

**NCOSS Submission to  
The Australian Senate Community Affairs Reference Committee**

***Inquiry into the  
Commonwealth State  
Territory Disability  
Agreement***



**August 2006**

**Council of Social Service of NSW  
66 Albion Street, Surry Hills NSW 2010**

**ph: 02 9211 2599 Fax: 02 9281 1968 email: [chris@ncoss.org.au](mailto:chris@ncoss.org.au)**



## Council of Social Service of New South Wales

66 Albion St, Surry Hills NSW  
phone 02 9211 2599 fax 02 9281 1968  
email [info@ncoss.org.au](mailto:info@ncoss.org.au) web [www.ncoss.org.au](http://www.ncoss.org.au)

abn 85001 797 137

---

### ABOUT NCOSS

The Council of Social Service of New South Wales (NCOSS) is the peak body for the social and community services sector in New South Wales. NCOSS works with its members on behalf of disadvantaged people and communities towards achieving social justice in this State.

NCOSS provides an independent voice on human services policy issues and social and economic reforms and is the major co-ordinator for non-government social and community services. It was established in 1935 and is part of a national network of Councils of Social Service, which operate in each State and Territory and at Commonwealth level.

NCOSS membership is composed of community organisations and interested individuals. Through current membership forums, NCOSS represents more than 7,000 community organisations and over 85,000 consumers and individuals. Member organisations are diverse; including unfunded self-help groups, children's services, youth services emergency relief agencies, chronic illness organisations, local indigenous community organisations, church groups, and a range of population-specific consumer advocacy agencies.

In preparation for this submission, NCOSS has drawn on discussions with the NSW Aboriginal Community Care Gathering Committee, the NSW HACC Issues Forum, the NSW Aged Care Alliance, Australian Council of Social Service (ACOSS), the Mental Health Coordinating Council (MHCC), the NSW Aged and Community Services Assoc NSW & ACT., and other peak agencies in NSW.

NCOSS appreciates the opportunity to provide submit to the Australian Senate Community Affairs References Committee Inquiry into the Commonwealth State Territory Disability Agreement (CSTDA).

Should further information be required, please contact NCOSS Christine Regan on 02 9211 2599 ext 117 or [chris@ncoss.org.au](mailto:chris@ncoss.org.au)

Yours sincerely,

**MICHELLE BURRELL**  
ACTING DIRECTOR



## A PICTURE OF DISABILITY SERVICES IN NSW:

The population of older people and people with disabilities in NSW is escalating. The NSW Department of Ageing Disability and Home Care (DADHC) estimates<sup>1</sup> that between 2000 and 2011, the population of NSW will grow by 8%, compared to the growth in the numbers of people with disabilities during that time of 18% and older people by 26%.

The Productivity Commission provides comparative information on the provision of Government Services across Australia each year. Some features of this year's report<sup>2</sup> on the provision of Disability Services in NSW include:

- The total number of users of CSTDA services in NSW was 26,846 and the number in Victoria was 44,581. In general terms, NSW has about 33% of Australia's total population while Victoria has around 25%.
- NSW reported the second lowest proportion (2.8%) of potential population using **accommodation support services** in 2003-04 (after the Northern Territory). The national average was 4.1% and Victoria had 5.2%.
- Excluding the territories (ACT & NT), NSW reported the lowest proportion (17.6%) of potential population using **employment services** in 2003-04. The national average was 19.6% and Victoria had 23.1%.
- NSW reported lowest proportion (2.8%) of potential population using **community access services** in 2003-04. The national average was 6% and Victoria had 7.7%.
- NSW reported the lowest by far number of users of community accommodation and care services as a proportion of all accommodation support service users in 2003-04. NSW was 73.1%, the national average was 82.9% and Victoria was 89.9%.
- Across Australia, people under 65 years born in a non-English speaking country had a disproportionately low usage of accommodation support services at 0.5% compared to the total population of 1.6% however NSW reported the lowest proportion of 0.2%.
- Similarly, NSW reported the lowest by far proportion of labour force and employment participation by people aged 15 – 64 years born in a non-English speaking country with profound or severe core activity restriction at 8.5%. The national average was 15.4% and Victoria was 20.6%.
- By all given financial measures for 2004-05, NSW was the highest spending jurisdiction on administration expenditure as a proportion of total expenditure by around 2%. Interestingly, this represents a reduction over previous years for NSW.

For the last two years NSW has mitigated its performance comparisons by explaining that there have been low returns on the Minimum Data Set, the mechanism by which data is recorded and transferred to government authorities for collation. Even when taking into account the low data return rates, NSW performance has been very disappointing.

The Productivity Commission has detailed a range of improvements to data collection and reporting which NCOSS supports; especially their intention to report on younger people with

---

<sup>1</sup> DADHC Future Directions document, August 2004

<sup>2</sup> Productivity Commission Report on Government Services 2006, Chapter 13 Disability Services

disability in residential aged care facilities from 2007. They will also report on respite services and community support services from 2007.

## **Stronger Together NSW Disability Services Plan**

Just prior to the 2006 State Budget, the NSW Government announced the release of the new **Stronger Together** package of disability support services, totalling \$1.3 billion spending measures over five years. This Package is certainly very welcome to begin to address the burgeoning and long overlooked unmet needs of people with disabilities in NSW. However, it is very obvious that only sustained growth investment over time will be necessary to provide sufficient confidence and resources into the disability support system to support people with disabilities and to realise equal participation in everyday life opportunities throughout the entire life cycle.

### TERMS OF REFERENCE

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

#### **Indexation and adequacy of funding**

The issue of unmet need will be discussed in later sections. While the *Stronger Together* Plan provides additional capacity for disability support, the existing funding of disability services may be inadequate to keep pace with the reasonable expectations of people with disabilities and the contracted obligations of funding bodies. Many disability organisations have been in service for an extended period of time and may be operating from a historically outdated funding base. Certainly, previous indexation rates have not compensated for increases in costs, including wages, activities and overheads, as well as external impacts such as insurance, workers compensation and fuel prices etc. This has resulted in a pattern of consistent underfunding with the net effect being diminished service capacity.

NCOSS recommends that the indexation rates for funded disability organisations be increased to cover the real increases in costs of providing support services to people with disabilities.

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

New South Wales is now working within its third five-year disability services agreement – the Commonwealth State/Territory Disability Agreement (CSTDA) for the period 1 July 2002 to 30 June 2007. This agreement forms the basis for the provision and funding of specialist services for people with a disability who require ongoing or long-term episodic support.

The CSTDA delivers funding to NSW under broad areas specified in the Agreement. Disability services are largely administered by the Department of Ageing, Disability and Home Care (DADHC) with services including:

- Accommodation services
- Employment services eg. Open / Supported Employment)
- Community Support (eg. Attendant care)
- Community Access Services (eg. Day programs and respite services)
- Information and Advocacy Services

NCOSS receives consistent reports of problems within the disability services support system at several levels. These problems can be summarized into the following points:

- Lack of confidence in the disability support system. People with disabilities, families and advocates are often fearful that appropriate supports will not be available when needs change or at critical life transitions.
- Unnecessarily complex disability service system. Funded programs vary between jurisdictions and often present artificial barriers to access as needs change eg Commonwealth employment programs, school leaver programs and day therapy programs.
- Inconsistent responses, (sometimes absence of support services) to people with some specific disabilities or conditions eg people with acquired brain injuries, people with mental health conditions and psychiatric disabilities, people with mild disabilities, people with episodic conditions eg Motor Neurone Disease etc.
- The actual size of the unmet needs of people with disabilities has never been publicly quantified.
- The impact of poverty on people with disabilities. Often the impact of disability on a person and their family can significantly restrict their financial opportunities. Those who are solely or substantially reliant on the Disability Support Pension and accompanying income supports are less likely to be able to access the opportunities or life chances that others take for granted.
- The impact of disability must not depend on the prior financial status of the person or their family. Nor should the impact of disability be dependent on the capacity of the family. People with disabilities must be able to choose an independent adult life, as can their non-disabled peers.
- The particular life experiences of Aboriginal and Torres Strait Islander people is not adequately acknowledged. Aboriginal and Torres Strait Islander people experience and identify disability differently from mainstream communities and must have suitably tailored service and support responses that are not merely add-ons from the mainstream system.
- Similarly, people with disabilities from culturally and linguistically diverse backgrounds must not be expected to “cope” for longer than mainstream communities without support and that support must be adapted to the needs of the individual.
- The absence of benchmarks for service provision. This means that the quality and quantity, adequacy and availability of disability supports cannot be guaranteed to a consistent level across levels of government, jurisdictions, geographical areas, age ranges, life stages or funded programs.
- Poor or non-existent linkages between service systems:
  - Community Care system: Approximately 30% of users of the Home & Community Care Program (providing in-home supports) are people with disabilities under the age of 65 years.
  - Health: People with disabilities may not have adequate access to health services, allied therapies, treatments and preventative strategies.
  - Housing: A significant number of people with disabilities live in insecure housing, eg boarding houses, people experiencing homelessness.
  - Retirement and Aged Care system: People with disabilities are living into retirement and past the age of 65 years into older age.

- Carer support: While carers provide 74% of the care provided to people with disabilities, many people with disabilities have no family carers or significant people to support them.
- Data returns and inconsistencies are a barrier to transparency and improvements for disability support systems
- Punitive measures designed to “encourage” people with disabilities could have the exact opposite effect eg mandatory requirements of welfare to work legislation
- Out-dated services. Many large disability institutions have not been closed despite promises from successive governments. People with disabilities, families and advocates are increasingly focussing on person-centred planning as a means of efficient and effective spending to address the needs of the individual with disability.
- Generic services and opportunities eg transport, housing, banking, shopping, leisure and other community infrastructure do not adequately encompass or respond to the needs of people with disabilities. The balance between generic services and specialist disability supports has not been deliberately identified.

## Leadership

The CSTDA represents an invaluable mechanism to provide leadership for and promotion of the value and contribution of people with disabilities in addition to the provision of specialist support services. To date, this leadership role has not been actively performed in a way that extends the opportunities and life chances of people with disabilities within the wider community. This leadership role could include productive linkages with government and non-government providers generic services such as of housing, financial products, health services, leisure, employment opportunities, access to education and other skills development, transport options, leisure and other activities, self-development and independence supports and training.

*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;*

## Unmet need

### **Actuarial Study**

The NSW government completed an Actuarial Study into the potential population to be served by its Department of Ageing Disability and Home Care. This Actuarial Study has never been publicly released. NCOSS recommends the public release of this Study.

### **Supported Accommodation**

There have been years of campaigning for more supported accommodation for people with disabilities in NSW. While the NSW State Plan declares that disability spending in the past nine years has increased by 125%, the provision of supported accommodation places has only risen during that time by less than 19%, despite escalating populations and demands.

The NSW *Stronger Together* Package promises 990 new supported accommodation places over five years, 180 provided by end June 2007. This is warmly welcomed as the commencement of designated funding to address many years accumulated unmet needs.

The 990 new places comprises 450 places for people with disabilities turning 18 years and leaving the Departmental responsibility as wards of the state, 200 places for people leaving the corrective services system and 340 places for other people with disabilities. It is vitally important that people with disabilities who are already within government systems receive ongoing supports.

However, there is grave concern that only 340 places are planned for people now living in the community, who would be counted under unmet needs. With the increasing proportions of people with disabilities and the ageing of carers, it seems that NSW will stay in crisis mode in responding to people in the community who require reliable supported accommodation during their adulthood. Two important recent collections of actual stories from individuals are *Ending the Silence*<sup>3</sup> by collated Michael Carman (2005) and *Living Stories*<sup>4</sup> published by the NSW Council for Intellectual Disability (2006).

NCOSS strongly recommends that a series of options for supported accommodation options be provided, ranging from individualised funding packages and home support services, through to private rental, shared care and co-tenancies, to small group living with support tailored to the individuals.

### **Disability Residential Institutions**

Despite promises in 1998 that all disability institutions would close by 2010, the Stronger Together package will close some and redevelop other facilities. NCOSS strongly recommends that all large disability institutions are closed and that additional funding for more appropriate accommodation for people with disabilities in community settings is guaranteed. Both Federal and State Government must declare a renewed commitment to this important advance.

### **Advocacy and Information**

The NSW Government has had a reform process underway since 2001 surrounding the Disability Advocacy and Information Program, a series of DADHC funded organisations providing some individual advocacy, systemic advocacy and specialist disability information. During that time that Australian Government has completed or commenced two reviews of Commonwealth funded advocacy projects. There is no doubt that the success of many new disability spending measures and access initiatives will depend on the provision of available, accessible and independent advocacy and information, both at individual and systemic levels. NCOSS has long called for an increase in individual advocacy and a streamlining (but not reduction) of information services to be more effective in reaching and meeting the needs of people with disabilities in NSW. The *Stronger Together* Package will be more effective if advocacy can be used as an enabling tool during implementation.

NCOSS strongly recommends that the Commonwealth and State Governments utilise the current Disability Advocacy and Information review processes to resource a comprehensive and equitable framework for advocacy and information services to people with disabilities and families. NCOSS further recommends that existing information agencies gather data about services and partnerships supporting people with disability in NSW. The Commonwealth Department of Health and Ageing (DoHA), DADHC, peak organisations, industry bodies and local services share this information and data throughout the disability sector.

### **Poverty and fees**

---

<sup>3</sup> Available on the NCOSS website at [www.ncoss.org.au](http://www.ncoss.org.au)

<sup>4</sup> Available from the NSW Council for Intellectual Disability



The advent of disability to an individual and their family necessarily changes their present circumstances and their view of the future. After the inevitable grieving and with appropriate supports, the future can be bright and valued for people with disabilities.

Many people with disabilities are reliant on the Disability Support Pension (DSP) as their income source. Consequently, many carers also need the Carer Payment or Allowance. The income of a person with disability might comprise the DSP, perhaps the mobility allowance and possibly rent assistance. Everyday costs of life ( food, power, transport, clothes etc) may be more expensive for the person due to their disability. The specific financial impact of the disability could manifest in additional costs like medical treatments, pharmaceuticals, equipment, specific disability consumables. Consequently, there may be very little if any remaining discretionary funds available for necessary supports (even excluding recreation and holidays that others take for granted). In NSW, 97% of people using HACC services are dependent on government income support.

Most disability support services, Health, community care and generic services require at least a “donation”, fee, co-payment or service charge from the user. If the person needs more than one service, the cumulative effect of even subsidised fee payments could prove to be prohibitive.

In NSW there is no coordination across service types or program boundaries, ie health, education, community care, transport etc, so people with disabilities are often forced to choose or even forego necessary service provision.

NCOSS recommends that Commonwealth and State Governments (in collaboration with industry and consumer groups) review and improve support payments for people with disabilities to ensure improved financial security, including income support. NCOSS further recommends that fees structures throughout CSTDA services and among other service systems to people with disabilities, be coordinated so as to reduce the financial burden on service users.

### **Coordination of services to adults with disability**

At present, the Commonwealth is responsible for providing employment services, including specific employment programs and business services (formerly sheltered workshops). State governments are responsible for providing school leaver programs to people with disabilities as well as day therapy centres. The responsibility for providing supports to people with disabilities during retirement is uncertain. As with several other programs and jurisdictions, there seems to be a reliance on what the Commonwealth or state is deemed by the other to provide in the design of adult services. In other words, a school leaver with disability might have the capacity to directly enter a Commonwealth employment program and so becomes ineligible for a state school leaver program, regardless of whether any Commonwealth employment programs are available or have vacancies.

Similarly, a school leaver who enters the NSW Transition to Work Program, providing two years intensive pre-employment or employment preparation skills, may be exited at the end of the program and be considered ready for a Commonwealth employment program whether or not the Commonwealth has assessed the young person as eligible or whether there are vacancies. These instances of un-negotiated assumptions on the part of both Commonwealth and state could (and have) left people with disabilities to fall through the gaps of jurisdictional boundaries. Comparable situations occur as the person with disability ages. Refer to later comments.

NCOSS strongly recommends that Commonwealth and state clarify entry and eligibility for programs to ensure seamless and appropriate access to people with disabilities.

## **Portability and flexibility**

Several government funding and support programs have flexibility built into their objectives, but, due to such factors such as demand exceeding supply, these programs are dictated by designated boundaries/guidelines which exclude or limit access to many people who need such support. A person's age should not limit their access to the support services they need.

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

Such streaming can be used as an exclusionary mechanism for people who require creative responses or have complex or unusual support needs. This works against the objective of portability of funding, where a system should be enabled to respond to the individual's needs as they change over time and not within a system which kicks in or cuts out depending on the funding program and the source of funds. Further, this can encourage people with disabilities to inappropriately continue in services which no longer meet their needs, for fear of receiving no ongoing support. "If I do not accept this inappropriate service, I may get nothing at all."

Ongoing work is required to enhance the flexibility of funding and packages, allowing people with disability to take advantage of a range of appropriate support services through different life stages and their needs change. Ultimately, the aim of services is to provide support to people on the basis of need: the assessment of suitability for services should measure and reflect functional ability. Program eligibility and guidelines should allow for flexibility to allow consumers to gain access to a comprehensive range of service options and, if required, receive a 'blend' of services from heterogeneous funding sources. Many service providers report that rigid program guidelines restrict the creation of flexible service solutions to meet individual needs.

Flexibility in service delivery to people with disability can be enhanced by utilizing different funding models, including the options of individualised funding packages, to enable where appropriate people to individually broker their own services or have them brokered on their behalf. Case management services and information services are an important element of any service spectrum, as is advocacy, and together these are essential to assist people to negotiate different service types and organisations.

NCOSS strongly recommends that the portability and flexibility of funds across program boundaries is increased in order to ensure access to services for people with disability as their needs change. This will particularly involve additional top up funding for existing service providers for people with disability who are ageing living in disability group homes and supported accommodation.

## **Linkages with Community Care and other service systems**

There are at least 17 community care programs<sup>5</sup> either funded solely by the Commonwealth or jointly by Commonwealth and state. A significant proportion of the HACC target population is people with disabilities. Access to many of these community care services is inconsistent across Australia and uncertain within NSW.

There is confusion among both service providers and government officers about the role, responsibility and purpose of community care programs in relation to people with disabilities.

---

<sup>5</sup> The Way Forward Community Care reforms Strategy, Department of Health and Ageing (2004)

HACC provides in home support services of a maintenance and support nature in order to avoid inappropriate admission to long term residential care (ie nursing homes). Disability services provide supports that can be developmental and opportunistic in nature and may include residential / accommodation supports. Many disability supported accommodation services are not funded for daytime in home supports but the resident people with disabilities are ineligible to receive the very HACC services they may require. It is important to note that people with disabilities in supported accommodation services consider that place of residence to be their home. Conversely, older people in self-care units in retirement villages (arguably another form of supported accommodation) are indeed eligible to receive HACC services.

NCOSS is alarmed that the current process of community care reforms, designed to coordinate the many community care programs, relate only to the needs of older people and connect with residential aged care. Little or no consideration is obvious under the community care reforms for the service requirements of people with disabilities regarding assessment, assessors, entry and exit criteria, fees, levels of service, carers, information or connections to other disability services.

NCOSS recommends

- that the inter-connections between community care and disability systems be clarified and strengthened,
- that people in disability supported accommodation services have equitable access to community care services,
- that joint funding arrangements be initiated between disability services and community care and aged care services

## **Workforce Issues**

The disability and aged service sectors are facing increasingly serious challenges in both recruiting and retaining suitable qualified staff. In 2001, there were 237,055 people employed in community services. 87% of workers in community services were female and 51% of these people worked part time. In 2001 nationally there were 1228 people employed in community services per 100,000 of population. NSW is well below the national average with only 1,077 people employed in community services per 100,000 of population<sup>6</sup>.

There is strong evidence to indicate that a large percentage of the workforce in this sector is itself ageing. A March 2001 survey of 149 aged and community care services conducted by the Aged & Community Services Association (ACS) found:

- one in ten nursing and personal care positions cannot be filled with permanent staff
- recruitment is particularly difficult in Sydney
- 65% of staff are aged over 40 – meaning the aged and community care workforce is itself ageing<sup>7</sup>

It is vital that Commonwealth and State governments work collaboratively to improve pay and conditions across the sector and look at creative means of recruiting and retaining staff in the disability and community care sectors.

NCOSS supports the following strategies address workforce shortages:

- improving the wages available in disability services through better government funding
- identifying and funding a benchmark of disability supports

---

<sup>6</sup> Australian Bureau of Statistics & Australian Institute of Health and Welfare (2001) *Health and Community Services Labour Force*, Canberra

<sup>7</sup> Aged and Community Services Association of NSW & ACT, ACS Update, September 2001

- improving collaboration between consumers, unions, industry, educational bodies and governments
- fostering a culture in services that values people with disabilities and workers
- strengthening educational and career pathways
- working to improve the image of people with disabilities and the disability sector.

NCOSS strongly recommends that a Workforce Issues Summit to address the workforce challenges in disability services be jointly convened by Commonwealth and State governments, in order to develop a workforce strategy that reflects the National Aged Care Workforce Strategy<sup>8</sup>.

### **Rural and remote service delivery**

Service providers in rural or remote areas are likely to face greater challenges in terms of:

- **Viability:** Viability issues for smaller community managed disability services may force them to either close down or amalgamate for economies of scale. While the aged care sector recognises the impact of rurality in residential aged care, there has been no similar acknowledgement for disability services and the funding provided makes it difficult to maintain quality services. Cost structures for such services may be different to those of larger urban services. Access to additional forms of funding is essential to build new services and to enable existing services to extend to address currently unmet and now escalating needs.
- **Workforce:** Rural and remote workforce issues can be acute. Providers have difficulty finding staff with appropriate qualifications, do not have access to flexible professional development or formal training for their staff, or the funds to purchase such training from far afield and do not have the resources to offer incentives for professionals to relocate to these areas (eg. GP's scheme).
- **Spread and Access:** Not all needed services are available in all local areas. There is extra pressure on service providers to compensate the barrier of distance for people with disabilities and families due to cost, added discomfort, length of time, need for escorts, contact with familiar social and family networks, cost of accommodation when away from home etc.

## Psychiatric disability and CSTDA

### **Background**

For the purposes of definition within this paper, a mental illness is a set of symptoms or range of illnesses of short or long duration which tend to be episodic in nature and from which the person can recover completely. Psychiatric disability is the disability that results from a severe or sustained mental illness.

In 1982 overlap and lack of co-ordination of funding by different tiers of government saw the negotiation of the CSTDA. It was decided that the CSTDA was to be implemented in NSW through the Community Services portfolio. The CSTDA targeted all disabilities including psychiatric disabilities but the mental health services in NSW found this difficult and opted to stay in the Health portfolio. Mental Health Non-government Organisations (NGOs) were nominated as Disability Services in the first CSTDA but were to continue to be administrated

<sup>8</sup> [www.health.gov.au/internet/wcms/publishing.nsf/Content/ageing-workforce-nacws.htm](http://www.health.gov.au/internet/wcms/publishing.nsf/Content/ageing-workforce-nacws.htm)

by the Health Minister in a complex arrangement with the Minister for Community Services. The result was predictable; no funds were made available through the reform process. In addition the HACC Act, implemented in 1986, resulted in little of the HACC funds being applied to people with a psychiatric disability.

At the time of the CSTDA, the Disability Services Acts were to be enacted in each state to ensure that the rights of all people with disabilities were protected and this included those funded through Health.

When the Commonwealth State Disability Agreement was first formulated, some services that were formerly funded by the Commonwealth were given to the State and the State returned some to the Commonwealth ie people with mild to moderate intellectual disability used to be funded by the Commonwealth along with those who were sight impaired, wheelchair dependent etc. If the service was for people with a psychiatric disability, the money was handed to Health to administer.

In turn, what used to be called Sheltered Workshops and/or work type programs were transferred to the Commonwealth. Health was concerned at the time that they would have to transfer their living skills centres to Commonwealth management which posed a problem for them as they were often sitting on Health property and Health did not want to transfer money or land to the Commonwealth. What they did at the time was to state that they had no rehabilitation/work related programs and proceeded to close these services and reabsorb the funds for these programs into core clinical services. In a very few cases these programs were transferred to NGOs but with greatly reduced resource allocation. In the main, however, provision of rehabilitation programs for people with psychiatric disability in NSW decreased markedly. Coupled with the devolution of NGOs to the Area Health Services without any clear processes for enhancement or development the situation has NSW well below the national average in provision of psychiatric disability and rehabilitation services.

### **Funding for psychiatric disability support**

The real importance of the CSTDA for people with disability as a result of mental illness lies in the transparency of the allocation of dollars from the Commonwealth and State to define who is specifically responsible for services to people with psychiatric disability. In Victoria there is a very clear funding stream for psychiatric disability and rehabilitation support services but in NSW it seems to fall through the gaps between NSW Health and the Department of Ageing Disability and Home Care (DADHC) with no-one taking overarching responsibility. It is generally agreed that significant inconsistencies and shortfalls are inevitable for as long as responsibility for psychiatric disability services are split between different departments without clearer delineation of responsibility and valuing of these services.

While the current CSTDA promotes some excellent policy principles, it falls short on effectiveness. The Mental Health Coordinating Council and NCOSS support a strong case for reforming the Agreement to ensure that it more effectively provides:

- resources to meet the need for disability services;
- better pathways and linkages between service systems administered by different jurisdictions;
- an improved interface between Disability and other programs such as Aged Care, Health, Education and Transport;
- publicly-available data that enable meaningful performance comparisons across jurisdictions, service planning and transparency in governmental expenditure; and
- a more consistent approach to quality.

It is important to note that without allocation of a distinct funding stream for psychiatric disability, resources have in the past been absorbed by acute mental health services creating an imbalanced system with high readmission rates due to lack of psychiatric disability support services in the community. Psychosocial rehabilitation services are an integral part of an effective mental health system and NSW has had difficulty providing access to these services because of its failure to recognise their value as distinct from acute services.

*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*

One of the successes of Australia's ageing society is the fact that people who have experienced an early onset and longstanding disability are now living longer. Around 45,000 Australians with severe or profound core activity restrictions report an early onset disability (ie acquired before the age of 18).

Many people with disability experience age-related changes at earlier chronological ages than their non-disabled counterparts. These changes can include the development of health conditions commonly associated with advanced age.

As these changes happen, people with disability who are ageing experience challenges in areas such as retirement options, support from services, accommodation options, opportunities to participate in society and entry into aged care services. Their carers have to cope with changes in the person with disability, increasing care needs and availability of support services now and in the future, as well as their own advancing age in the case of parents.

NCOSS has participated in a working group over the past four years which completed broad consultation on the issues facing people with disability who are ageing and the services that seek to support them. While finding some encouraging initiatives in some areas, overall the picture is one of uncertain policy and funding frameworks.

The Australian Government provides eight dollars to every one dollar by State Governments for aged and community care. By contrast, the NSW Government provides four dollars to every one Commonwealth dollar for disability services. Consequent arguments about cost shifting represent a considerable disincentive to seamless and flexible service delivery programs for people with disability who are ageing.

In summary, NCOSS is calling for:

1. Stronger policy collaboration between Australian and NSW Governments and between separate departments.
2. Designated funding streams to address the specific needs of people with disability who are ageing.
3. Improved assessment processes, involving disability expertise
4. Provision of a range of accommodation and support service options.
5. Improved understanding of the issues facing people with disability who are ageing and their carers, both by disability services and aged care staff.
6. Flexible and seamless social supports.

NCOSS strongly urges that State and Australian Governments work collaboratively with the aged care, community care and disability services, consumers and carers in NSW to improve services and outcomes for people with disabilities who are ageing.

NCOSS supports the following recommendations developed from this working group:

1. That further and specific strategic and collaborative planning and research on people with disabilities with mental illness who are ageing and their carers, be urgently conducted to design suitable service and support responses.
2. That the specific needs of people with disabilities who are ageing and living in Boarding Houses are specifically addressed especially including:
  - a) That the relocation of residents with high and complex support needs to more appropriate community based supported living arrangements is accelerated with additional funding provided by the NSW Government.
  - b) That individual assessments are regularly provided to people in boarding houses, particularly people with disability who are ageing who have mental illness. This will require close collaboration between DoHA and DADHC.
  - c) That the Australian Government and NSW Government utilise the 2003 Department of Ageing, Disability & Home Care review of the *Youth and Community Services Act 1973*, to develop a whole of government approach to boarding house accommodation for people with disabilities.
  - d) Legislation is required in all states and territories which grants residents of boarding houses similar rights and security of tenure afforded to other tenants in the private rental market.
3. That the needs of people with disability who are ageing with dementia are specifically recognised through the development and implementation of:
  - a) Assessment tools for people with disabilities which enable an appropriate diagnosis of dementia,
  - b) Dementia specific care packages available to people with disability who are ageing where necessary.
4. That a project is funded to identify and develop suitable service responses to the needs of people with disability who are ageing from Aboriginal and Torres Strait Islander communities and their carers. This should be initiated and undertaken in conjunction with Aboriginal communities.
5. That a project is funded to identify and develop suitable service responses to the needs of people with disability who are ageing from culturally and linguistically diverse backgrounds and their carers. This should be initiated and undertaken in conjunction with culturally and linguistically diverse communities.
6. That the Australian Government increases the funding and number of care packages specifically targeting ageing carers of people with a disability.
7. Funding is provided for a series of pilot projects over three years to trial non-vocational retirement options for people with disability who are ageing. Continued funding must be guaranteed to successful projects which should then be extended.
8. A joint action plan to improve health outcomes for people with disability who are ageing is developed collaboratively by Commonwealth and State Governments. This will:
  - build on the success of the ComPacks scheme to implement hospital discharge practices ensuring that the health and support needs of people with

- disability are appropriately planned and addressed initially via increased funding of ComPacks as well as better review and monitoring mechanisms;
  - Provide additional funding to improve access to health screening services for people with disabilities who are ageing;
  - Provide additional funding to educate General Practitioners and community health workers (including community nurses and mental health workers) about the needs of people with disabilities who are ageing.
- 9. That appropriate assessment tools and protocols/models are developed to identify the needs of people with disability who are ageing. This must jointly involve DADHC and DoHA working with key industry and consumer groups.
- 10. That aged care, disability services and community care providers establish ongoing training and education to staff to foster understanding of ageing and disability and develop collaborative projects for sharing information and resources. These training needs should be funded by DADHC and DoHA. Training should be available to existing service users.
- 11. That an annual National Roundtable be convened jointly by DoHA and DADHC. All relevant government agencies, together with key industry and consumer organisations should be invited to the Roundtable. The Roundtable should:
  - a) Identify priorities for long-term collaboration between inter-governmental and intra-governmental agencies;
  - b) Develop options for cross-departmental funding of programs targeting the needs of people with disability who are ageing;
  - c) Improve planning processes between Australian and NSW Government for people with disability who are ageing; and
  - d) Implement appropriate assessment tools and protocols for people with disability who are ageing.
- 12. That a range of pilot projects which explore innovative responses to the needs of people with disability who are ageing are cooperatively funded by DoHA and DADHC. Pilot projects that have responded effectively to the needs of people with disability who are ageing should be recurrently funded.
- 13. That priorities for research into the needs and responses to people with disabilities who are ageing are collaboratively determined by DOHA and DADHC, industry and consumer groups. Importantly, the needs of people with disabilities who are ageing and are from Aboriginal and Torres Strait Islander communities and also from culturally and linguistically diverse backgrounds should be a priority for this research. This should include the identification of costs of quality service provision and examples of innovative service responses.

### **Younger People in Nursing Homes**

NCOSS supports the position that younger people with disability should not reside in nursing homes. The solution to this issue lies in intensive and deliberate Commonwealth and state negotiations and commitments. NCOSS notes the new Commonwealth funding from the 2005 budget, which NSW has agreed to match, to relocate some younger people into more appropriate supported accommodation. With no clear implementation plan and uncertain



commitment to a no new admissions policy, it is doubtful that younger people with disabilities will not be entering residential aged care facilities into the future.

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

NCOSS contends that before a re-distribution of funding and program responsibilities between Commonwealth and state jurisdictions could be effected, any change to the existing arrangements must deliver guaranteed measurable qualitative and quantitative improvements to the provision of services and supports to people with disabilities and carers across Australia and in NSW in particular.

As a consequence, until guaranteed improvements could be ascertained, both Commonwealth and state levels of government should maintain joint responsibility and accountability for the provision of disability programs and services.

In late 2005, the NSW Aged Care Alliance developed feedback on the prospect of major structural change to residential aged care funding and community care funding in advance of the COAG decisions of 10 February 2006. This COAG meeting was to determine whether aged care and community care funding structures should remain as is or whether there should be a Commonwealth state split in responsibilities between these programs. The CSTDA was specifically quarantined from these discussions. The decision taken by the Prime Minister and Premiers was to maintain the status quo but work to improve current systems. Given this recent decision, NCOSS draws on the work of the NSW Aged Care Alliance in considering any major structural change or jurisdictional split in responsibilities for the CSTDA.

Similar to the aged care and community care systems, the CSTDA disability funding arrangements are confusing and uncoordinated. NCOSS contends that the CSTDA programs must be streamlined, coordinated, must provide clearer eligibility and entry criteria, consistent quality of service, adequate availability and level of service provision in all areas and across the target population especially including special needs groups (including Aboriginal and Torres Strait Islander communities, people from culturally and linguistically diverse backgrounds, people with dementia, people in rural and remote areas and financially disadvantaged people).

NCOSS does not discount the possibility of structural change to national disability programs. NCOSS has considered possible strengths and weaknesses of a major structural change, as well as the strengths and weaknesses of maintaining the existing arrangements.

Both the NCOSS and the NSW Aboriginal Community Care Gathering Committee are concerned that the needs of Aboriginal people may not be an initial consideration in considering significant changes to disability support systems. These considerations should form part of the initial deliberations and not be included as a later adjunct at implementation. This similarly applies to considerations of the needs of other population groups, including people from culturally diverse backgrounds, people with dementia, people in rural and remote locations and people who are financially disadvantaged.

**NCOSS believes that the CSTDA should remain a joint Commonwealth State and Territories program. The following considerations set out the basis upon which NCOSS recommends maintaining the existing shared arrangements until guaranteed measurable improvements can be delivered to people with disabilities.**

### **Considerations for Major Structural Change**

NCOSS identified potential and predictable advantages and disadvantages in splitting jurisdictional responsibility for disability support services.

#### Advantages of a SPLIT

- One clear decision maker, per identified population in community care
- Avoidance of duplication of administration
- Possibly easier reforms in service provision
- Planning could improve
- Commonwealth has an existing growth funding formula for aged care services which could be reflected to provide growth funding to disability programs
- Impact of inter-governmental politics would be reduced

#### Disadvantages of a SPLIT

- More rigid program boundaries and people falling through cracks
- More rigid focussing on specific responsibilities to the exclusion of Commonwealth/state coordination and loss of complementary supports
- Duplication of systems between services for older people and people with disabilities eg. Home modifications and maintenance or personal care etc for older people at Commonwealth level would have to be recreated for provision to people with disabilities at state level.
- Different systems could appear in different states for people with disabilities, loss of national consistency for people with disabilities in community care
- Concern at how people with disabilities might move into an aged care system: Addressing the needs of people with disabilities who are ageing and reaching retirement age and require aged care support services
- Addressing the needs of younger people in nursing homes
- Concern that major structural change will delay and disrupt the implementation of necessary long-anticipated improvements to clients and service systems
- Major disruption to the service industry in that providers could be expected to reconfigure
  - Possible duplication of administration of receiving both Commonwealth and state funding for programs – as now occurs
  - Possibility of creating more providers where providers choose to relate only to one level of government
  - Reduced flexibility of provision
  - People with disabilities could be marginalised
- Patchy history of the success of programs devolved to a single government – expectations not necessarily met between Commonwealth and state jurisdictions
- NCOSS believes that insufficient attention has been given to the effect of a split on people with disabilities because such consideration must involve predictable and significant impacts on existing arrangements for the Home and Community Care Program and state provided disability support services.

### **Considerations for Continuing Existing Arrangements**

NCOSS considered the effects of maintaining current arrangements BUT emphasised that systemic improvements to funding and practice must be applied in any case.

#### Advantages of continuing current arrangements

- Two levels of government allows greater program and administrative scrutiny
- Greater accountability of governments
- National consistency can be maintained and improved
- Potentially healthy interaction between Commonwealth and states

- Allows improvements to the existing system where the problems are already clearly identified
- Allows decision-making about level and type of service provision to be closer to the actual client; concern that the Commonwealth could be remote from some decisions regarding state operated services
- Avoids further duplication
- Does not discount the Australian Government taking a more active role in the provision of disability services
- The industry would only have to respond to improvements of the current system without major structural change
- Despite the complexity etc, the system is familiar.
- NCOSS believes that there is measurable value and advantage to all involved in both levels of government maintaining expertise and experience in services and issues for people with disabilities.
- NCOSS are committed to maintaining a diversity of size of provider within the community care industry. NSW government has acknowledged the value of such diversity. The Australian Government is uncertain on this point.
- There was acknowledged value in the Australian Government providing policy and standards guidance and the states and territories fulfilling the manager/operator role. It was noted, however, that there is room for improvement at both levels of government.

#### Disadvantages of continuing current arrangements

- Intergovernmental rivalry or cost shifting could worsen
- Clarity of roles and access criteria are still unclear
- Commonwealth/state co-ordination needs improvement

NCOSS notes that many of these disadvantages could be addressed through clearer intergovernmental agreements.

Consequently, NCOSS recommends that the CSTDA be continued and strengthened as a joint Commonwealth State agreement.

## CONCLUSION

NCOSS appreciates the opportunity to provide submit to the Australian Senate Community Affairs References Committee Inquiry into the Commonwealth State Territory Disability Agreement.

Should further information be required, please contact NCOSS Christine Regan on 02 9211 2599 ext 117 or [chris@ncoss.org.au](mailto:chris@ncoss.org.au)

- o o o -