

SENATE COMMUNITY AFFAIRS COMMITTEE INQUIRY INTO THE COMMONWEALTH/STATES AND TERRITORIES DISABILITY AGREEMENT (CSTDA)

This is a personal submission (i.e. not representing the official position of any organisation).

It is based on my own experience and observations as a parent of a 25 year old son with a severe intellectual disability, a disability advocate, and more recently as a researcher in the disability field.

I have not sought to provide a comprehensive response to all the terms of reference nor to replicate substantial issues covered in other submissions, but rather to highlight those issues in which I have a more personal interest and which I believe require further consideration. Most of the references are available on the web, and I have included the relevant links throughout (rather than provide a consolidated list of references).

My submission includes a number of questions for which I hope the current inquiry will provide some answers.

I acknowledge all those parliamentary representatives who have recognized the human and social importance of this issue and especially their efforts in establishing this parliamentary inquiry which reflects such a priority.

Deirdre Croft

Key Points:

- The current review of the CSTDA should build upon rather than attempt to recreate the substantial body of work that has already been undertaken in relation to the issues cited (most especially the Yeatman review of the first CSTDA and the Australian Law Reform Commission review of the Commonwealth Disability Services Act. Both reviews were completed in 1996).
- Agreement is required on the interjurisdictional commitment to the principles of the 1986 Commonwealth Disability Services Act (and equivalent principles in State and Territories legislation which confer certain rights to people with disabilities) before any meaningful consideration and negotiation can be undertaken of the administrative and funding arrangements for disability services provision across Australian jurisdictions.
- By virtue of its assumed “human rights and social justice responsibilities on behalf of all Australian citizens”, the Australian Government has a leading role, and a responsibility in ensuring that the rights of people with a disability and their family carers are upheld and enforced.
- At a policy level, the expected balance between public and private responsibility for meeting the support needs of people with disabilities at different life stages needs to be clarified and clearly stated.
- The citizenship rights and human needs of people with disabilities should be the paramount consideration in determining eligibility for disability service support (particularly in relation to long-term care arrangements) rather than the capacity of their family carers.
- The adoption of a “whole-of-disability” approach to disability service funding, provision and reporting does not distinguish between the unique characteristics and needs of people with differing types of disability (nor the unique characteristics and needs of their informal carers). These distinctions need to be clarified and stated to enable better monitoring of needs, outcomes and performance over time.
- The issue of “unmet need” is fundamentally a resourcing issue. People who, due to disability, cannot independently meet their own needs require support from others. This support requires resources (whether or not they are provided privately or through public funding).

From a personal perspective:

Based on my experience of and contact with the disability sector, my overwhelming personal impression is that over the past decade or so:

- disability service eligibility criteria have become increasingly more restrictive
- the level and criticality of unmet need for disability service support has increased
- the circumstances presented by people who are unable to access service support (or to access adequate service support) have become more extreme
- the level, or adequacy, of support for many of those already accessing services has decreased (through reduced service hours or resulting from increased service needs due to changing circumstances)
- under pressure to contain costs, the quality of service provision is decreasing (and under increasing threat).

For each of the problems of need/unmet need identified above, the core issue appears to me to be less a question of principle (already stated in legislation), than of practicality, and more specifically, a question of money.

Thus, in each case, the question/issue seems to come back to the resources available to ensure the provision of services that meet the needs of people who, due to some form of disability, rely on support from others to achieve a reasonable quality of life.

At essence then, the bottom line policy concern or question (and the apparent inter-jurisdictional debate around funding responsibilities and alleged cost shifting) continues to be: how much will it cost, for what return, and who pays the bill?

If this is a fundamental issue of importance to the values of the Australian community, an alternative question might be – how can we best provide the resources that are required?

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The title of the original 1991 cooperative disability services agreement was the Commonwealth and States Disability Agreement (CSDA) which was subsequently revised to the Commonwealth, States and Territories Disabilities Agreement (CSTDA).

For simplicity's sake, and given that this inquiry occurs within the framework of the latest agreement, I have used the acronym CSTDA and its longer title throughout.

1. CONTEXT:

The conduct of this Senate Inquiry into the CSTDA (in 2006) coincides with the anniversary of a number of international and national events of particular relevance to the rights and needs of people, and especially Australians, with disabilities:

- the **25th anniversary** of the 1981 United Nations International Year of Disabled Persons in which the international community was exhorted to break down the barriers that prevented people with disabilities from participating fully in the social and economic life of their community
- the **20th anniversary** of the Australian Government's Disability Services Act (1986) which, amongst other things, affirmed that Australians with disabilities had the same human, citizenship and social rights as any other Australian citizen
- the **15th anniversary** of the signing of the first Commonwealth/State Disability Services (CSDA) Agreement - subsequently renamed the Commonwealth States and Territories Disability Agreement (CSTDA) which sought to establish a cooperative interjurisdictional approach to disability services provision in Australia.
- the **10th anniversary** of the public release of two major government reviews which included many recommendations of relevance to the terms of reference of the current inquiry i.e.:
 - The Australian Law Reform Commission Review into the Commonwealth Disability Services Act (**Making Rights Count**, ALRC, 1996)
 - the Review of the first Commonwealth/State Disability Agreement (**Getting Real**, Yeatman, 1976)

1.1. REVIEWS, REPORTS and STUDIES

Since the first CSTDA, there have been numerous other official reviews, reports and studies inquiring into different dimensions of the issues being canvassed in the terms of reference for the current Senate Inquiry.

To build upon, rather than recreate, the work that has already been undertaken, I believe it would be valuable to revisit the relevant national and jurisdictional reviews and studies already undertaken since the first CSTDA.

The following summary lists some of the relevant work undertaken at a national level. However, a great deal of work, inquiry and consultation has also been undertaken at a State/Territory level some of which is also cited below and may also warrant consideration.

Review of the Disability Services Act (1996)

In 1992, the Australian Law Reform Commission was asked to undertake a number of reviews of the legislation which came within the ambit of the then Commonwealth Department of Health, Housing and Community Services (including child care, aged care and disability services). The Disability Services Act (1986) was included in the legislation to be reviewed with a stated expectation that revised legislation would be drafted and submitted for consideration by the parliament by around 1997.

Amongst other things, the Terms of Reference required the Australian Law Reform Commission to:

- *make recommendations on how Commonwealth legal policies (including administrative law, secrecy, privacy and criminal law), **social justice and human rights** should be reflected in new legislation (emphasis added).*

The process for the review of Commonwealth responsibilities in relation to the Disability Services Act (1986) was based on:

- documentation and public distribution of an initial issues paper (May 1995)
- distribution a more substantial discussion paper seeking more broadly based public input (August 1995)
- distribution of a public report “**Making Rights Count**” (ALRC 79,1996) which integrated the findings of the consultation process and made recommendations for a new Disability Services Act.

The Australian Law Reform Commission recommended that the 1986 Commonwealth Act be replaced by new legislation. However the Commission web-site states that:

“No formal response has been made to ALRC 79, and the Disability Services Act 1986 (Cth) remains in operation with only minor changes since it was reviewed by the ALRC”.

A number of the ALRC recommendations, however, seem pertinent to the current Senate Inquiry.

In particular, the ALRC report made recommendations on:

- the funding and accountability requirements under the Commonwealth/State Disability Agreement
- a process for identifying and planning to meet the need for disability services.

The Commission also recommended that an Office on the Equal Status of People with a Disability be established (Recommendation 19). The responsibilities of the proposed Office would include the preparation of an **impact statement** on any major disability initiative to be implemented.

“The impact statement should include assessment of such things as the:

- *benefit to the disability population of the proposal*
- *detriment to the disability population of the proposal*
- *cost to government of implementing the proposal*

- *benefits to government of implementing the proposal*
- *impact on special needs groups of the proposal*
- *effect on the disability population if the proposal is not undertaken*
- *practicality of the proposal*
- *effect of the implementation of the proposal on sectors other than the disability sectors*
- *the infrastructure necessary to implement the proposal” (Chapter 6).*

Given the extensive consultation process that was undertaken as part of the ALRC legislative review and with respect to the careful thought and effort of those who made submissions, I believe there would be value in revisiting the report to determine which of its recommendations may still be relevant to the current Senate Inquiry.

A copy of the ALRC report is available at:

<http://138.25.65.50/au/other/alrc/publications/reports/79/>

Review of the First CSTDA (1996)

At the signing of the first five year CSTDA in or around 1991, Australian Governments also agreed that a review would be conducted as a precursor to any ongoing commitment.

In 1995, a series of studies was commissioned exploring different dimensions of a cooperative national approach to disability services provision in Australia including the extent of the need/unmet need for specialist disability services.

The results of these studies were integrated and reported on as part of the agreed independent review. The resulting report “**Getting Real: the final report of the review of the Commonwealth State Disability Agreement**” was published a decade ago (Yeatman 1996)¹. (The basis for the substantive title “Getting Real” was not explained in the report although it begs the question as to why a call to “get real” may have been considered necessary).

The Yeatman review of the first CSTDA also drew on broad ranging community consultation and input. In the listing of submissions and contributors in Appendix 1 (p.125), I counted up approximately 350 written submissions received from individuals and organizations and approximately 750 people who attended community forums. In addition, about 65 or so representatives of disability agencies around the country contributed their perspectives, expertise and insights to the Review’s four advisory committees.

In all, this represents a massive investment of people’s time, energy and expertise all of which was given freely and in good faith that it would lead to improved outcomes for Australians with disabilities.

¹ Yeatman, A. (1996) *Getting Real: The final report of the review of the Commonwealth/State Disability Agreement*. Australian Government Publishing Service, Canberra

The review made 50 recommendations on how a second CSTDA might be improved including redressing problems identified in the first Agreement.

Specifically, Yeatman commented that a number of **new** problems had emerged since the first agreement including:

- *gaps between employment and accommodation service systems;*
- *a lack of development of service types such as non-employment services and advocacy;*
- *access inequities across jurisdictions; and*
- *less cooperation and strategic planning between governments, especially in ways to meet the growing demand for support (p. x)*

The same issues could be variously interpreted to also apply to the terms of reference for the current Senate Inquiry.

Yeatman also identified a number of **implementation problems** in the first CSTDA that still needed to be “sorted out” (i.e. in 1996) including the following:

- *the initial base was calculated in different ways for different States and Territories;*
- *there was no overall plan, structure or process for implementation, tracking of effort and monitoring of performance;*
- *inadequate funding and provisions for upgrading of services or to meet growth in unmet need;*
- *lack of joint planning among governments; and*
- *different interpretations of the Agreement and its objectives (p. xiii).*

All of the items identified above appear to represent ongoing issues of concern for the operation of the third CSTDA and presumably any that will follow it.

Although the Yeatman review has been widely cited in subsequent reports and submissions, my web search has failed to uncover any official response from government/s to its conclusions and recommendations.

Given that many of the problems identified in the review of the first CSTDA appear to be equally relevant a decade later (including to the terms of reference for the current Senate inquiry), I believe that there would be considerable value in revisiting the earlier review, and in particular to:

- identify which of the recommendations have been acted upon
- assess the outcomes that resulted from the recommendations that have been implemented
- determine the extent to which recommendations not acted upon may still apply.

Studies on Unmet Need

Since the first CSTDA, the Australian Institute of Health and Welfare has undertaken two major studies on the issue of unmet need for disability support services both of which are available on the Institute's website:

<http://www.aihw.gov.au/disability/publications.cfm>

The web-site lists the purpose of the two studies as below:

Demand for disability support services in Australia (1997)

"Presents the results of a study of unmet demand and growth factors for services provided under the Commonwealth/State Disability Agreement in 1996. Estimates the level of unmet demand for accommodation and support, respite, and day programs; the national costs to government of meeting this unmet demand; and the projected growth in demand for specialist disability services arising from demographic changes over the five years featured".

Unmet Need for Disability Services: Effectiveness of Funding and Remaining Shortfalls (2002)

"Australian governments committed \$519 million additional funding to disability services over the two years 2000-01 and 2001-02, in recognition of unmet needs in the community. This publication reports the findings of a study the AIHW was commissioned to undertake on the effectiveness of this funding, particularly in providing additional services and on the remaining level of unmet need in the community".

Both reports made a number of recommendations which are relevant to the terms of reference of the current inquiry and, in particular, the need for better data to enable a more accurate assessment of need/unmet need and future need as a basis for informing long term planning.

The most recent report (AIHW 2002) recommended:

"A policy framework, including criteria for decision making and processes designed to involve those with the most relevant information on individual's needs, would not only guide decisions about the future service needs of individuals, but would also help to refine statistical estimates of the numbers of people involved" (p.203).

Studies on Disability Services Funding Requirements

The 1997 AIHW study included estimates of the funding required to address the unmet needs of people with disabilities for accommodation, respite and day options.

The 1996 Yeatman review of the first CSTDA recommended that funding of disability services should:

"ideally... be based on achieving certain population expenditure targets in each jurisdiction. One of the merits of this kind of approach is that population-based targets allow for any population growth which results in increased demand" (p.65)

In 2002, the NSW Social Policy Research Centre was commissioned by the National Disability Administrators to:

“provide advice on appropriate indexation and demand factors for Commonwealth funding to the States via the Commonwealth State Disability Agreement”.

The report considered pricing factors that may impact on the ability to sustain the volume and quality of service provision, as well as factors that may lead to a growth in demand, both of which would require additional funding to at least maintain the status quo in the balance between supply and demand.

The report, **Methods to Address Requirements for Changes in Funding Disability Services brought about by External Change** is available at:

<http://www.sprc.unsw.edu.au/reports/Methods%20to%20Address.pdf>

Jurisdictional Reviews, Studies, Reports

At a jurisdictional level, numerous reports, reviews, and studies have also been undertaken that are relevant to the terms of reference for this inquiry. Most jurisdictions have conducted reviews and made refinements to their disability services legislation, while a number of others have attempted to develop a more systematic approach to the issue of “unmet need”. Many of these reports and reviews can be accessed through the web-sites of the relevant Government agency. I have cited only a very small sample below i.e. from New South Wales and my own home state of Western Australia.

New South Wales

In 1999, the NSW Law Reform Commission published a report of its review of the NSW Disability Services Act (1993). While primarily focused on issues of concern within a NSW context, the report canvassed a number of issues that appear to also have some application to the current review particularly in relation to:

- the historical and ideological context underpinning the principles of the legislation (acknowledging its relationship to the over-riding Commonwealth legislation/disability services framework)
- concerns about the capacity to apply legislative principles without the resources to do so
- recommendations on the need for, and means of, data collection to inform service planning.

Other recommendations dealing with: service access, funding, quality and enforcement may also have some relevance.

The Law Reform Commission **Report 91 - Review of the Disability Services Act (1993)** is available at: <http://www.lawlink.nsw.gov.au/lrc.nsf/pages/r91toc>

In 2000 and 2002, the NSW Legislative Council Standing Committee on Social Issues published the results of its inquiry into the provision of residential care and other services that support people with disability.

The first report **A Matter of Priority** noted the extent of public interest in the matters under inquiry which was reflected in the number of written submissions from individuals and organizations (i.e. 309 written submissions many of which reported on the human consequences of the level of unmet need for accommodation support services).

The NSW Legislative Council Standing Committee on Social Issues **A Matter of Priority, Report on Disability Services** (2000) is available at:
[http://www.parliament.nsw.gov.au/prod/parlment/committee.nsf/0/11ba37e6e319e86eca256cfd002a63bb/\\$FILE/Second%20Report.PDF](http://www.parliament.nsw.gov.au/prod/parlment/committee.nsf/0/11ba37e6e319e86eca256cfd002a63bb/$FILE/Second%20Report.PDF)

The second and final report of the Standing Committee's Inquiry made 61 recommendations, a number of which are relevant to the current Senate Inquiry including in relation to:

- the need "to develop an approach to funding under the CSTDA that links growth funding from the Commonwealth to identified unmet need" (Recommendation 49)
- the need to clarify Commonwealth/State responsibilities "to fund specific programs and services and to fund increases in the cost of providing services" (Recommendation 50)

The NSW Legislative Council Standing Committee on Social Issues **Making It Happen: Final Report on Disability Services** (2002) is available at:

<http://www.parliament.nsw.gov.au/prod/parlment/committee.nsf/0/9A5132F0DCB5E159CA256D25000D5D05>

Western Australia:

Western Australia has also reviewed its Disability Services Act over the timeframe. However, the numerous reviews conducted into accommodation support and, in particular, the unmet need for accommodation support are perhaps most relevant to the terms of reference of the current inquiry.

In 2001-02, two reports were commissioned by the then Minister for Disability Services:

- to provide an estimate of the current and future needs for accommodation support (prepared by the Unmet Needs Working Group)
- to review the accommodation support funding process (prepared by the Dyson Consulting Group).

Subsequently, an Accommodation Blueprint Steering Committee was established with a brief to develop a forward plan for responding to accommodation support needs of Western Australians with disabilities. More than 200 individuals and agencies contributed to the consultation process for the report which made 60 recommendations. Those recommendations of most relevance to the terms of reference for the current Inquiry relate to:

- the need for better data on the needs and unmet needs for accommodation support to inform long term planning (Recommendations 2-3)
- the need for additional funding to respond to the current backlog and projected growth in demand for accommodation support (Recommendation 5) with a particular focus on the needs of ageing carers (Recommendation 20)

- the need for “more adequate Commonwealth funding” (Recommendation 10)
- the need for a cooperative Commonwealth/State approach to provide more suitable accommodation for younger people currently living in nursing homes (Recommendations 25-29)
- the need for a cooperative Commonwealth/State approach to address the needs of people with disabilities who are ageing (Recommendations 30-31).

A copy of the **Accommodation Blueprint Steering Committee Final Report and Recommendations** (2003) is available at:

http://www.dsc.wa.gov.au/cproot/798/2/1accomodation_blueprint.pdf

1.2. PROGRESS:

Over the period identified above, Australians with disabilities have benefited from many positive developments in the broader social environment, reflected in the changing attitudes and public commitment to meeting the needs of people with disabilities. Specifically:

- public attitudes to people with disabilities have become more accepting, inclusive and less discriminatory
- people with disabilities have greater access to mainstream services than ever before including greater access to services that are available to other Australian citizens in relation to:
 - health care
 - education and training
 - housing
 - transport services etc.
- barriers in the physical and built environment have increasingly been “broken down” through access improvements and application of universal design principles enabling people with disabilities to move about and access public spaces more freely and with less restriction than was ever the case previously.

With respect to the provision and availability of more specialized disability support services, it also acknowledged that:

- disability service provision has a higher public and policy profile than ever before
- dedicated government funding for disability services is higher than it has ever been before (*although in determining the “real” impact of these funding increases, the service provision cost increases, inflationary impacts and population growth over time would also need to be taken into account*)
- more people with disabilities are accessing disability services than ever before (*again it is not clear as to how much of this reflects the overall growth in the number of people with disabilities in the population, or whether the increased service usage can be attributed to improvements in service accessibility and a higher service take-up rate/service reach for people with disabilities*).

HOWEVER ... I would also suggest that attitudinal and access improvements have been of **most benefit** to people who have the intellectual and social capacity to make the most of the opportunities that have become available (i.e. people whose

disability limits only their physical or sensory abilities and/or who have less significant physical support needs).

By the same line of reasoning, I would contend that, in a hierarchy of human needs, these more broadly-based social achievements may be less relevant to the **priority quality of life issues** confronting people who, due to the severity, or nature of their disability (especially those with impaired cognitive/adaptive capacity) may require more intense, specialist and/or lifelong disability service support.

These are the people, I would suggest, who are **most reliant** on support from the specialist disability support system funded and provided under the Commonwealth/States and Territories Disability Agreement if they are to achieve a “reasonable quality of life”.

2. SOME FUNDAMENTAL ISSUES TO BE RESOLVED

The terms of reference for this Inquiry are specific to the operation of the Commonwealth/States and Territory Disability Agreement.

However, the operation of an interjurisdictional agreement on disability service provision presupposes that there is already agreement on other “higher order” issues which can then be translated into public policy and administration, and from there into practice, including agreement on issues such as:

- the rights of Australians with disabilities (specifically stated and presumably enforceable)
- the rights of people who provide informal care and support to people with disabilities
- the role and responsibility of Australian Governments in ensuring these rights are upheld.

Unless these fundamental issues are agreed upon, the administrative arrangements further down the line will, in my opinion, continue to be at the mercy of fluctuating, often unstated, agendas.

2.1. THE RIGHTS OF AUSTRALIANS WITH DISABILITIES

The agreed national framework for the first Commonwealth/State Disability Agreement was based on a series of legislative principles drawn from the Commonwealth Disability Services Act (1986). As part of the agreement, States and Territories agreed to enact complementary legislation.

The principles enunciated in Disability Services legislation at both a Commonwealth and States and Territories level assert that Australians with a disability have the same basic human rights as any other Australian citizen.

However, the legislation does not enumerate on the exact nature of these rights (other than that they are “the same” as those shared with other members of Australian society).

It is difficult to comprehend how rights may be assumed to have the status of “rights” unless they are specifically articulated and also enforceable.

Therefore, I would ask:

- What are the basic human rights that Australians with disabilities share with other Australian citizens?
- Should/do Australian citizens who provide care and support to Australians with disabilities also have the same rights as other Australian citizens and, if so, what are they?

The Commonwealth Disability Services Act (1986) lists seven legislative principles.

Principle (c) implies a **right** to equality of opportunity:

c) Persons with disabilities have the same rights as other members of Australian society to realize their individual capacities for physical, social, emotional and intellectual development

- What is required to enable people with disabilities to realize their individual capacities for physical, social, emotional and intellectual development?
- Who is responsible for providing the means/opportunities for people with disabilities to realize their individual capacities for physical, social, emotional and intellectual development?
- Who is responsible if people with disabilities are unable to access the means/opportunities to realize their individual capacities in these domains of life?
- What are the consequences to individuals, families and Australian society if people with disabilities are unable to access the means/opportunities to realize their individual capacities in these domains of life?

Principle (d) implies a **right** to service support:

d) Persons with disabilities have the same rights as other members of Australian society to services which will support their attaining a reasonable quality of life

- How is a “reasonable” quality of life defined?
- What rights do people with disabilities have to support services that will support their attaining a reasonable quality of life as defined?
- Who is responsible for providing the support needed by people with disabilities?
- Who is responsible if people with disabilities are unable to access services that will support their attaining a reasonable quality of life?
- What are the consequences for individuals, families and Australian society if people with disabilities are unable to access services that will support their attaining a reasonable quality of life?
- How can a right to services which will support attaining a reasonable quality of life be reconciled with the rationing of service access based on priority (or more increasingly, criticality) of need?
- Who determines the criticality of such needs and by what means?

- How can an orderly system of service provision be planned if the criterion for access to services is based on the relativity between the extent of individual and family “crisis” – (assuming that a crisis situation cannot usually be planned for, although planning for a response to a crisis can be)?

2.2. DIFFERENTIATING THE NEEDS OF PEOPLE WITH DISABILITIES

Prior to 1993, a separate Government agency existed in Western Australia to support the needs of people with an intellectual disability and their family carers. At that time, Western Australia was regarded as a national leader in its approach to meeting the needs of people with intellectual disabilities.

The commitment to the CSTDA saw the establishment of a new Government agency, the WA Disability Services Commission, which became responsible for the support needs of **all** Western Australians with a so-called “profound or severe core activity restriction that occurred before the age of 65”. The effect was that over a one to two year time-frame, the potential population to be served increased between four and six-fold. The budget of the new agency also increased but by nowhere near the same extent.

Within such an integrated “whole-of-disability” framework in Western Australia and in other jurisdictions, the reported increases in budget expenditure can be cited to support a case that overall funding and support to people with disabilities has increased, while, in fact, the support provided to people with disabilities of different types, origins, and onset of disability may not be so reflected if they were accounted for as distinct categories.

It is my belief that the needs and experiences of people with an intellectual disability are **qualitatively different** from those of people with other forms of disability including the nature of their relationship with their family/parent carers.

The deficits in adaptive behaviour associated with intellectual disability mean that, to a greater or lesser extent, people with an intellectual disability experience difficulty in adjusting to the demands of their physical and/or an increasingly complex social environment. Their support needs may therefore also include a need for guidance and supervision and ongoing developmental opportunities over the course of their life - quite apart from any physical care needs they may also have. While people with other forms of disability may also require support to meet their personal care needs, they do not experience these adaptive limitations.

In my experience, people with physical disabilities seek to have their own intellectual competence recognized i.e. as a group they do not wish to be confused with those who have more limited intellectual capabilities.

Just as people who have **superior** physical abilities are not grouped with those who have **superior** intellectual abilities as if they were one and the same, I cannot see the logic as to why people with physical **dis**-abilities and people with intellectual **dis**-abilities are so grouped for the purposes of public policy.

The rhetoric of disability service provision acknowledges that “individual needs” take precedence over “disability category”. However there are many other people in

society who also have dependency needs at different life stages who could be similarly grouped within an overarching administrative framework if a need for ongoing care and support was the sole qualification.

- On what basis are the issues of priority concern to people with different types of disabilities (and their family carers) reconcilable under a single policy and administrative framework?
- Are the needs of and outcomes for people with different types of disabilities appropriately accounted for in a whole-of-disability reporting framework?

2.3. THE BALANCE BETWEEN PUBLIC AND PRIVATE RESPONSIBILITY

That public funding is allocated to the provision of disability support services at all would imply that the Australian community (through its elected Governments) accepts it does have a responsibility for ensuring that Australians living with disability receive some measure of public support.

As a corollary, if responsibility for meeting the support needs of people with a disability was considered to reside entirely in the private/family domain, the disability services role for Government would either not exist or be limited to only the most extreme of cases. The Yeatman review of the first CSTDA noted:

“Governments have a responsibility to intervene in spheres of activity where the community and markets, left to themselves, do not or cannot provide basic support to individuals in society. Without this support some people experience unacceptable levels of disadvantage, standards of living, lack of opportunity, and inequality in relation to the rest of society” (p. 87).

The expected balance between private responsibility and public responsibility in ensuring that needed care and support is provided to people with disabilities is, however, not explicitly stated.

At present, it would appear that the government commitment to meeting the long term care and support needs of people with disabilities vis a vis the implied role expected of their family carers varies according to whether the disability is lifelong, acquired or age-related.

For example, the current policy position seems to be that:

- People with a **lifelong disability** should and will have their needs met indefinitely by their family/parent carers until the family/parent carer is no longer capable of providing for these needs. The expectation of parental care applies irrespective of the developmental needs, or wishes, of the person with a disability to attain greater independence, or the wishes of their family carers to relinquish their role as primary caregivers at an age-appropriate life stage.
- Adults with an **acquired disability** who have already attained some measure of independence are more likely to be offered public support to enable them to retain their independence unless and until it is deemed too costly to sustain. While funding for such support may come from government, it may also derive from insurance or from litigation if it can be established that another person or agency is held to be responsible for the person’s acquired disability.

- People with an **age-related disability** will be offered alternative care if assessed as appropriate and requested (most often by their offspring or other family members who would otherwise be providing the care that is needed).

In other words: differing policy expectations are applied and resourced according to:

- the age of onset of the disability (lifelong, adult acquired, age-related)
- whether any other person or agency can be held accountable, and therefore financially responsible for meeting the person's care and support needs.

Such distinctions do not appear to accord with the stated Commonwealth, States and Territories legislative principles on the rights of people with disabilities "whatever the origin, nature, type and degree of disability".

The assumed resourcing responsibilities identified above also delineate the boundaries of current Commonwealth/State responsibilities in the provision of accommodation support services based on whether the disability was acquired before or after the age of 65.

- What is the role, expectations on, responsibility of Government/s in the funding/provision of services to meet the long term care and support needs of people whose disability occurs at different life stages and/or through different causes?
- What is the role, expectations on, responsibility of family to support family members with a disability the onset of which occurs at different life stages?

2.4. THE ROLE OF THE AUSTRALIAN GOVERNMENT

Leadership

In supporting the need for a national approach to disability service provision, and, by implication, the leadership role of the Commonwealth Government, the 1996 Yeatman review of the first CSTDA commented:

"Without a national approach... many critical values are sacrificed. The most important of these concern what it is to live as a person with a disability in the Australian citizen community. There are the standards of personhood by which Australians want to live, and the translation of these standards into principles and values regarding respect for the personhood of Australians with disabilities. Without a national value orientation of this kind that translates into Australia-wide standards, equity, and service quality, and into the required levels of cooperation across Australian governments to achieve these national standards, there cannot be a disability service system which is oriented to the needs of Australians" (p. 9-10).

The commitment to a national approach, based on shared Australian values, was reinforced again with the statement:

"The principles which should govern disability services make sense only in terms of a conception of including people with disabilities within a citizen

community, and citizenship talk makes sense only with reference to the national citizen community” (p.97).

The Yeatman review referred to the significance of public support for disability service provision in an Australian value system which attributed rights to the ‘personhood’ of all its citizens.

Human Rights and Social Justice Responsibilities

The Australian Law Reform Commission review of 1996 also affirmed the leadership role of the Commonwealth Government by virtue of its “*human rights and social justice responsibilities towards all Australians*”

*16.58. Since the Commonwealth gives money to the States and Territories for disability services, and since the Commonwealth has **human rights and social justice responsibilities towards all Australians**, the Commonwealth should be responsible for ensuring quality services that meet needs, respect rights and achieve outcomes for people with a disability on a national basis.....*

2.5. THE DIVISION OF COMMONWEALTH/STATE RESPONSIBILITIES

Assuming the Australian Government does have “*human rights and social justice responsibilities towards all Australian citizens*”, there appears to be no clear logic in the current division of health, human service and more specifically disability service responsibilities between the Commonwealth and State and Territory Governments. For example:

- On what basis does the Commonwealth assume a funding responsibility in relation to the dependency needs of younger children (through child care), and for seniors with an age-related disability (through residential aged care) but not for the long term care and support needs of younger Australians with disabilities?

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

Even so, in the most recent CSTDA, the Australian Government contributed funding for respite services for ageing carers (who are arguably more concerned about long term care arrangements), but not for younger carers (for whom respite may mean the difference between being able to continue to care or not). Again, there appears to be no clear rationale that may explain how these different funding commitments have been determined.

The boundaries of funding responsibility between employment services and day programs have also been a source of expressed interjurisdictional concerns about “cost shifting” practices.

At core, the question of and answer to the problem of unmet need again seems to come back to one of resourcing – i.e. who will pay?

3. UNMET NEED

In its submission to the NSW Parliamentary Inquiry into the Residential and other Support Needs of People with a Disability (2000), the NSW Community Services Commission stated:

“The disability service system is neither a short term nor a crisis care system, yet it operates as if it were. The time for a well planned, appropriately resourced, efficient, quality care system with the rights and aspirations of people with disabilities at its centre is long overdue” (p.36).

3.1. IDENTIFYING THE NEED

The level of so called “unmet need” depends on how “need” is defined.

The extent of the need/unmet need is therefore contingent upon the criterion applied for access to service support.

A criterion based on the level of “crisis” in the life of the person with a disability and/or their family carers will lead to a substantially different assessment of need and/or unmet need than one which is based solely upon an assessment of the ongoing support needs of the person with a disability, the extent to which these are being met, and by whom.

Clarification of the definition of “need” (and perhaps if and how this also relates to the person’s “rights”) would appear to be a necessary prerequisite for determining any meaningful measure of “unmet need”.

The questions I would therefore pose are:

- On what basis should the need for disability support services be defined e.g. assessed need, stated need, relativity of need, criticality of need?
- What are the individual, family and social consequences of basing service eligibility on these different criteria?
- Should the primary consideration be based on the needs of the person with a disability or the capacity of their family to meet these needs?
- To what extent should the needs and choices of family carers and the consequences for other family members also be taken into account?
- Should the life stage of the person with a disability and the life stage of their family carer also be taken into account in an assessment of needs?
- If the Australian community accepts it has a responsibility to support the needs of people with disabilities, as defined above, how can this responsibility best be realized and resourced?

4. RESOURCING OPTIONS

Whether in the private or the public domain, the capacity to meet the needs of people who cannot independently meet their own needs requires a commitment of resources.

In the domestic sphere, the time and energy expended on meeting the needs of the person who is dependent on such support may not be costed in monetary terms. However, this does not detract from the fact that resources are required, and consumed, just as they would be if the same services were funded via the public purse.

In anticipation of an increasingly ageing Australian population requiring support due to age-related disabilities, there has already been a large body of research and policy analysis undertaken on how the support needs of older Australians can best be resourced.

The advantages and disadvantages of the various options have also been canvassed although, at present, resourcing of residential aged care for dependent senior citizens continues to be drawn from general taxation revenue and largely paid for by the Australian Government.

Options for resourcing the support needs of people who have a lifelong or acquired disability have not yet attracted the same research or policy interest. However, those studies that have been conducted on aged-care resourcing options and requirements acknowledge the cross-over in issues and options for funding “long term care” irrespective of the time of acquisition of the disability.

The references to the articles/reports presented below recognise the same resourcing needs and overlaps. The first three originate from and present an Australian perspective within a comparative international context. The fourth reference examines the resourcing of long term care in Germany drawing comparisons to the needs in the United States.

- Fine, M., Chalmers, J. (2000). User pays and other approaches to the funding of long-term care for older people in Australia, *Ageing and Society*, 20, 5-32. (Based on a report written for the New South Wales Committee on Ageing)
- National Aged Care Alliance. (2002). *Options for Financing Long-Term Care for Older People in Australia*, from http://www.naca.asn.au/pdf/report_03.pdf
- Henwood, M. (1999). Home and Away, *Reflections on Long-Term Care in the UK and Australia*, Social Policy Research Centre, Discussion Paper, No.101, from <http://www.sprc.unsw.edu.au/dp/dp101ab.htm>
- Harrington, C., Geraedts, M., Heller, G. (2002). *Germany's long term care insurance model: Lessons for the United States*, from http://www.findarticles.com/p/articles/mi_qa4020/is_200201/ai_n9037661

(I have included the full text of the above article in a separate attachment)