

Interchange Respite Care (NSW) Inc.

Leading, Supporting and Enhancing Respite Service Provision across NSW

August 18, 2006.

The Secretary
Senate Community Affairs References Committee
PO Box 6100
Parliament House
Canberra. ACT.
2600.



**The Carrington Centre
2 Carrington Square
Campsie, NSW 2194**

**Ph: (02) 9789 1348
Fax: (02) 9789 3081
ABN: 6898-5026-718**

**www.interchangensw.com.au
admin@interchangensw.com.au**

We would like to submit this brief submission to the Senate Inquiry into the Funding & Operation of the Commonwealth States & Territories Disability Agreement (CSTDA).

Interchange Respite Care NSW is the peak body for organisations involved in providing respite care to families who have a member with a disability, or a family member who is frail aged. Our role is to support these organisations in delivering quality services to their families and clients. We do this by providing members with a range of services, around information, resource support, training, networking, advocacy, and representation to government and funding bodies. We represent 95 respite care providers across NSW, many in the disability sector. We understand and reflect the practices & philosophies of these service providers.

Respite care is a very much under-funded service support system within the disability population in comparison to the level of need, with many of our members reporting clients who are requesting more respite support hours to meet their needs, along with referrals and families on waiting lists. Historically demand has always outstripped supply and providers are constantly having to juggle resources to try and meet the needs of clients.

Over the past 8 months we have been trying to engage both the Commonwealth government and the NSW government to reform the Home & Community Care Guidelines for Respite Care to provide a more flexible and accessible support system. To support this position we have been hosting a series of Carers & Stakeholders Respite Forums to gather the opinions and feedback of carers, families, etc, as to how they want respite support delivered and what they hope to attain from service support.

To date we have held 6 Forums at various venues across the state with an attendance of approximately 220 carers and family members, and there is a consistency in the messages and desires expressed by participants. These being:

- services are difficult to access and the service system landscape seems to be fragmented & complex.
- availability of respite support is decreasing
- Service support needs to be flexible and responsive to meet individual needs
- Many families & carers believe their future respite needs will only continue to increase
- For a number of families long term supported accommodation is their real need for service support and respite care merely hides this.

Respite care has been a growing service type for many years and in some areas, for some families, has been a last resort service support due to the lack of more appropriate service

types. The inadequacy of funding through the various array of disability service programs has led to respite support in some circumstances being substituted for other types of service support need, such as accommodation, day programs, vacation care programs, etc. Respite has been seen and used by governments and bureaucrats as bandaid solutions and forced some families into situations of permanent care roles which they ultimately do not wish to pursue.

The CSTDA has become a symbol of the inefficiency of bureaucracy to deliver necessary and adequate service support to citizens who deserve and require this. The constant haggling and blame between Commonwealth & State governments over under funding issues, and cost shifting issues has fostered a cynicism amongst both clients and providers as to the genuine intent of governments to meet the needs of families living with disability.

Briefly, we believe the following areas should be addressed in relation to the CSTDA.

Firstly, the provision of disability services should be a **consistent national program** and totally administered by **one level** of government. As carers and families identify that the service system landscape is complex, fragmented and difficult to access, the multitude of different funding programs with differing target groups, eligibility criteria, and modes of service delivery has created an inefficient system.

Respite service delivery has evolved over the last 15 years to be much more client focussed in providing support to both carers & care recipients by way of models that best meet both parties needs. With certain funding programs (particularly HACC) having various restrictions on how a respite service can be provided and when, it makes it difficult for providers to consistently meet the expressed needs of clients and provide the maximum benefit of service support with the resources they have.

For respite care, there should be **1 National Funding source** with far greater parameters of how and when respite care can be provided, and **administered by one level of government**.

Secondly, there needs to be a revised **Planning Framework** developed that encapsulates a **Population Based Bench Mark Funding** formula as expressed in both the submissions from the National Carers Coalition and ACROD. Constructive and meaningful planning is a prime responsibility of government and should not be neglected. Funding for the service delivery requirements of such a plan is also a responsibility of government. People with disabilities as citizens of this country should have a right and entitlement to support. This should not be planned and delivered within a rationing mentality.

This should be undertaken on a national level and incorporate demographic changes, current & future needs & expectations of carers and care recipients, and capacities of service providers.

As identified through our forums, and by many other organisations, there is an imminent crisis looming with regard to ageing carers of adult children with disabilities to whom they still provide primary care. Piece-meal programs such as the recently funded Ageing Parents Carers Respite Program do nothing to address the future long term supported accommodation needs of such care recipients. And still for many other younger families, their real needs and aspirations for their sons & daughters are still being ignored with governments of both persuasions placing increased expectations on families that they must maintain the primary care duties for their children with a disability for the term of their natural life.

A number of parents at our Forums have commented that they feel that the right of passage for their adult children to move from the family home to a more independent life has been denied.

Funding bench mark formulas as developed for the aged care sector must be developed and implemented for the disability sector to meet the current level of unmet need and the future growth in need. There is no shortage of evidence, particularly from the Australian Institute of Health & Welfare, that there is an outstanding level of the disability population who have unmet needs in relation to community support.

Thirdly, Research needs to be increased to help support the planning activities to determine future need, the development of innovative models of service delivery that best utilise resources and meet client needs, and to identify & develop appropriate tools to measure client outcomes. Non government organisations and peak representative groups should be more widely involved in such research projects and also in determining as to what areas research should be conducted. Peak bodies such as ourselves have close connections with families, carers, and care recipients, as well as service providers, to facilitate & support meaningful research that can guide new initiatives and future spending patterns.

Forthly, Service compliance & Monitoring Systems need to have some commonality across funding programs. Although broader than the CSTDA, there is an issue for providers who receive funding grants from multiple program sources and hence need to comply with multiple quality monitoring systems. This is applicable to funding programs such as HACC, and the National Carers Respite program where providers need to meet & respond to different monitoring systems. It would be helpful if there was 1 consistent service monitoring approach applicable to all funding programs, and hence reduce the cost and administrative load on providers with regard to monitoring and compliance.

Fifthly, Workforce and Service Funding issues. The failure by the Commonwealth government in recent years to pass on CPI costs in its funding contributions to state grants programs has impacted on respite providers and slowly erodes their service capacity. The workforce in this sector (in NSW) is predominantly paid under the Social & Community Services Award, and as agencies are not commercial enterprises and do not trade to make a profit, we are reliant on the same source of funds as the Public Service to maintain a competitive & skilled workforce. Adequate and competitive remuneration plays a significant role in developing and retaining a skilled and motivated workforce.

Recognition of the administrative costs which continually climb and impact on service providers, such as Workers Compensation, training, rent, travel, quality compliance, etc. need to be factored into funding grant components to allow services to maintain viability.

We would like to see a commitment to a recognition of these types of cost factors and an on-going monitoring of these to ensure services maintain a level of viability to meet such costs that does not erode into service delivery costs.

Kevin Marron
Executive Officer
kevinm@interchangenw.com.au