



**NSW Council for  
Intellectual Disability**

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**Response from NSW CID to the  
Australian Senate Community Affairs Committee  
*Inquiry into the funding and operation of the  
Commonwealth/State Disability Agreement*  
August 2006**

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## **1. About NSW CID**

The NSW Council for Intellectual Disability (NSWCID) is a peak body representing the rights and interests of people with intellectual disability in NSW. Council's roles include providing policy advice, systemic advocacy, community education and information provision and dissemination. We undertake all of our work with the active participation of people with intellectual disability and work to enhance the meaningful participation of people with intellectual disability in their communities.

## **2. About Intellectual Disability**

Prior to defining any group of people it is important to note that no one individual is the same, but generally, in order for someone to be given a 'diagnosis' of intellectual disability, there are three core features people must have:

1. An IQ of less than 70-75
2. Difficulties with 'adaptive skills' – such as following and understanding directions, understanding abstract concepts, etc
3. The existence of the first two characteristics prior to the age of 18

Intellectual disability does not preclude people from living active lives in their communities and they should be provided appropriate support to participate in meaningful employment and day time activities and live in ways that reflect the norms and expectations of the rest of the community.

## **3. Introductory Comments**

NSW CID views the first CSDA, signed in 1991, as a very important mechanism at the time to attempt to achieve a level of consistency and equity in the funding and provision of disability services. In 1991 it was a positive step toward a national framework for the funding and administration of specialist disability support services. However the first and subsequent Agreements fall well short in relation to the 'pursuit of a just and inclusive society' as described in the 3<sup>rd</sup> Agreement.<sup>1</sup>

NSW CID believes that there is need for an overall Disability Strategy similar to the National HIV/AIDS strategy with implicitly stated commitments to action and implementation that go far beyond the statements of principle and priority areas of current and past CSTDAs. Another

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<sup>1</sup> Preamble; 3<sup>rd</sup> CSTDA

example of a more robust strategy is the area of Mental Health where there has been concerted action in recent times with the endorsement by COAG in July of the *National Action Plan on Mental Health 2006-2011*. This plan states clearly the responsibilities of all Governments with detailed action plans.

The original CSDA in 1993 aimed to coordinate funding and support for people with disability across all States and Territories. Yet there is still unilateral decision making without reference to other States and Territories and there is no reference to an overall planned strategy. These inconsistencies occur across all areas of program funding; for example; funding levels for respite and supported accommodation and employment and day service supports.

This response from NSW CID focuses solely on the issues affecting people with intellectual disability. We are a member of the recently formed *National CSTDA Community Alliance* and we urge the committee to consult further with spokespeople from this Alliance.

#### **4. Response to the Terms of Reference**

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

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

In 1996, the Yeatman Report, *Getting Real* highlighted that the two broad aims of the 1<sup>st</sup> Agreement were to firstly; 'establish an initial framework for the rationalization of the administration of disability services by the Commonwealth and States, and' secondly; 'to develop, on a national basis, integrated services to ensure that people with disabilities have access to appropriate services to meet their individual needs'.<sup>2</sup> Many of the recommendations from this report are yet to be addressed and we are moving toward the 4<sup>th</sup> CSTDA in July 2007.

The five strategic policy priorities of the 3<sup>rd</sup> CSTDA; listed below, remain key priorities areas with significant work required to achieve success in all of the areas.

*i) strengthen access to generic services for people with disabilities;*

In NSW there is still limited access to generic services for people with intellectual disability. In 2001/2002 the NSW disability agency, the Department of Ageing Disability and Home Care (DADHC) introduced a system of Local Area Coordinators, whose role it is to link people into local services with a focus on generic services. By 2005 there were 20 positions across the

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<sup>2</sup> *Getting Real* – the final report of the Review of the Commonwealth/State Disability Agreement. Anna Yeatman, July 1996.

State. NSW CID has received relatively positive reports about the work of the Local Area Coordinators. However the main obstacle remains the reluctance of some mainstream services to include people with intellectual disability, usually as a result of misperceptions about people's behaviour and an overall lack of skill and awareness in disability issues. In order to achieve the necessary shift in perception of people with disability in the mainstream communities there must be leadership demonstrated at all levels of Government. Over the past 3 years the NSW Government with DADHC taking lead, have supported high profile state-wide events to celebrate the International Day of People with Disabilities. This is an important step toward improving community awareness and inclusion of people with disability and is something that should be embraced more consistently in other States and Territories and within the Australian Government.

*ii) strengthen across Government linkages;*

The issue of young people with disability being inappropriately placed in aged care facilities is a glaring example of where the lack of linkages across levels of Government and Government agencies have failed people with disability. While there has been recent discussion in COAG to address this, many people with disability languish in inappropriate services waiting for supported accommodation options to become available and this occurs against the backdrop of significant unmet need for accommodation across all States and Territories.

Another area where linkages need to improve is the transition from state run post school programs to Commonwealth run employment programs; there is still a great deal of uncertainty for people in this area. There is a need for better co-ordination of services to people requiring access to other service systems, such as aged care and mental health service while continuing to receive a disability service.

*iii) strengthen individuals, families and carers;*

Families remain the main source of support for people with intellectual disability – the majority of whom live with unpaid carers. While family resilience must be developed and enhanced, the right of people with intellectual disability to live independent adult lives must not be compromised. Much of the recent support for families of people with intellectual disability has been in the form of increases to respite services. While this is welcomed by many families it often means people remaining with ageing carers way beyond what is reasonable to expect from the families and it also denies people the opportunity to a life independent of their families.

*iv) improve long-term strategies to respond to and manage demand for specialist disability services;*

The key issue in relation to this is to identify consistent mechanisms for identifying demand. This is discussed in Term of Reference b) relating to unmet need.

*v) improve accountability, performance reporting and quality.*

There needs to be consistent approaches at all levels of Government to quality assurance and continuous improvement. Additionally more work needs to be done to develop meaningful measures of quality of life outcomes for people with disability.

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

The current CSTDA provides no real vision or plan to meet the needs of people with disability. There needs to be more detailed strategies linked to clearer performance measures in order to identify and address unmet need. In NSW, and no doubt other States and Territories a key issue is the lack of data collection in order to determine the real levels of unmet need. We know that most people with intellectual disability live with carers outside of the disability supported accommodation system.

Since the 2002 Australian Institute of Health and Welfare report<sup>3</sup> into unmet need in disability little has changed in terms of service access for many people with disability and their families. There continues to be an estimated 25,600 people with disability across Australia who require some form of accommodation, community access or employment support. The detrimental effects on families and additional effects on people with disability, such as skill loss for the person with disability and family breakdown are at times catastrophic.

*Unmet Need – Accommodation Supports*

The 2001 NSW Parliamentary Inquiry into unmet need<sup>4</sup> recommended 200 additional accommodation places for the next 5 years. The recent 10 year plan, *Stronger Together*, released by the NSW Government, which NSW CID has welcomed, has promised this. However when the recommendation was made in 2001 no consideration was given to the large numbers of people with intellectual disability requiring accommodation when exiting correctional facilities so while we applaud the Government's commitment in this area there is still significant

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<sup>3</sup> *'Unmet Need for Disability Services: Effectiveness of Funding and Remaining Shortfalls* AIHW 2002

<sup>4</sup> *A Matter of Priority*, Parliament of NSW Legislative Council Social Issues Committee. 2001

numbers of people who will miss out on support. Additionally since 2001 the numbers of people requiring services has increased.

#### *Unmet need - Employment*

There is insufficient employment support for people with intellectual disability who actually want to work. For other people without intellectual disability this is a basic entitlement. Many people with disability are 'relegated' to supported employment or day services that, in the majority of cases, do little to enhance and maintain skill development and in the case of Business Services they are paid a sub-standard wage. However, sadly, too often, they and their families cling to such services for fear of having nothing to do with their time – and from the parents and families perspective there is concern that the person with disability will be at home constantly, leading to social isolation and reduced independence.

There is clear evidence that people with intellectual disability, even those with high support needs can obtain and keep a job – with the right type of supports. Models include; the Best Buddies Jobs program and the Oklahoma model in the U.S, the CAPRE model in Canada and the Workbridge model in NZ<sup>5</sup>. With the right supports people can achieve greater independence in their adult roles and significantly reduce reliance on Governments in terms of income support.

#### *Unmet need and equity*

Too frequently people with disability of culturally and linguistically diverse background and Indigenous people are overlooked in discussions about unmet need. There is anecdotal evidence that of the approximately 30% of people with disability in high schools in NSW are people of culturally and linguistically diverse background and only 5% of them go onto the State funded post school programs. The 4<sup>th</sup> CSTDA needs to do more to address issues of inequity through better performance management in this area.

- (c) ***an examination of the ageing/disability interface with respect to health, aged care and other services, including the problems of jurisdictional overlap and inefficiency; and***

There appears to have been little work done in this area in NSW; DADHC initiated an ageing/disability intersection project in 2001 but there has been no clear outcome from this project; at least none that has been publicly promoted by the Department.

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<sup>5</sup> Contact NSW CID for more information on these models.

One of the issues relating to this is the lack of clarity between the role of the CSTDA and the HACC agreements. In NSW there is low utilisation of HACC services by people with disability because there is a perception that they are only for older people. There needs to be greater flexibility to allow people in State funded accommodation services to access Commonwealth community care to support people with disability who are ageing.

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

There is an abundance of research and work<sup>6</sup> that has been done in relation to funding mechanisms for disability services. Factors that must be taken in account include the need for flexibility and individualized responses to ensure a person with disability can live a satisfying independent adult life. Clearly this must be balanced with getting the most value for money but service quality must not be compromised.

NSW CID is of the opinion that a system of self managed funds including Direct Payments is likely to lead to the most effective outcomes for people with disabilities and be more flexible to adapt to people's changing needs.

An example of what might be a more sustainable funding model exists in Germany in the form of their Long Term Care insurance model. NSW CID recommends that the Committee explore this and other international models.

## **5. Other issues**

- Thirteen years after the Disability Services Act (NSW 1993) and twenty years after the Commonwealth Disability Services Act (1986) were passed, we still have significant lack of compliance in both State and Australian Government funded services. The Commonwealth continues to fund supported employment models that congregate people with intellectual disability together and minimize opportunity for access to the community. While many Business Services work well for some people, this is still an outmoded service model that should be phased out over time and more flexible innovative models adopted that provide for greater independence and community access. In NSW there is significant concern that the aforementioned 10 Year Plan for disability services in NSW has no commitment to closing the remaining large residential centres that accommodate more than 2000 people with disability.

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<sup>6</sup> See *Interaction, Volume 19, Issue3*: National Council on Intellectual Disability.

- In the 1996 Yeatman report there are several recommendations relating to independent advocacy and disability peak bodies. Ten years on there is still much to be achieved in this area; with some States still not funding consumer systemic advocacy for people with intellectual.
- Funding needs to be at a sufficient level so that where people pay board and lodging to disability service providers there is some money left over for people to have some discretionary spending; currently too many people with disability live very impoverished lives.
- People with disability living in Boarding House experience significant disadvantage particularly in relation to cross jurisdictional issues such as mental health, criminal justice and disability supports.
- In 1996 the Yeatman report recommended (recommendation 6) the development of industry awareness in relevant professional education training program. This continues to be an issue in service provision in NSW and no doubt in other States/Territories. While the NSW Government has made some provision in the 10 Year Plan to address workforce development issues there is still insufficient funding to seriously address this issue.
- The issue of transport is constantly raised by families whose sons and daughters are going to employment or post school programs and also social activities. For many transport was provided for young people when they were at high school and this allowed families to continue with their work and daily lives. NSW CID has heard too many stories of mothers (it is usually the mother) who have to give up work in order to drive their son or daughter to their post school program. Transport must be seen as an 'enabling' issue and ways must be found to address this issue; for example; expanding access to the Mobility Allowance for people who are unable to use public transport.

## **6. Conclusions and recommendations**

In concluding this response to the Senate Inquiry NSW CID makes the following recommendations to the Committee:

- i) That consideration is given to the development of a National Disability Strategy that goes beyond the scope of the current and previous CSTDAs.
- ii) That the 4<sup>th</sup> CSTDA incorporate mechanisms across all jurisdictions for consistent data collection to determine unmet need.



- iii) That the 4<sup>th</sup> CSTDA incorporates performance management measures to ensure people of culturally and linguistically diverse backgrounds and Indigenous people with disability are able to access services.
- iv) NSW CID recommends strongly that the next CSTDA enshrines a commitment to only funding accommodation supports and services that are compliant with Commonwealth and State legislation and that support adults with disability to live in a manner that is in keeping with community norms; i.e. people living alone or sharing houses or flats where they have their own room
- v) NSW CID strongly recommends that the 4<sup>th</sup> CSTDA enshrines a commitment to only funding employment supports for adults with disability to work in a manner that is in keeping with community norms; i.e. paid a living wage, having work that is interesting and having career development opportunities.
- vi) That work is done to explore the development of more flexible mechanisms to allow for self-managed funding, more case-based models and direct payments to people with disabilities and families.
- vii) NSW CID recommends that the Committee explore the potential of the German Long Term Care insurance and other international models.

**Thank you for the opportunity to have input into this inquiry.**  
***Helena O'Connell***  
***Executive Officer***