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).

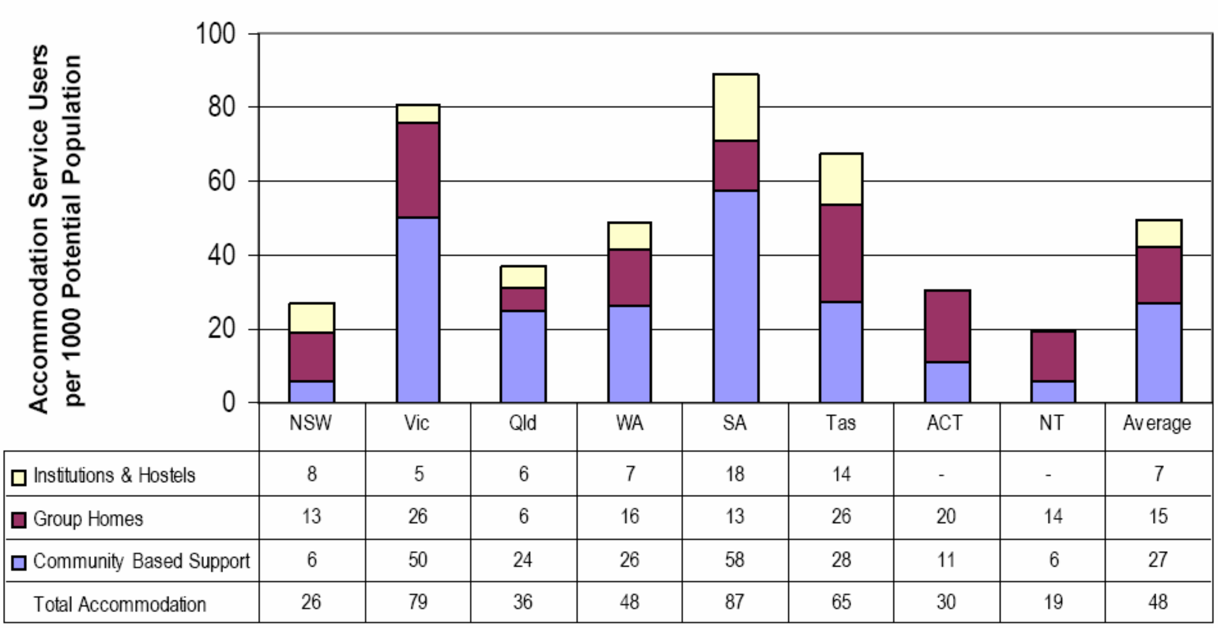
4.46 As noted above, the AIHW 2001 study identified a high level of unmet need. While governments have responded to increasing demand for specialist disability services, witnesses pointed to evidence of a growing gap between demand for disability services and the supply of those services. That gap is 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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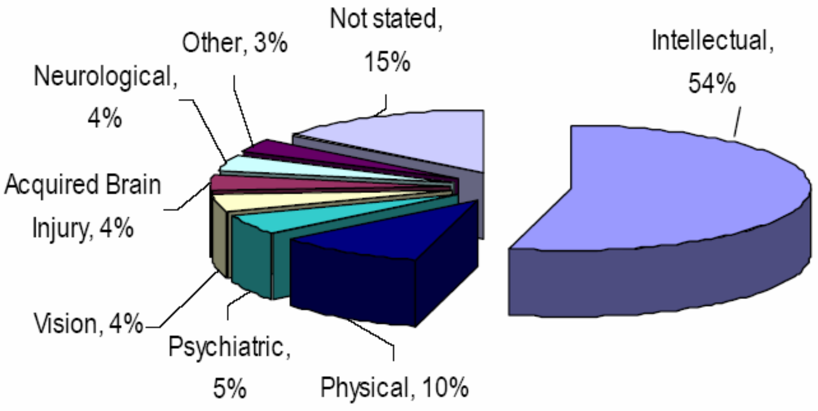
[33] *CSTDA Annual Public Report 2004-05*, p.60.

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).