



Australia

SUBMISSION

SENATE COMMUNITY AFFAIRS REFERENCES COMMITTEE

Inquiry into the Funding and Operation of the Commonwealth State/Territory Disability Agreement

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UNITINGCARE AUSTRALIA

INQUIRY INTO THE FUNDING AND OPERATION OF THE COMMONWEALTH STATE/TERRITORY DISABILITY AGREEMENT AUGUST 2006

A. INTRODUCTION

UnitingCare Australia welcomes the opportunity to comment on issues regarding the funding and operation of the Commonwealth State/Territory Disability Agreement being examined by the Senate Community Affairs References Committee.

UnitingCare, one of the largest non-government providers of community services in Australia, is primarily concerned with those population groups who are most disadvantaged in society. With 400 agencies nation-wide, UnitingCare provides a wide range of services to 1.8 million children, young people and families; people with disabilities; and older Australians, in urban, rural and remote communities. Services offered by the UnitingCare network to people with disabilities include accommodation and support services, employment services, case management, community access services and post school options for school leavers.

Our policy and advocacy work is based on the expertise of our service providers, the experience of our service users, current research, and the vision and values of the Uniting Church in Australia.

UnitingCare Australia argues from a stand of social justice – and calls for a decent life for all in society. We work together with other local providers to prevent the escalation of need, to strengthen individuals and families and to support people to live as inclusive members of their communities.

We have drawn the material for this submission from the research and policy development work of agencies within the national UnitingCare network, as well as from the direct experience of workers and service users in our programs.

In our submission we will address, particularly, the following term of reference: (a) an examination of the intent and effect of the three CSTDAs to date.

B. RECOMMENDATIONS

1. UnitingCare Australia recommends that all levels of government:

- a) consider the impact of policy decisions on people with disabilities and ensure that these decisions do not impact negatively on these people;
- b) recognise people with disabilities as stakeholders and participants in decision making, especially around the issues that affect them.

2. UnitingCare Australia recommends that the Australian Government, in co-operation with the State and Territory governments and in consultation with people with disabilities, their families and carers:

- a) develop a national social policy framework through which people with disabilities, their families and friends may make choices and explore opportunities that will help them live well and participate in society;
- b) commit to the development of an adequately resourced national accommodation system for people with disabilities;
- c) through the CSTDA, refine and develop models of provision that support people's aspirations and allow them to make choices which enable them to live a decent life;
- d) provide leadership in resolving the issues of responsibility and the shortfall in resources for the provision of services accessible to people with disabilities within a range of accommodation settings;
- e) commit to an integrated approach to planning for and supporting people with disabilities across the life spectrum to make choices which match their needs and aspirations within the community;
- f) undertake detailed planning and implement programs to provide support for carers of people with disabilities;
- g) place a greater focus on assistance and flexible options for people with disabilities to live at home with the support of family and friends;
- h) make available a wider range of out of home accommodation and support services for those people with disabilities unable to live at home.

C. BACKGROUND

1981, declared the International Year of Disabled People by the United Nations, brought about, for the first time, a recognition of people with disabilities as citizens.

Since then a great deal has been accomplished in the disability field. Of the greatest significance has been the closure of large institutions in favour of community based accommodation and support services for people with disabilities.

However, the hard won progress that led governments to pass the Disability Discrimination and Disability Services Acts in 1986 and 1992 respectively, and which paved the way for the positive changes that have come about, need to be re-assessed and reaffirmed in light of the experiential and research evidence that is now available regarding the needs of, and options for, people with disabilities.

Based on our experience as providers of services for people with disabilities, UnitingCare believes that the contemporary planning proposals indicate that the principles and objectives of the Disabilities Services Act are now being compromised by a system that is primarily 'economically driven'.

Under the CSTDA services are provided to people with disabilities where the disabilities:

- are attributed to an intellectual, psychiatric, sensory, physical or neurological impairment or acquired brain injury, or combination of both;
- are likely to be permanent; and
- result in substantially reduced capacity for self care and management and/or mobility and/or communication; and

- manifest before the age of 65 years; and
- where significant ongoing or long-term support is required.

Services are targeted at people with a need for ongoing support in everyday activities, and aim to maximise the opportunity for social and economic participation in the community. The agreements specifically focus on accommodation support services, community support services, community access services, respite services and employment services.

Current state and territory policy directions for disability support services vary between jurisdictions, but common areas of focus are:

- a family-orientated approach to services focussing on supporting young people with disabilities and their carers;
- supporting young people with disabilities so they can live in the community; and
- the provision of flexible services aimed at serving the needs of individuals (funding packages) and the desire to move people from inappropriate settings.

D. (a) AN EXAMINATION OF THE INTENT AND EFFECT OF THE THREE CSTDAs TO DATE

The 2002 – 07 CSTDA and the previous two agreements provide the national framework for the funding and provision of disability support services with the Federal Government having responsibility for the planning, policy setting and management of employment services under this agreement, and the states and territories being responsible for all other disability support services.

The agreements commit the parties to work together to address key issues for people with a disability, including:

- flexibility between service provision by different levels of government;
- the situation of young people living in Australian Government-funded residential aged care facilities; and
- issues facing people with disabilities who are ageing.

The Third CSTDA builds on the work of the previous two agreements and reflects the current policy environment and the initiatives on which all governments have embarked. This agreement aims to build the capacity of individuals and communities, and promote the inclusion and participation of people with disabilities across all areas of life. It seeks to achieve these aims in partnership with people with disabilities, their families and carers, service providers and the community.

The vision and core principles that underpin the framework established under the CSTDA are based on the premise that communities are enriched by the inclusion of people with disabilities and that positive assumptions about the gifts and capacities of people with disabilities, including those with high support needs, are fundamental to their experience of a good life and to the development and delivery of policy, programs and services¹.

¹ Commonwealth State/Territory Disability Agreement Annual Public report 2003-04 pg 5

The agreement recognises that both levels of government fulfil complementary roles in the development and delivery of public policy and services, and that both have a pivotal role in promoting the rights, equality of opportunity, citizenship and dignity of people with disabilities².

As such, the intent and spirit of the CSTDA encompasses the Principles and Objectives outlined in the Commonwealth Disability Services Act 1986, the Commonwealth Disability Discrimination Act 1992 and complementary State and Territory legislation. The rights of people with disabilities under the United Nations Declaration of Rights of Disabled Persons are also affirmed. It is important, therefore, that these values do, in fact, drive the way we provide social, accommodation and care-services for people with disabilities.

Accommodation Services and Support

It is important, here, to consider the extent to which contemporary and future services funded under the CSTDA are consistent with the core principles of the Agreement³:

- responding to individual needs as they vary across stages and areas of life;
- acknowledging the heightened vulnerability of people with high support needs, Indigenous Australians with disabilities and people from culturally and linguistically diverse backgrounds;
- recognising and supporting the pivotal role of families and carers and others in close relationship with people with disabilities;
- promoting the development of innovative solutions to address the broad scope and range of supports needed to create conditions where people with disabilities, their families and carers can thrive and have their opportunities enhanced; and
- continuing collaboration and partnerships with individuals, families, carers, community agencies, service providers, advisory and advocacy bodies and local government.

Accommodation support includes services that provide accommodation to people with a disability - and services that provide support needed to enable a person with a disability to remain in their existing accommodation or to move to more suitable or appropriate accommodation.

While not in any way meeting the current demand for accommodation and support for people with disabilities, different accommodation-types are provided by governments across Australia: These include:

- institutions – large and small;
- hostels;
- group homes; and
- in-home accommodation with community support (e.g. attendant care, assistance with personal care) to enable people to live with their families or independently in the community.

In 2003-2004 a total of 187 806 service users accessed CSTDA - funded services in Australia.

² Ibid

³ Ibid

Of these consumers, 18 per cent (33,175) accessed accommodation support, 5303 of whom were accommodated in institutions.

42 percent used community-based services – other than institutions and hostels - with an increase from 60 per cent in 1995 to 73 per cent in 2001 and 2002 in the proportion of people using community based services.⁴

Services provided under the CSTDAs - including accommodation support services, community access, employment services, community support and respite – are severely limited due to shortage in funding. Unmet need has not been adequately addressed and is still growing.

It has been recognised that a “one size fits all” policy for the provision of accommodation and support services for people with disabilities does not meet the needs of many people with impairments. **Funding allocations should therefore provide for the delivery of a range of options according to the needs and choices of individuals and families.**

There is overwhelming evidence to suggest that the larger types of accommodation (e.g. institutions) offer a poorer quality of life than smaller forms of accommodation (e.g. group homes)⁵.

It is therefore of great concern to UnitingCare Australia that contemporary planning proposals in a number of States appear to indicate that the principles and objectives of the Disability Services Act are being compromised by a move towards the provision for out-of-home accommodation services in congregate or cluster settings where residents will be segregated from the community at large.

“On the basis of historical, moral and human rights concerns, institutions cannot be supported..... For community housing, cluster housing and large community housing cannot be recommended even though their negative impact has been found to be generally less than institutions. The best alternatives focus on attempts to achieve an ordinary life in the community for individuals with as many natural supports as possible. Modern approaches indicate the selection and training of staff with the ‘right relationship’ is critical, and the focus needs to be on an ordinary life, which will automatically involve the family and community as well as the individual in all major life decisions⁶.

A National Accommodation System for People with Disabilities

An adequately resourced national accommodation system for people with disabilities should:

- allow people to make choices that fit their physical, social and spiritual needs, strengths and their aspirations;

⁴ AIHWpp235

⁵ Interaction Volume 19 Issue 3 2006: Presenting the Evidence: Accommodation and Support for People with Disability

⁶ R.L. Jackson Centre for Disability Research and Development, Edith Cowan University Joondalup WAQ

- be integrated with and include improved access to supports and services such as transport, health, and community access;
- incorporate a national assessment tool for people with impairments which ensures better coordination and planning of care and supports;
- provide information about accommodation options and what they offer;
- include improved access to respite care;
- include improved access to rehabilitative care;
- ensure that young people in aged care nursing homes have equity in access to disability services and supports;
- incorporate measures to avoid inappropriate placement of young people within aged care facilities and relocation and diversion where desired;
- include the immediate funding of demonstration models as a way of exploring more appropriate community-based accommodation options with ready access to services and social networks leading to the establishment of permanent and secure housing for people with disabilities; and
- allow parents to relinquish their role as primary carer as they do for other non-impaired children.

One of the consequences of the initial review of services for people with impairments which led to the Disability Services Act 1986 was a shift from institutional care to care within a home environment. While this shift has enabled many to maintain contact with their family and friends, deinstitutionalisation has not been matched with sufficient resources to support people with impairments to live in the community – there is a significant level of unmet need.

Poor access to services for people with impairments coupled with a lack of accommodation options has contributed to the widespread situation of people with disabilities struggling at home - or inappropriately accommodated in respite, crisis accommodation or in nursing homes. Specifically there is:

- limited access to supported accommodation options available to meet high level needs and in particular high nursing/medical needs for people with impairments who require 24 hour support/supervision; and
- limited access to community services for people with impairments coupled with an increasing demand, especially amongst people with high and complex needs.

This is of particular concern for the ageing parents/carers who are unable to arrange secure and suitable accommodation for their children with disabilities when they are no longer able to care for them themselves. Neither do the current funding allocations allow for adequate access to community-based programs.

Across the UnitingCare network there is general concern regarding signs of a move towards more congregate models of support. A recent example of policy, funding and service model change in South Australia gives cause to be concerned about the level of commitment to the Principles and Objectives of the Disability Services Act.

In South Australia, Day Options have undergone significant change over the last year or so in response to greater demand from school leavers, a limit on available funds to support growth and maintenance of current support levels and a demand from parents / carers for a guaranteed 6.5 hours per day, 5 days per week 48 weeks per year service.

The new model which is based upon a 'price setting' approach using benchmarks has reduced individual funding allocations by 20% whilst at the same time having an expectation that the 'guaranteed' levels noted above are met. Providers are required to deliver more service with less funding. This is expected to be possible in part by congregating up to twenty people in one site.

Two pilot services were developed initially with one of the services being offered on the site of a large institution. Not only are people with disability being congregated in groups of up to twenty, they have been co-located with hundreds of other people with disability in a segregated environment separate from the community.

The parents of those attending this programme are delighted with the service because it provides what they need - a guaranteed service model based on five days per week. While it is appropriate that parents are supported in their caring role, meeting the needs of carers does not necessarily ensure that the needs, hopes and aspirations of people with a disability will be met.

Government does of course expect providers who deliver services under the new model do so in line with the National Standards for Disability Services. Who will complain if they don't?

The Government, in announcing the new model, promised the sector that the two pilots would be evaluated against the Standards. This has not happened. There are now a number of providers operating with the new model.

The sector response to these changes has been limited to expressing concern with the exception of one large provider who ultimately chose to discontinue a service that had been provided since the inception of 'Moving On' funding rather than compromise the principles and philosophy of the programme provided until these changes were introduced.

The new model of Day Options in South Australia has the potential to significantly compromise the core principles and values contained in the Disability Services Act and the concern is to what extent is this a signal of future directions. If these important principles, reinforced in the CSTDA agreement, can not be maintained, it would appear that economic realities are a stimulus for change.

Disability Services Manager, UnitingCare Wesley Adelaide

Young People in Nursing Homes

While UnitingCare does not believe that it is appropriate for young people with impairments to be living in residential aged care facilities, it does accommodate some young people within its aged care homes because this may be the best option available due to the lack of alternatives.

Young people in residential care facilities experience restriction to their social lives and little peer support leading in many instances to distress and depression. Their opportunities to develop relationships with other than paid workers are greatly restricted. They also report living with reduced expectations about their capacities and potential.

Young people within residential aged care facilities report limited appropriate professional care with little or no access to rehabilitative services. Nurses are trained to provide personal care to frail aged people and are not trained to provide services to people in their youth or middle years who need different therapies to sustain their lives and build their skills. Staff have insufficient time and there are insufficient resources to adequately care for younger people with impairments. Once a client has been admitted to residential care, and is receiving a Commonwealth subsidy, it is often difficult for them to access community services.

Individual funding models

An approach to service provision that is creative and innovative will undoubtedly ensure that a range of services will be available to meet the differing needs of people with impairments – and, with the worldwide shift from institutional services and professional control to an emphasis on self-determination and community involvement, self management must be one option available for the delivery of service and supports.

In 2003-2004 only 17 per cent of Australian service users reported that they received individualised funding which had been granted on the basis of a needs assessment and funding application.⁷ (Those in respite and employment were most likely to report such funding arrangements.)

Features of self-determination include having an individual budget, exercising control over services and decision-making, having person-centred planning, independent support brokerage and a fiscal intermediary.

I would like to see a commitment to individual support for any person with a disability who is unable to continue to live at home. This would involve commitments to introduce direct payments and support systems for self management.

I have been involved through UnitingCare Community Options with a number of families who have sought individual arrangements for their son or daughter in terms of accommodation or occupation. There are a number of young people who just finished school who we are supporting. Each of them has a severe disability but they are enjoying such things as university attendance (for audit), book clubs at neighbourhood houses etc with 1:1 support because they are using their funding as they like. We are also supporting a number of people who want to move out of home but not with other people with a disability. They are developing community connections

⁷ Australia's Welfare 2005 pp 235-239

and friendships with shared arrangements with non-disabled peers as their goal. They will still have paid staff support but not all the time. The tendency to offer group activities continues to be justified either in terms of people "preferring to be with their own kind" or the cost issue. The facts have shown people like to be with those with whom they have common interests in places where they are pursuing those interests and that such arrangements don't have to cost huge amounts. In fact, the overheads associated with many congregate services push up the cost despite having a low staff ratio.

UnitingCare Community Options, Victoria

E. CONCLUSIONS

- The current demarcation between jurisdictional responsibilities means that people wishing to transfer between options or undertake a mix of options are required to negotiate their way through two different service systems with differing policy and funding priorities.
- A need exists to simplify the system to make it easier for consumers to access and navigate. This means ensuring that improved pathways between Commonwealth and State funded services are two-way thereby enabling a smooth transition into and between programs and services according to people's changing needs at different times and life stages.
- Cross jurisdictional approaches to service provision need to be further developed to encourage people to experiment with new or a mix of options without risking the security of their placement.