could then still be maintained for acquired injuries within this framework.[18]

6.27 Some State and Territories have insurance options for catastrophic injury caused by motor vehicle accidents or work-related injury. The Victorian Government commented that a more general catastrophic injury scheme would alleviate some of the cost burden to States and Territories of responding to people with acquired disability. A catastrophic injury scheme could also include acute inpatient care, rehabilitation, specialist and expert medical care, pharmaceuticals, and disability support. The Victorian Government supported a national approach to the development of a catastrophic injury compensation scheme but if this was not developed 'Victoria will proceed with exploring options for a catastrophic injury compensation scheme locally'.[19]

Accommodation and care options

6.28 The Committee received evidence about parent initiatives to finance accommodation options for their children. The Disability Advocacy and Complaints Service of South Australia commented that a group of parents, in partnership with government, had developed a model of accommodation in a regional centre. DACSSA commented that 'these partnerships may indicate a future trend where the government uses resources provided by parents to ensure the future accommodation needs of their

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[16] *Committee Hansard* 28.09.06, p.27 (BIA).

[17] *Committee Hansard* 28.9.06, p.5 (YPINHNA).

[18] *Submission* 44, p.26 (Ms R West).

[19] *Submission* 99, p.15 (Victorian Government).

children with disabilities'. However, DACSSA warned that although parents may fund the accommodation, there must be adequate care packages for long term viability.[20]

6.29 In 2005 the Commonwealth announced changes to make it easier for parents of children with severe disability to make private financial provisions for their children's future care and accommodation needs by enabling parents to put up to $500,000 into a trust without being affected by the means test.[21]

Recommendation 25

6.30 That a review of alternative funding arrangements be undertaken through the research and development program of the next CSTDA which specifically considers, amongst other elements:

- **the likely costs and benefits of individualised funding;**
- **the issues encountered in the introduction of alternative funding overseas;**
- **provisions and alternatives to allow people with disabilities to choose the level of self-sufficiency with which they are comfortable;**
- **the provision of decision support tools and services to assist people with disabilities, their families and carers.**

That the findings of the review be reported to the relevant Ministerial Council.

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[20] *Submission* 68, p.17 (DACSSA).

[21] *Submission* 96, p.17 (Australian Government).

CHAPTER 7

SHARED AREAS OF RESPONSIBILITY

7.1 This chapter will cover shared areas of responsibility under the CSTDA and other issues which were raised by submissions and during hearings including consultation with the disability community and occupational health and safety issues.

Information services

7.2 The complexity of the set of programs and services provided under the current CSTDA arrangements has been noted in Chapter 3. In such an arrangement information services become a crucial guide for people with disabilities and their carers on how to access appropriate disability services. A number of submissions and witnesses to the inquiry commented on the difficulties in obtaining information about which disability services were available. For example Brightwater Care Group commented:

> Families are often challenged by the responsiveness of the Disability system, not so much because of what might be available, but more because of their inability to understand the system and the easiest way to manoeuvre through it. While options for accommodation support may be available for people with disabilities, their carers lack clear and consistent information on how to access such support. This often leads to people giving up, or not applying for support they may be entitled to. This issue is often stronger for people with acquired disability who have not had natural entry into the system in childhood.[1]

7.3 The difficulties with navigating the current system raised the issue of the need for a single point of information - a 'one stop shop' for people with disability and their carers to obtain information regarding available services.[2] Ms Teresa Hinton of Anglicare Tasmania commented:

> There is no one point of information for people to go to. They may go to one agency and get a bit of the picture, and they go to another agency and get another bit of the picture. But there is no one point of information that can give them a picture of all the services they might be entitled to. A very common experience in the research was for people to tell us, "Well, it took us 14 years to find out that we could get assistance with shoes", for instance.[3]

7.4 The Committee also found there was a reliance on print and internet based solutions for disability information services that would be inappropriate for many

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[1] *Submission* 22, p.7 (Brightwater Care Group).

[2] *Committee Hansard* 5.10.06, p.26 (Mr P Smale).

[3] *Committee Hansard*, 22.11.05, p.25 (Anglicare Tasmania).

people with disabilities such as the vision impaired and people without internet access.[4] The Committee was also concerned at the low proportion of people from non-English speaking backgrounds who access CSTDA services as well as have access to interpreters. Ms Diana Qian of the National Ethnic Disability Alliance commented:

> One of the causes of the inequity, we believe to be a lack of information that is accessible in community languages. Information is the first step one can take to making informed choices, and if you cannot get accessible information about essential services—about what is available so you know where to go—you are basically stuck.[5]

Research and development

7.5 Under the current CSTDA the States and Territory governments jointly contribute, on a pro-rata basis in proportion to their respective populations at the time of contribution, $200,000 per annum to the national research and development fund which the Commonwealth matches.

7.6 A work plan linked to the CSTDA implementation plan is developed by the National Disability Administrators (NDA) and endorsed by Ministers to address key national and strategic research, development and innovation priorities. The CSTDA provides:

> 10 (5) The work plan will include the investigation of the need for new services, or enhancement of existing services, as well as innovations in planning and service delivery and the measurement of outcomes for people with disabilities using these services.[6]

7.7 The amount of CSTDA funding devoted to research and development was criticised as not sufficient to reflect the importance of the subject matters. Dr Ken Baker commented:

> It is really symptomatic of the weakness of the CSTDA that it allocates only about—on my calculation—0.012 per cent of total expenditure toward research. There is just no emphasis at all put on research which could help inform budgetary planning and which could drive innovation and continuous improvement.[7]

7.8 The ANAO audit of the administration of the CSTDA also dealt with research and development:

> The ANAO encourages FaCS to advise the NDA to have a greater level of consultation with relevant non-government stakeholders when developing

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[4] *Committee Hansard*, 13.10.06, p.28 (Women with Disability Australia).

[5] *Committee Hansard* 3.10.06, p.8 (NEDA).

[6] *Commonwealth State Territory Disability Agreement 2002-2007*

[7] *Committee Hansard* 13.10.06, p.40 (ACROD).

> and implementing the R&D Programme. The ANAO also considers that it is important that stakeholders have access to the results of the research.[8]

7.9 At the request of the Committee the AIHW also suggested a number of priority areas of research and analysis that could inform the CSTDA and related policies. The AIHW noted that its role as the CSTDA Data Agency is funded from the research and development budget (at approximately $150,000 per annum) and that during 2002-2007 no funds have been directed to data quality improvement. The AIHW recommended that the policy relevance of the CSTDA NMDS could be improved by adding new data items (on funding, outputs and outcomes) and improving the quality of data already available. The AIHW identified a number of priority areas for research and analysis including:

- improving the availability of information about met and unmet demand for disability services;
- ensuring that future work on met and unmet demand for disability services extends to analysis of community support services;
- conducting analysis of multiple data sources, both administrative data and population survey data, to research the interfaces between disability, aged care, mental health and other health and community services programs;
- increasing research efforts into the health of people with disabilities; and
- a systematic review of national equipment services, focusing on the improvement of nationally comparable information available on these services.[9]

Recommendation 26

7.10 That additional funding for research and development should be committed under the next CSTDA within agreed policy priorities.

Advocacy

7.11 Advocacy services are designed to enable people with a disability to increase the control they have over their lives through the representation of their interests and views in the community. Advocacy services can include individual advocacy, citizen advocacy, group advocacy and systemic advocacy. Under the CSTDA, advocacy is an area of joint responsibility for the Commonwealth, State and Territory governments.

7.12 As in several other areas of the CSTDA, the coordination of services between the jurisdictions also seems to be problematic. The NSW Government indicated advocacy was an area where there could be better clarity of roles and responsibilities and considered that having two quite separate streams of funding and directions for

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[8] ANAO, *Administration of the Commonwealth State Territory Disability Agreement*, Audit Report No. 14 2005-06, p.106.

[9] *Submission* 65a, p.8 (AIHW).

advocacy was probably not the most appropriate way to support the sector.[10] The Victorian Disability Advocacy Network also noted that there was no framework for shared planning or development for advocacy services between the jurisdictions.

7.13 A number of submissions and witnesses raised proposed changes to the National Disability Advocacy Program (NDAP) with the Committee. The NDAP funds 71 advocacy organisations to provide advocacy services on issues affecting the daily lives of people with disability. The Commonwealth invested $12 million in 2005-2006 into the program, which assisted over 17,000 people.

7.14 In 2006 FaCSIA initiated a review of the NDAP which involved analysis of data and other information held on the program by the department as well as engaging consultant Social Options Australia to assess how the program was operating against its stated goals and objectives. The final report *Evaluation of the National Disability Advocacy Program* found:

- The objectives of the program need to be measurable and realistic. The performance data currently collected does not allow a good assessment to be made.
- Funding of advocacy agencies is variable, and funding for many smaller agencies is not enough to meet the full costs of running the service, which compromises their ability to provide effective services. It is apparent that funding from the Australian government and state and territory governments does not match the population distribution of people with disabilities.
- The current quality assurance system of annual self-assessment by services and 5-yearly audits by FaCSIA does not guarantee that advocacy services are providing an appropriate level of service. The current Disability Services Standards could be improved by replacing the 101 supporting standards with a smaller number of Key Performance Indicators.
- Six types of advocacy are now funded – individual, self, citizen, systemic, parent and family - but the different types are not available everywhere and it is hard to compare outcomes.
- Geographic coverage is uneven and advocacy services are not available in many regional areas.
- Coordination between NDAP advocacy services and other bodies providing advocacy needs to be improved.
- Many people with disability are unaware of the disability advocacy programme or other available advocacy support, such as the Human Rights and Equal Opportunity Commission. They also lack knowledge about rights

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[10] *Committee Hansard* 3.10.06, p.48 (NSW Government).

and responsibilities. All services have unique names and some do not mention disability or advocacy in their title.[11]

7.15 In September 2006 FaCSIA released a consultation paper *Enhancing the National Disability Advocacy Program*.[12] The paper proposed:

- introducing measurable programme goals and objectives;
- introducing standard operating policies and procedures across all funded services as a condition of funding;
- introducing a 'priority table' as a condition of funding setting out which cases advocates will give priority to, to make sure advocacy services are directed at those most in need of assistance;
- requesting services to meet benchmarks for service to people with particular types of disability, indigenous people with disability and those from culturally diverse backgrounds;
- focusing disability advocacy services on individual and family/parent advocacy, with smaller effort directed to systemic and citizen advocacy;
- re-balancing funding across States and Territories to better reflect the distribution of the disability population;
- ensuring people with disability know more about their rights and responsibilities by promoting services and introducing a centralised referral service with a single free-call telephone number; and
- improving the quality assurance system, including the introduction of Key Performance Indicators and external auditing that services meet the quality standards. Require minimum qualifications for paid advocates.

7.16 The consultation paper provided that organisations funded through the National Disability Advocacy Program (NDAP) would be offered new funding contracts extending for the period 1 January 2007 to 30 June 2008. The new contracts would require increased reporting of outcomes from advocacy services. Another key proposed change was that in September 2007, a competitive funding round would be scheduled and would also be open to organisations that are not currently providing services under the NDAP.

7.17 On 16 November 2006 the Minister for Community Services, John Cobb, announced an additional $600,000 funding over the next 18 months to increase the availability of and increase access to advocacy to people with disability and their families.

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[11] Social Options Australia, *Evaluation of the National Disability Advocacy Program*, Final Report, 2006. Available from www.facsia.gov.au.

[12] FaCSIA, *Enhancing the National Disability Advocacy Program*, 2006. Available from www.facsia.gov.au.

7.18 Advocacy groups were critical of the processes involved in the review of the NDAP and the consultation paper as well as the reduction in emphasis on citizen and systemic advocacy. For example Ms Su-Hsien Lee from the Development Disability Council of WA commented:

> In particular, there has been a push against systemic advocates. There are little bits of funding here and there for individual advocacy but nothing for systemic advocacy. You have to be cynical and ask why. Individual advocacy, as much as it is valued and it is necessary, only deals with one issue at a time. It does not focus on the system as a whole…[13]

Ms Barbara Page-Hanify commented:

> The whole process has been incredibly flawed and rushed. There has been NO opportunity to discuss the planned service, no chance to discuss any short or long term benefits for those who need advocacy, but more importantly, no discussion at all on likely short and long term detrimental and potentially life-threatening outcomes from the planned service.[14]

7.19 Other advocacy groups had concerns regarding the timing of funding contracts following the review and the implications for their organisations. For example Ms Lyndell Grimshaw of Brain Injury Australia commented:

> With the current review and the fact that all disability advocacy providers were in receipt of a letter saying their funding is ceasing at the end of December, you can imagine small organisations trying to run their businesses and support individuals with whom they may be midstream while also having responsibilities to employees…
>
> There seems to be little understanding that organisations are run and operated by committees of management, or boards of management, who have responsibilities. They have responsibilities to staff; they have responsibilities to the people they meet with. They cannot wait until the eleventh hour to make decisions about their future.[15]

Carers Advocacy

7.20 Carers Australia noted that the current CSTDA definition of advocacy services excludes families and carers of people with disabilities. It also highlighted that in 2005 the ANAO audit of the administration of the CSTDA suggested that FaCSIA (then FaCS) in consultation with the National Disability Administrators consider extending access to advocacy services to the families and carers of people with disabilities in any future CSTDA. Carers Australia argued that carers also need advocacy services as they are service users in their own right, they access health, social and financial benefits, they as a population group with distinct needs and often

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[13] *Committee Hansard* 5.10.06, p.98 (Development Disability Council of WA).

[14] *Submission* 116, p.1 (Ms B Page-Hanify).

[15] *Committee Hansard* 28.9.06, p.19-28 (Brain Injury Australia).

act on behalf of those for whom they provide care.[16] The National Carers Coalition highlighted the important contribution of unpaid family carers and also urged 'that any government reform of disability services under the CSTDA is inclusive of the urgent need for funding of disability family advocacy at the national, state and regional level'.[17]

Recommendation 27

7.21 That the Commonwealth defer the implementation of its restructure of the national disability advocacy program and incorporate planning for advocacy services, including carers advocacy, in the negotiation of the next CSTDA.

Consultation with the disability community

7.22 In the CSTDA the Commonwealth and the States/Territories acknowledge the role of the Disability Advisory Bodies to ensure that the government hears the views of people with disabilities and carers on disability-related issues. Under the CSTDA the Commonwealth makes up to $314,000 available in funding contributions per annum to State and Territory Disability Advisory Bodies.

7.23 The Disability Advisory Bodies allow people with disabilities, carers, families and others to: provide advice regarding the planning, delivery and evaluation of services; advise their respective Ministers on progress against meeting the CSTDA objectives and priorities; provide advice on directions for research and development; and consult with the National Disability Advisory Council (NDAC) on matters of broader national significance that impact on people with disabilities, their families and carers.[18]

7.24 However, Committeed About Securing Accommodation for People with Disabilities (CASA) raised concerns that the NDAC had been closed down in August 2005 and the new National Disability and Carers Council had not at that stage been announced:

> The families once again feel that their voices have been silenced, or not deemed important. Family carers are often confused, exhausted, frustrated and disempowered. They feel that because of the demands of their caring role, and their low profile that their work has in the community, and at the government level, that they don’t have a voice in the decision making.[19]

7.25 In October 2006 the Minister for Families, Community Services and Indigenous Affairs, the Hon Mal Brough, announced the appointment of the executive and members of the new National Disability and Carer Ministerial Advisory Council.

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[16] *Submission* 52, p .10 (Carers Australia).

[17] *Submission* 28, p.29 (National Carers Coalition).

[18] *Commonwealth State Territory Disability Agreement 2002 - 2007* Part 6 (7).

[19] *Submission* 66, p.3 (CASA).

This Council brings together the previously separate advisory councils for people with disabilities and carers.[20]

Recommendation 28

7.26 That the next CSTDA continue to incorporate a prominent role for disability and carer advisory bodies as well as the new National Disability and Carer Ministerial Advisory Council. These bodies should be able to provide advice to government on service delivery, progress made in meeting objectives and priorities and directions for research and development.

Occupational health and safety and paid carers

7.27 Carers' groups raised the problem of the home becoming a workplace as a consequence of an increased emphasis on home-based care for people with a disability.[21] Emerging issues included occupational health and safety requirements and the home owner's liability when care workers visit a person's home. The National Carers Coalition commented:

> What is becoming more and more apparent is that this industry of 'paid help in the home' is not only an ever increasing encroachment upon the privacy of the family home, but it has now declared the family home to be a "workplace".
>
> This declared workplace is now a place in which families are being sued as "third party liable" under workcover regulations in some if not all states. Laws which protect paid care workers but give "NO PROTECTION" to the caring family are an abomination that will see more and more families think twice before having any in-home help for which they can be potentially sued.[22]

7.28 This is a difficult area as the homes of service clients are workplaces for the paid carers and health professionals providing support. The Committee understands many service providers conduct off-site checks including assessments of health and safety issues before an initial home visit. People with a disability and the family also have a responsibility to cooperate to ensure the health and safety of paid carers is protected.

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[20] *Committee Hansard* 13.10.06, p.99 (Australian Government).

[21] *Submission* 8, p.4 (Gippsland Carers Association).

[22] *Submission* 28, p.29 (National Carers Coalition).

Recommendation 29

7.29 That Commonwealth, State and Territory governments ensure that people with disabilities and their families are not discouraged from accessing care services in their homes because of potential occupational health and safety liability.

Senator Gary Humphries
Chairman

February 2007

APPENDIX 1

LIST OF PUBLIC SUBMISSIONS AND TABLED DOCUMENTS AUTHORISED FOR PUBLICATION BY THE COMMITTEE

1 Olle, Ms Liz

2 Pawagi, Ms Val (QLD)

Supplementary information

- CSTDA Interstate Portability Protocol, Letters from various complaint bodies, 16.11.06 provided at hearing 17.11.06
- Supplementary submission dated 14.12.06

3 Western Australian Government (WA)

Supplementary information

- Responses to questions on notice following hearing on 5.10.06, dated 6.11.06

4 Kennedy, Ms Catherine (NSW)

5 Name withheld

6 South Gippsland Carers Group (VIC)

7 Murray, Ms Catherine (NSW)

8 Gippsland Carers Association Inc (VIC)

Supplementary information

- 'The reality of unpaid family caring', 'the Victorian Disability Big Picture', 'The first real answer to the CSTDA services crisis – population based bench mark funding', 'Re: Victorian SRS's Amendment Bill – July 2006', Table – Service users per 1,000 of the potential population, Carers dumped – leaflets tabled at hearing 28.9.06
- Supplementary submission received 16.10.06
- Additional information following the hearing on 28.09.06 received 18.10.06

9 Mortimer, Ms Stephanie (VIC)

10 Shields, Ms Estelle (NSW)

11 Wright, Mr Tom and Mrs Denise (QLD)

12 Martin, Mr Bruce (QLD)

13 Skinner, Mr Bill (VIC)

14 Ratten, Mrs M (SA)

15 Women with Disabilities Australia (WWDA) (TAS)

Supplementary information

- Additional information following hearing 13.10.06, dated 28.10.06

16 Hart, Mrs Florence (QLD)

17 Toowoomba Intellectual Disability Support Association Inc (TIDSA) (QLD)

18 Mid North Coast Area Disability Committee (NSW)

19 Bigby, A/Professor Christine (VIC)

20 Australian DeafBlind Council (VIC)

21 Mckenzie, Ms Fay (QLD)

22 Brightwater Care Group (Inc) (WA)

23 Walsh, Mrs Mary (QLD)

Supplementary information

Provided at hearing 17.11.06

- Advocacy and the CSTDA
- Ideology and the interface with service personnel
- Summary of poker machine numbers and tax for the local government areas of Burnett shire and Bundaberg City Council

24 Physical Disability Council of Australia Ltd (PDCA) QLD

25 Deafness Forum of Australia (ACT)

26 Queensland Advocacy Incorporated (QLD)

Supplementary information

- Supplementary submission received 29.9.06

Provided at hearing 17.11.06

- A fairer deal for Queenslanders with a disability – Just the beginning
- In Control, Simon Duffy, Valuing People Support Team
- Everyone has human rights Understand yours! A guide to human rights for people with disability, QAI, September 2006
- Towards Human Rights Indicators for Persons with Disability, Disability Studies & Research Institute, Stage 1 Project Report
- Weaving our Magic through Connectedness for Indigenous People with a Disability, QAI, July 2004
- Opening Doors to Life, QAI, June 2001
- Legislation and Life, QAI, September 2003

27 Geach-Bennell, Ms Anita (VIC)

28 National Carers Coalition (VIC)

Supplementary information

- National Carers Coalition agenda, Qld workplace health and safety legislation and Dual Diagnosis Project chapter 6 Discussion and Recommendations provided at hearing 3.10.06

29 Ryan, Ms Margaret (VIC)

30 Park, Ms Jennifer (QLD)

31 Motor Neurone Disease Association of Australia (MNDAA) (NSW)

32 Aged & Community Services Australia (ACSA) (VIC)

Supplementary information

- Additional information following the hearing on 6.10.06, received 18.10.06

33 Council of Intellectual Disability Agencies (Vic) Inc (CIDA) (VIC)

34 Association for Children with a Disability NSW (NSW)

35 Clark, Ms Katrina (NSW)

36 Compass SA Inc (SA)

37 Cerebral Palsy Australia (WA)

Supplementary information

- CP Australia information including briefing on Australian Cerebral Palsy Register provided 5.10.06

38 Independent Living Centre of WA Inc (WA)

Supplementary information

- Additional information following hearing 5.10.06 relating to Assistive Technology schemes, received 9.11.06

39 Metro North Disability Support Group (NSW)

40 Motor Neurone Disease Association of Victoria Inc (VIC)

41 Parkinson's Australia (ACT)

Supplementary information

- Opening statement provided at hearing 17.11.06

42 Disability Advisory Council of Victoria (VIC)

43 Dalton, Mr Cale (SA)

44 West, Ms Raelene (VIC)

Supplementary information

- Supplementary submission dated 30.10.06

45 ACROD (ACT)

46 NSW Council for Intellectual Disability (NSW)

47 Collier, Dr Paul (SA)

48 Torr, Dr Jennifer (VIC)

Supplementary information

- Supplementary submission received 25.10.06

49 Buckley, Mr Bob (ACT)

50 National Council on Intellectual Disability (ACT)

51 Client Guardian Forum Inc (ACT)

Supplementary information

- Additional information following the hearing on 13.10.06 received 17.10.06

52 Carers Australia (ACT)

Supplementary information

- Opening statement provided at hearing 13.10.06

53 Ryde Area Supported Accommodation for Intellectually Disabled Association (NSW)

54 Crouch, Mrs Jacqueline (TAS)

Supplementary information

- Opening Statement – Unmet Needs provided at hearing 22.11.06

55 Donald, Mr Bill

56 Name withheld (QLD)
57 UnitingCare Australia (ACT)
58 Brown, Ms Nell (NSW)
59 Minchin, Lisa
Mroz, Melissa
Dodgson, Kim
Sont, Arahni
Ratten, Bryan
Bewley, Lyn
Lie, Cindy
Kasner, Jenny
Cooper, Darani
Wright, Fiona
60 Disability Coalition WA (WA)
61 Name withheld
62 Carroll, Mr Michael & Paterson, Ms Alli (WA)
63 Broken Rites (Australia) Collective Inc (VIC)
64 Developmental Disability Council of WA (WA)
65 Australian Institute of Health and Welfare (AIHW) (ACT)
Supplementary information
- Response to questions on notice following the hearing 13.10.06, dated 17.11.06

66 Committed About Securing Accommodation for People with Disabilities (CASA) (WA)
67 Storey, Ms Lyn (QLD)
68 Disability Advocacy and Complaints Service of SA Inc (SA)
69 Tasmanian Government (TAS)
Supplementary information
- Additional information provided following hearing 22.11.06, dated 4.12.06

70 Australian Physiotherapy Association (APA) (VIC)
71 Vision 2020 Australia (VIC)
72 Australian Blindness Forum (ACT)
73 Royal Society for the Blind of SA Inc (SA)
Supplementary information
- Notes for hearing, 2004-05 Annual report and CD for schools 3VI provided at hearing 6.10.06
- Additional information concerning Equipment Programs following hearing on 6.10.06, dated 15.11.06

74 Autism Aspergers Advocacy Australia, A4

75 Inability Possability Inc (VIC)

Supplementary information

- *Still the doors are open – writings of life* tabled at hearing 28.9.06

76 Foster, Mr John (VIC)

77 Davis, Ms Janet (QLD)

78 Disability Council of NSW (NSW)

79 Edwards, Ms Deborah (QLD)

80 Brain Injury Australia (VIC)

Supplementary information

- Information pack tabled at hearing 28.9.06

81 Lawson, Mr Ben (QLD)

82 Shepherd, Ms Di (WA)

83 Smith, Ms Chris & Mr Max (ACT)

84 New South Wales Government (NSW)

Supplementary information

- Additional information received following hearing 3.10.06 relating to negotiations between NSW Department of Ageing, Disability and Home Care and the Nardy House Management Committee, dated 10.1.07

85 Jobsupport Inc (NSW)

Supplementary information

- Statistics on post school destinations for school leavers from Sydney 'IO' classes provided at hearing 3.10.06

86 Health Services Union (HSU) Victoria (VIC)

87 Brain Injury Association of Tasmania (TAS)

88 Multiple Sclerosis Society of South Australia and Northern Territory (SA)

Supplementary information

- Correspondence to retain Julia Farr Centre provided at hearing 6.10.06
- SA Government Disability Budget 2006/07 provided following hearing on 6.10.06, received 6.10.06

89 Victorian Disability Advocacy Network (VIC)

Supplementary information

- 'National Disability Advocacy Review, Agency Forum 28 July 2006'; 'Get Real – A Just Deal for Disability Advocacy Services' Revised Discussion Paper tabled at hearing 28.9.06

90 Australian Federation of Disability Organisations (VIC)

Supplementary information

- Additional information following hearing on 6.10.06 concerning division of responsibility of CSTDA agreement dated 13.10.06

91 Interchange Respite Care NSW Inc (NSW)

92 Edwards, Ms Catherine

93 MS Australia (VIC)

94 Victorian Office of the Public Advocate (VIC)

95 New South Wales Council of Social Service (NCOSS) (NSW)

Supplementary information

- An End to the Silence, The Crisis in Supported Accommodation for People with a Disability in NSW, October 2005 provided at hearing 3.10.06
- Additional information following hearing relating to the Isolated Patients Travel and Accommodation Assistance Scheme, received 9.11.06

96 Australian Government (ACT)

97 Jones, Ms Marilyn & Mr Richard

98 Young People in Nursing Homes National Alliance (VIC)

99 Victorian Government (VIC)

100 South Australian Council on Intellectual Disability(SACID) (SA)

101 Croft, Ms Deidre (WA)

Supplementary information

- Outcomes of combined application funding round (WA) provided 5.10.06

102 People with Disability Australia Incorporated (PWD) (NSW)

Supplementary information

- Evidence to inquiry with updated recommendations and Complaints Resolution and Referral information provided at hearing 3.10.06
- Family Advocacy February 2006, *Presenting the Evidence: Accommodation and Support for People with Disabilit,* provided following hearing on 3.10.06, received 19.10.06

103 HOPES Inc (TAS)

104 Allen, Ms Lynette & Mr Ian (NSW)

105 Gibilisco, Dr Peter (VIC)

106 Northern Territory Government (NT)

107 National Ethnic Disability Alliance (NSW)

108 Australian Council of Social Service (ACOSS) (NSW)

109 Holst, Mr David (SA)

110 Bradley, Mr Keith and O'Kane, Ms Kerry (ACT)

111 Mercy Disability Services (QLD)

Supplementary information

- Additional information following hearing on 17.11.06, dated 17.11.06

112 Queensland Government (QLD)

Supplementary information

- Responses to questions on notice following hearing 17.11.06, dated 5.12.06
- Response to evidence given at hearing 17.11.06 re access to respite at Toowoomba, received 5.2.07

113	Casella, Ms Livia & Parsons, Ms June
114	Nash, Mr Allan (WA)
115	Multiple Sclerosis Society of Queensland (QLD)
116	Page-Hanify, Ms Barbara (QLD) *Supplementary information* • Additional information provided relating to new NDAP contracts received 6.12.06
117	Endeavour Foundation (QLD) *Supplementary information* • Supplementary submission dated 7.12.06
118	NovitaTech (SA)
119	Engineers Australia (ACT)

Additional information

ACT Government

Response to questions on notice following the hearing 13.10.06, dated 9.11.06

ACROD Tasmania

Disability Impact Statement State Budget 2006/07, received 23.8.06

Spinal Injuries Australia

An accessible Australia and media article provided at hearing 17.11.06

Evaluation of the National Disability Advocacy Program, Final Report, Social Options Australia, FaCSIA, July 2006

APPENDIX 2

WITNESSES WHO APPEARED BEFORE THE COMMITTEE AT PUBLIC HEARINGS

Thursday, 28 September 2006
Stamford Grand Hotel, Melbourne

Committee Members in attendance

Senator Humphries (Chair)	Senator McLucas
Senator Moore (Deputy Chair)	Senator Patterson
Senator Adams	Senator Siewert

Witnesses:

MS Australia

Mr Alan Blackwood, Manager Policy and Community Partnerships

Mr Bushy Laird

Young People in Nursing Homes National Alliance

Dr Bronwyn Morkham, National Director

Inability Possibility

Ms Megan Atkins, Secretary

Brain Injury Australia

Ms Lyndall Grimshaw, Executive Officer

Ms Merrilee Cox, Executive Officer, Headway Vic

Gippsland Carers Association Inc

Mrs Jean Tops, President

South Gippsland Carers Group

Mr Bill Skinner, President

Associate Professor Christine Bigby

Dr Jennifer Torr

Office of the Public Advocate

Mr Julian Gardner, Public Advocate

Dr David Raymond, Manager, Policy and Education

Victorian Government

Mr Arthur Rogers, Executive Director, Disability Services Division

Ms Raelene West

Victorian Disability Advocacy Network

Ms Merrilee Cox

Mr Paul Hume

Tuesday, 3 October 2006
Jubilee Room, Parliament House, Sydney

Committee Members in attendance

Senator Humphries (Chair)
Senator Moore (Deputy Chair)
Senator Adams
Senator Bartlett
Senator McLucas
Senator Patterson

Witnesses:

Jobsupport Inc

Mr Philip Tuckerman, Director

National Ethnic Disability Alliance

Ms Diane Qian, Executive Officer

Motor Neurone Disease Association of Australia (MNDAA)

Mrs Carol Birks, National Executive Director

Mr Alex Malley, Former National Executive Director

Association for Children with a Disability NSW

Ms Sue Griffin, President

National Carers Coalition

Mrs Felicity Maddison, Queensland Liaison Carer

Mrs Nell Brown, New South Wales Liaison Carer

Council of Social Service of New South Wales (NCOSS)

Ms Michelle Burrell, Acting Director

Ms Christine Regan, Senior Policy Officer

NSW Government

The Hon John Della Bosca, MLC, Minister for Disability Services

Ms Janet Milligan, Executive Director, Strategic Policy and Planning, New South Wales Department of Ageing, Disability and Home Care

Ms Carol Mills, Deputy Director General, New South Wales Department Of Ageing, Disability and Home Care

Australian DeafBlind Council

Mr Seven Topp, President

Mr John Finch, Administrative Officer

People with Disability Australia Inc

Ms Heidi Forrest, President

Mr Matthew Keely, Senior Legal Officer

Thursday, 5 October 2006
Duxton Hotel, Perth

Committee Members in attendance

Senator Humphries (Chair)	Senator Patterson
Senator Moore (Deputy Chair)	Senator Polley
Senator Adams	Senator Siewert
Senator McLucas	Senator Webber

Witnesses:

Western Australian Government

The Hon Tony McRae, Minister for Disability Services

National Council on Intellectual Disability

Ms Sue Harris, Acting Chief Executive Officer

Ms Mary-Louise Allen, Board Member representing Western Australian

Mr Paul Smale

Brightwater Care Group

Dr Penny Flett, Chief Executive Officer

Mrs Janet Wagland, Manager, Services for Young People

Independent Living Centre of WA Inc

Ms Gerri Clay, Chair

Ms Sally Hunter, Manager ILC Tech and Country Services

Cerebral Palsy Australia

Ms Anita Ghose, National Project Manager and Chair, Scientific Committee and National Editor

Ms Deidre Croft

Development Disability Council of WA

Ms Su-Hsien Lee, Joint Chief Executive

Committed About Securing Accommodation for People with Disabilities (CASA)

Ms Carol Franklin, Cofounder

Ms Amanda Simes

Mr Richard Diermajer

Friday, 6 October 2006
Stamford Grand Hotel, Glenelg, Adelaide

Committee Members in attendance

Senator Humphries (Chair)
Senator Moore (Deputy Chair)
Senator Ferris
Senator McLucas
Senator Patterson

Witnesses:

Australian Federation of Disability Organisations (AFDO)

Mr Maurice Corcoran, President

Ms Collette O’Neill, National Policy Officer

South Australian Council on Intellectual Disability (SACID)

Ms Delphine Stagg, President

Disability Advocacy and Complaints Services of SA

Ms Monika Baker, Senior Advocate

Aged and Community Services Australia (ACSA)

Mrs Patricia Sparrow, National Policy Manager

Royal Society for the Blind of South Australia

Mr Andrew Daly, Executive Director

Mr Tony Starkey, Future Solutions Officer

Multiple Sclerosis Society of SA & NT

Ms Meg Lees, Chief Executive Officer

Ms Sharon Barlow, Senior Nurse Educator and Social Worker

Ms Libby Morris, Senior Occupational Therapist

Ms Jan Victory, Social Worker

Friday, 13 October 2006
Parliament House, Canberra

Committee Members in attendance

Senator Humphries (Chair)
Senator Moore (Deputy Chair)
Senator Adams
Senator Barlett
Senator McLucas
Senator Patterson
Senator Siewert

Witnesses:

Carers Australia
Ms Joan Hughes, Chief Executive Officer

Ms Sally Richards

Autism Aspergers Advocacy Australia
Mr Bob Buckley, Convenor

Women with Disabilities
Ms Susan Salthouse, Vice-President

ACROD
Dr Ken Baker, Chief Executive Officer

Australian Institute of Health and Welfare
Dr Penny Allbon, Director
Dr Xing-yan Wen, A/g Joint Head, Functioning and Disability Unit
Ms Louise York, A/g Joint Head, Functioning and Disability Unit
Mr Tim Beard, Senior Analyst, Functioning and Disability Unit
Ms Cathy Hales, Senior Analyst, Ageing and Aged Care Unit

ACT Government
Ms Katy Gallagher MLA, Minister for Disability and Community Services
Ms Lois Ford, Executive Director Disability ACT

Client Guardian Forum
Mr John Thorn, President
Ms Christine Smith, Secretary
Mr Glenn Cocking, Committee Member

Australian Government

Mr Stephen Hunter, Deputy Secretary, Department of Families, Community Services and Indigenous Affairs

Mr Evan Lewis, A/g Group Manager, Housing and Disability Group, Department of Families, Community Services and Indigenous Affairs

Mr Ben Wallace, Branch Manager, Disability and Carers Branch, Department of Families, Community Services and Indigenous Affairs

Ms Peta Winzar, National Manager, National Disability Operations, Department of Families, Community Services and Indigenous Affairs

Ms Lynne Curran, Group Manager, Specialist Services and Income Support Group, Department of Employment and Workplace Relations

Friday, 17 November 2006

Undumbi Room, Parliament House, Brisbane

Committee Members in attendance

Senator Humphries (Chair)
Senator Moore (Deputy Chair)
Senator Adams
Senator Barlett
Senator McLucas
Senator Patterson
Senator Siewert

Witnesses:

Queensland Government

Mr Stirling Hinchcliffe MP, Parliamentary Secretary to the Minister for Communities, Disability Services, Seniors and Youth

Mr Brad Swan, Assistant Director General, Disability Services Queensland

Ms Helen Ferguson, Executive Director, Strategic Policy Directorate, Disability Services Queensland

Ms Mary Walsh

Toowoomba Intellectual Disability Support Association

Mr Anthony Lanigan, President

Mercy Disability Services

Mr Kevin Lewis, Director Lifestyle Support

Mr Lawrence Shaw, Financial Controller

Endeavour Foundation

Ms Page Armstrong, Manager Community Advocacy Support Unit

Queensland Advocacy Incorporated

Mr Kevin Cocks, Director

Ms Melinda Ewen, Community Living Advocate

Ms Valerie Pawagi

Spinal Injuries Australia

Mr John Mayo, Manager, Community Relations

Multiple Sclerosis Society of Queensland

Dr Wayne Sanderson, Manager, Individual and Family Services

Mr Craig Rowley, Regional Service Coordination

Parkinsons Australia

Associate Professor George Mellick, President, Parkinsons Queensland

Ms Astrid Firrell, Executive Officer

Mrs Marion Leggo

Wednesday, 22 November 2006

Parliament House, Hobart

Committee Members in attendance

Senator Humphries (Chair)
Senator Adams
Senator Barlett
Senator Carol Brown
Senator McLucas
Senator Patterson
Senator Siewert

Witnesses:

Tasmanian Government

Ms Alison Jacob, Deputy Secretary, Department of Health and Human Services

Mr John Nehrmann, Project Management Office, Disability Services, Department of Health and Human Services

ACROD Tasmania

Ms Margaret Reynolds, Executive Officer

Alderman Mary Guy, Ministerial Advisory Council

Tasmanians with Disabilities

Professor Christopher Newell

Mr Robin Wilkinson

Mr Philip Crouch

Mr Patrick Eadington

Anglicare Tasmania

Mr Daryl Lamb, State Manager, Community Service

Ms Mandy Clarke, Manager, Disability Support Services

Ms Teresa Hinton, Research and Policy Officer, Social Action and Research Centre

Brain Injury Association of Tasmania

Ms Deborah Byrne, Executive Officer

HOPES

Mr David Pearce, President

Mr Matthew Vickers, Committee Member