

NATIONAL COUNCIL ON



DISABILITY
Incorporated in the ACT

Submission

Australian Senate Inquiry into Commonwealth State/Territory Disability Agreement (CSTDA)

August 2006

The National Council on Intellectual Disability (NCID) was established over 30 years ago by parents and friends in an endeavour to improve the quality of life of people with intellectual disability and to fill the need for national unity and information.

The Council is the recognised national peak body with the single focus on intellectual disability, ie, our actions and priorities centre on issues that affect the lives of people with intellectual disability and their families. Our mission is to work to make the Australian community one in which people with intellectual disability are involved and accepted as equal participating members.

NCID has over 5,000 members representing all 8 States and Territories. In addition to having people with intellectual disability on its Board, NCID receives policy advice from Our Voice. Our Voice is a committee the membership of which is exclusively people with intellectual disability representing all States and Territories.

Contact Information

National Council on Intellectual Disability
PO Box 771
Mawson ACT 2607

02 6296 4400

ncid@ncid.org.au

www.ncid.org.au

President: Rob Allen
Acting Executive Director: Sue Harris

Australian Senate inquiry into funding and operation of the CSTDA

Submission – Australian Senate Inquiry into Commonwealth State and Territory Disability Agreement – 2006.

Contents

1. Introduction
2. Scope of NCID's Submission
3. Background – NCID's perspective on CSTDA to date
4. Unmet need
 - 4.1 Unmet need for accommodation support
 - 4.2 Unmet need for employment support
5. Other Issues
 - 5.1 Fee for Services
 - 5.2 Data consistency
 - 5.3 Evidence based research
6. Recommendations

Attachments

Interaction Volume 19 Issue 3

Interaction Volume 19 Issue 4

Fees and Charges, Presentation to 2001 CIDA Conference by Christine Scott

1. Introduction

For hundreds of people with disability and the families, the current CSTDA falls well short of providing a national framework that makes a positive difference to their lives. The CSTDA is unclear in relation to the funding responsibilities of each level of government and sets no vision to meet the current and future needs of people with disabilities across Australia. As such, it is used as a platform for avoiding responsibility and for a piecemeal provision of services.

Disability is a national issue and people with disabilities are best served by engaging both levels of government. The CSTDA remains the key vehicle for establishing a co-ordinated and national framework for the provision of disability services.

For the CSTDA to make a positive difference in the lives of families living with disability it must address the central and fundamental issue of unmet need. Any Agreement which does not directly confront this issue and provide certainty to the thousands of people with disability urgently needing support will be judged a failure – no matter what else the Agreement might contain.

In July 2006 the Council of Australian Governments (COAG) endorsed the National Action Plan on Mental Health 2006 – 2011. The Plan included significant new funding to address unmet need and it also clearly set out the responsibilities of all Governments with detailed individual action plans.

The National Action Plan on Mental Health is a good example of what the 4th CSTDA must look like.

2. Scope and structure of NCID's submission

NCID's submission focuses on a number of core issues which confront people with intellectual disability and their families and which can only be addressed at a national level through a CSTDA.

The issues canvassed in this submission must not be taken as exhaustive and NCID is aware that many organisations will be making submissions that will address particular issues that those organisations have expertise in.

This submission was formulated from comments made by people with intellectual disability and their families during consultations that NCID has conducted over the past six months.

One of the major (secondary) comments that NCID received was that NCID's submission must be written in plain English and in easy to understand points, as opposed to large tracts of text.

NCID was also asked to request that the Senate Committee's final report be in a format that 'ordinary' people can read.

3. Background – NCID’s perspective on CSTDA to date

The CSTDA - Background

- The first CSDA was signed in 1991.
- It was intended to provide a national framework for the funding and administration of specialist disability support services.
- It rationalised the arrangements separating responsibility for the “approval, administration and evaluation” of services between the different levels of government whilst maintaining “joint responsibility for contributing funds for the provision of services”.
- The current CSTDA is the third such agreement spanning 2002/03 to 2006/07.
- The services covered by the agreement include accommodation support, community support, community access, respite, employment, advocacy, information and print disability.

Shortcomings of the Current CSTDA

- It has not achieved its potential for providing the supports and services that people with disability and their families require; **thus over 25,000 people are in urgent need for accommodation and day support.**
- It provides no vision or plan to meet the needs of people with disabilities across Australia.
- It falls well short of providing a comprehensive national framework that makes a positive difference to the lives of thousands of people with disability.
- It is unclear in relation to the funding responsibilities of each level of government.
- There are inadequate measures in place to ensure good outcomes for people with disability.
- The shortcomings of the current CSTDA result in a very heavy cost to people with disabilities and their families, to government and to the taxpayer.

Why another CSTDA?

- Disability is a critical national issue and people with disability are best served by engaging both levels of government.
- A CSTDA that addressed the above shortcomings would enable the provision of the supports and services that people with disability and their families require.
- One of the key goals of the original CSDA was to provide a forum for the co-ordination of funding and support for people with disability but we still see both the Australian and State/Territory Governments making decision without

Australian Senate inquiry into funding and operation of the CSTDA

reference to the other and without reference to an overall plan/strategy. For example, allocation of respite and supported accommodation funding and the allocation of employment support and day service support.

4. Unmet need

The principal issue confronting people with intellectual disability and their families is a lack of funding to provide the support that people with intellectual disability need to participate in the Australian community.

Before the 3rd CSTDA was negotiated the Australian Institute on Health and Welfare (AIHW) published a report '*Unmet need for disability services: effectiveness of funding and remaining shortfalls*'. The purpose of the report was to provide information on "the effectiveness of the unmet need funding in reducing unmet need for disability services" and "identify any remaining need".

NCID understands that the AIHW has been commissioned by the National Disability Administrators to prepare a similar report to inform the negotiations for the 4th CSTDA. NCID commends the National Disability Administrators on this important initiative.

The AIHW will make an estimate of the 'known' unmet need for support, it will also make comments about the 'unknown' unmet need that exists in the community. In the past this situation has led governments to inaction as they state that they cannot plan for meeting the unmet need within the community until they know the full extent of the unmet need. This stance is totally unreasonable as the full extent of unmet need will never be known as most States and Territories do not keep waiting lists/needs registers and therefore it becomes impossible to determine how many people need support and what they need support for.

This stance is also unacceptable as there is sufficient evidence that thousands of people are in desperate need now:

- there are regular accounts in the newspapers of families living in very difficult situations for these accounts to be documented in the media, the situations of the families must be desperate and they therefore will only represent the tip of an iceberg,
- politicians are regularly contacted by families and agencies with personal stories of the families in need the families are often in crisis and have nowhere to turn,
- the 2002 AIHW report clearly states that as of 2001 there is unmet need for the following specific services¹:
 - 12,000 people need accommodation and respite services
 - 8,200 people need community access support, and,
 - 5,400 people need employment support.
- There are 5,894 parents aged 65+ caring for children with severe and profound disabilities; this estimate very conservative and is taken from the 2003-04 CSTDA funded service data. *AIHW 2005, (p.34)*.

¹ The AIHW based these figures on " a conservative basis, with the aim of providing reliable 'lower bound' estimates. This is considered more useful than making higher estimates which, while perhaps more in the mid-range, may be subject to more debate." (2002, p.205)

Australian Senate inquiry into funding and operation of the CSTDA

The obvious question is, given that all governments have known since 2001 that the unmet need for support is 25,600 people why have they not responded to meet this already known need?

For NCID this is the central question that the Senate Committee must answer.

Recommendation 1.

That the Commonwealth and State and Territory Governments commit to funding all known unmet need, as estimated by the soon to be released AIHW report, within the 5 year time-frame of the 4th CSTDA.

4.1 Unmet need for daily living support

Unmet need for daily living support is the major area of need for people with intellectual disability and their families. Daily living support is also the one area of need that is neglected by all Governments.

For example, a good indication of the 'crisis' that has arisen because of the neglect of Governments in providing daily living support is the fact that there are over 5,000 people with severe and profound disability living with parents who are aged over 65; a situation which is not sustainable due to the age of the parents.

The question for the Senate Committee here is: what is being provided to support these 5,000 families?

An additional issue is the provision of respite care. Respite care is important for families, particularly where the respite care is flexible. **But, respite care is never a substitute for daily living support**, and furthermore, it should not be such, as daily living support allows the maximum 'normality' that can be achieved when a family member has a disability.

The issue of respite care raises another important issue, ie, the lack of co-ordination between the Commonwealth and States and Territories. The Commonwealth continues to provide additional funding for respite without reference to the States and Territories which occasionally increase daily living support. This is not a comment on respite care as such, respite care is needed and flexible respite care is what many families want but in recent times the Commonwealth has not provided additional funding for daily living support, though it has provided increased respite care to parents over the age of 70. Parents over the age of 70 want certainty for their son or daughter and a quality of life that for their son and daughter that they as elderly people are unable to give; they want long term daily living support not the occasional day.

In a recent State funding round for daily living support only 50% of people with parents over the age of 70 obtained funding.²

² The particular state is not mentioned as it is one of the few to produce good, comprehensive and public data about its funding rounds. In the year of the funding rounds only 34.5% were successful in obtaining daily living support funding; only 58% were successful in obtaining alternatives to employment funding.

Recommendation 2

That the Commonwealth and State and Territory Governments commit to funding all known unmet need for daily living support and respite care, as estimated by the soon to be released AIHW report, within the 5 year time-frame of the 4th CSTDA.

4.2 Unmet need for employment support

The Australian government does not provide employment support to all people with intellectual disability who want to work. This is in sharp contrast to the rest of the Australian population who get employment support as an entitlement. This stance forces many people with intellectual disability onto State/Territory funded alternatives to employment services or to be at home with parents.

We know that people with a significant intellectual disability can obtain and keep a job. We also know that as a consequence they are more likely to participate in other community activities and to lead healthier lives. The major obstacles are a lack of commitment from the Commonwealth to provide flexible funding and uncapped funding.

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 programmes.

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, 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.

Recommendation 3

That the Commonwealth Government commit to funding all known unmet need for employment support (including preparation for employment), as estimated by the soon to be released AIHW report, within the 5 year time-frame of the 4th CSTDA.

4.3 Individual (case based) funding and self-managed funding.

Research clearly demonstrates³ that if we want people to have access to an ordinary life then the support system that is offered must offer choice and be flexible both in

³ See Interaction Volume 19 Issue 3; this Issue of Interaction provides an analysis of research of daily living support and what approaches give best quality outcomes for people with disability, ie, 'value for money'.

Australian Senate inquiry into funding and operation of the CSTDA

terms of meeting the person's individual needs and in adapting to a person's changing needs.

Research clearly demonstrates⁴ that the only way to achieve flexible support arrangements is for governments to provide funding to individuals on an individual basis with real control over how that funding is to be utilised to meet their individual needs.

The Commonwealth has already started this move with Case Based Funding for employment support. This system provides employment support funding to people with disability based on an assessment on their individual needs.

Individualised self-managed funding allows people to make a genuine choice of service model, it gives them control. In doing so it frees governments from having to construct models that they think are what people with disability want.

There are many myths about individualised self-managed funding:

- individualised self-managed funding enables people to approach a service provider of their choice to provide their support
- it does not prevent people from pooling their funds to establish a service model of their own
- it does mean that people have real choice about their support structure
- it does mean that people are making choices that meet their individual needs, and for which they will have to take the consequences if they make a mis-judged decision until they fix it.

An important component of all funding approaches is the necessity to base funding decisions on a 'person-centred plan'. This is also true of individualised self-managed funding, and the funding allocated must make provision for development of a 'person-centred plan'.

"I would rather live my own mistakes than the mistakes of others".

Recommendation 4

That from 1 July 2007 all individuals (and their families) be offered:

- **a person centre plan,**
- **individualised funding - as a choice,**
- **self-managed funding - as a choice .**

⁴ See Interactoin Volume 19 Issue 4; this Issue of Interaction reviews self-managed funding over the last decade in the USA and reports on its implementation in the UK.

5. Other Issues

5.1 Fees for Support Services

Increasingly disability support services are charging fees for services that people with intellectual disability use⁵. Services such as transport, alternatives to employment, accommodation and home care are charging fees that are greater than the Disability Support Pension (DSP); where the fees exceed the DSP and where the fees do not leave the person with disability with sufficient funds to live on parents are being forced to make up the difference. There are of course people who do not have close family and their situation is particularly difficult and uncertain. Many people in boarding houses are in this situation and it is safe to assume that they live in extreme poverty.

NCID endorses the following principles with regard to fees for support services:

- No-one should be denied a service due to their lack of capacity to pay (Capacity to pay should never be part of a funding/needs assessment).
- For people over the age of 18, only the income of the individual must be taken into consideration in an assessment of capacity to pay service fees.
- Where a number of services charge an individual fees the services that charge fees are responsible for co-ordinating the level of fees charged to maintain the above 'cap'.
- Governments must put in place robust safeguards to ensure that people have access to services they need and also that people with disability are not forced into poverty.

Recommendation 5

People with disability must be left with a minimal level of income, 50% of pension or its equivalent, 25% where board is provided.

5.2 Data consistency

For the 4th CSTDA to be a successful Agreement there is a need for comprehensive and comparable data across time and jurisdictions to ensure that agreed actions are met. In particular the issue of unmet need can only be successfully addressed if the keeping of waiting lists/needs register is mandatory.

Data is important to be able to obtain evidence of what funding is achieving for individuals. It is also important for people with disability and their families to be able to provide qualitative information/data directly to governments about the outcomes of the support that they receive and for this to be included in any data collection.

Recommendation 6

⁵ See attached paper, Fees and Charges for more detailed information. Though the paper was written in 2001 (and hence the figures are 'out of date') the situation has not changed with many saying that it is "getting worse".

That the collection of unmet need data be mandatory for all signatories to the CSTDA, that all aggregated information is publicly available in an understandable format and that people with disability and families are an integral element of the collection and dissemination of data/information.

5.3 Evidence based research

While there is much talk of the need to fund support on the basis of what we know delivers good quality outcomes for people with disability there is little evidence that the Commonwealth or State/Territory Governments apply this rigorous test to the decisions they make to achieve their policy outcomes.

This must change if people with disability, their families and taxpayers are to get value for money.

Recommendation 7

That the Commonwealth State and Territory Governments enshrine in the 4th CSTDA a commitment to publish evidence based research to account for their policy and funding decisions.

6 Recommendations

Recommendation 1.

That the Commonwealth and State and Territory Governments commit to funding all known unmet need, as estimated by the soon to be released AIHW report, within the 5 year time-frame of the 4th CSTDA.

Recommendation 2

That the Commonwealth and State and Territory Governments commit to funding all known unmet need for 24hr daily living support and respite care, as estimated by the soon to be released AIHW report, within the 5 year time-frame of the 4th CSTDA.

Recommendation 3

That the Commonwealth Government commit to funding all known unmet need for employment support (including preparation for employment), as estimated by the soon to be released AIHW report, within the 5 year time-frame of the 4th CSTDA.

Recommendation 4

That from 1 July 2007 all individuals (and their families) be offered:

- a person centre plan,
- individualised funding - as a choice,
- self-managed funding - as a choice .

Recommendation 5

People with disability must be left with a minimal level of income, 50% of pension or its equivalent, 25% where board is provided

Recommendation 6

That the collection of unmet need data be mandatory for all signatories to the CSTDA, that all aggregated information is publicly available in an understandable format and that people with disability and families are an integral element of the collection and dissemination of data/information.

Recommendation 7

That the Commonwealth State and Territory Governments enshrine in the 4th CSTDA a commitment to publish evidence based research to account for their policy and funding decisions.

Australian Senate inquiry into funding and operation of the CSTDA

Reference material

Australian Institute on Health and Welfare (AIHW) 2005. Disability and disability services in Australia. Cat. no. DIS43. Canberra: AIHW.

Australian Institute of Health and Welfare (AIHW) 2005. Disability support services 2003–04: national data on services provided under the Commonwealth State/Territory Disability Agreement. AIHW cat. no. DIS 40. Canberra: AIHW.

Australian Institute on Health and Welfare (AIHW) 2002. Unmet need for disability services: effectiveness of funding and remaining shortfall. Cat. no. Dis 26. Canberra: AIHW.

Australian Law Reform Commission (ALRC) 1996. Making Rights Count. ALRC 79. Canberra.

Australian National Audit Office (ANAO) 2005 – 06. Administration of the Commonwealth State and Territory Disability Agreement. Audit Report No. 14. Canberra.

Dempsey I and Nankervis K (eds) (2006). Community disability services: an evidence-based approach to practice. Sydney: UNSW Press.

Developmental Disability Council of WA 2003. When needs go begging. Perth WA.

Stancliffe RJ and Lakin KC (eds) (2005). Costs and outcomes of community services for people with intellectual disabilities. Baltimore: Paul H Brookes Publishing Co.