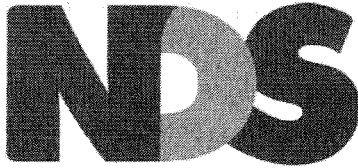


A.O.C. 7/7/08

Submission No. 579

(Inq into better support for carers)



National Disability Services

## **Submission to the House Standing Committee on Family, Community, Housing and Youth Inquiry into better support for carers**

### **Introduction**

NDS welcomes this opportunity to make a submission to the 'Inquiry into better support for carers'. The extraordinary contribution of carers to the social fabric of Australia should not be underestimated and, indeed, should be better supported. Collectively carers provide in excess of a billion hours of support per year to people with chronic illness, disability or frailty. Nearly 65 per cent of primary carers over the age of 15 years spend more than 40 hours per week caring for a person with a profound core activity limitation.<sup>1</sup> This is of benefit, directly or indirectly, to all Australians. Supporting carers in their role is crucial to the sustainability of the Australian health and community care systems.

NDS member organisations work collaboratively with carers to support people of all ages and with all forms of disability. In doing so, they hear regularly of the concerns of carers—from the parents of children with disability seeking access to early intervention and respite services; from the people juggling work and caring responsibilities; and from older carers anxious about the future.

This submission will focus on the need for carers of people with disability to have reliable and adequate access to a range of appropriate and flexible formal support services. In doing so, it will draw on information provided by the carers with whom our members work in partnership to improve the lives of people with disability.

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<sup>1</sup> ABS 2004, *Disability, ageing and carers: summary of findings*, ABS, Canberra, pp. 54 & 33.

## Key issues

### ◆ The role and contribution of unpaid carers in society and how this should be recognised

For many carers of people with disability, the most important recognition of their role and contribution will come from acknowledgement that the care role is not theirs alone—they want to be informed about options and assured that access to formal support services for the person they care for will be available when required. To assist carers engage with the formal support system they need: information about the support services that are available to assist them in their care role; access to the levels and types of support services that are sufficient to meet their needs to juggle other responsibilities, other roles and other interests; and to be assured the person they care for will be well supported by the formal service system.

While the demand for disability support services continues so markedly to exceed the supply, carers will not have that assurance. In 2007, AIHW conservatively estimated that 23,800 Australians with disability need access to accommodation or respite services and 3,700 people require community access services (9,400 if recreation and holiday programs are included). This demand for services will rise with population growth, population ageing and the decreasing availability of family carers. AIHW estimates that the number of Australians with severe or profound disability will increase by 34,600 between 2006 and 2010<sup>2</sup>. Acknowledging the large unmet need for services, the 2007 Senate Inquiry in the Funding and Operation of the CSTDA recommended that the level of funding contributed by both levels of government substantially increase<sup>3</sup>.

NDS welcomes the Australian Government's commitment to develop (with States and Territories) a National Disability Strategy and its recent injection of new money (\$1 billion) into the Commonwealth State and Territory Disability Agreement. However, as the Government itself has acknowledged, this is only a first step towards tackling the chronic under-funding of disability support services.

The Australian Government has also initiated an inquiry into investment in the disability sector – to explore ways to attract private and philanthropic funds to support people with disability. Again, this is worthwhile— but, realistically, these sources of funding will not nearly bridge the gap. Potential profit margins from the provision of disability services are low and households which contain a person with disability are typically poor<sup>4</sup>. It is imperative that governments—Commonwealth, State and Territory—agree on a funding mechanism that guarantees lifetime support and care for people with disability who require it. That would go a long way towards providing carers with the assurance they deserve.

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<sup>2</sup> AIHW 2007, *Current and future demand for specialist disability services*, AIHW, Canberra.

<sup>3</sup> Senate of Australia 2007, *Funding and operation of the Commonwealth State/Territory Disability Agreement*, Canberra.

<sup>4</sup> Edwards, B. et al 2008, *The nature and impact of caring for family members with a disability in Australia*, AIFS, Melbourne, pp 25–6 & 28.

◆ **Barriers to social and economic participation for carers, including employment**

Caring responsibilities can restrict social and economic participation. Recent Australian Institute of Family Studies' research highlights these restrictions: it found that women's caring responsibilities come at a personal financial cost.

The study, *Caring and Women's Labour Market Participation*, found that 7 out of 10 carers wanted to be employed but have difficulty finding flexible working hours and alternative care for their family members. In addition, nearly 70 per cent of those receiving Carer Allowance and over 53 per cent receiving Carer Payment who were not employed said they wanted to work. Almost half of carers had worked immediately prior to commencing their caring role and more than three-quarters of those said that providing care was the main reason for leaving their job.<sup>5</sup>

***Current service system limitations***

Insufficient access to reliable and flexible formal support services undermines the ability of carers of people with disability to participate in their community, to undertake education or training, or to be employed. This limited access to support may take the form of lack of appropriate before-and-after school care, the insufficient availability of planned respite (in or out of home), or the inadequate access to appropriate community participation programs or supported employment services.

Carers living in regional areas of Australia may have to travel for up to 3-4 hours to access suitable services. For parents with a child with disability attending school, barriers to participation can also be associated with the expectation that parents are permanently on call for the one-to-one classroom support the school does not provide. And parents with an adult child may need to be home by 3.00 or 4.00 pm to provide care at the close of the community participation program or supported employment service.

An increase in the availability of respite programs, community participation services, classroom support and supported employment would reduce the participation barriers that carers face.

***Workplace inflexibility***

The lives of some carers of people with disability are marked by uncertainty. These carers need the flexibility at work to be able to drop what they are doing to respond to a need (sometimes crisis) of the person they care for. Carers would also be assisted if their work day could be structured around the times support services are available. The findings of the HREOC National Inquiry into Employment and Disability to better enable carers to secure and retain employment need further consideration.<sup>6</sup>

Research by the Australian Taskforce on Care Costs concluded that, under current arrangements, "carers find it difficult to access the full range of flexible work practices, and implementation varies across and within organisations." More than one in three carers report that "their job/career has suffered because of the competing demands of

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<sup>5</sup> 'Family Matters' <http://www.aifs.gov.au/institute/pubs/fm2008/fm78.html>, Australian Institute of Family Studies, 2008

<sup>6</sup> *WORKability 2 Solutions* [http://www.hreoc.gov.au/disability\\_rights/employment\\_inquiry/final/index.htm](http://www.hreoc.gov.au/disability_rights/employment_inquiry/final/index.htm)

their caring responsibilities.” The Taskforce found that the strategies which would most assist carers to balance their work and caring responsibilities are improved access to support services; greater workplace flexibility; and improved support services. It has recommended that: “Employers ensure greater access to the full range of flexible work practices (ie beyond part-time work) for all carers (ie beyond the current focus on childcare). In addition, employers work towards greater consistency of implementation by managers across their organisations.”<sup>7</sup>

In response to the National Employment Standards Exposure Draft (April 2008) NDS recommended that

*employees with disability and employees who care for people with disability be eligible to seek flexibility in working arrangements under the proposed National Employment Standards.*

Employers should be strongly encouraged to provide employees who care for people with disability with the flexibility they require in their working arrangements.

#### ◆ **Practical measures and key priorities required to better support carers**

NDS welcomes the initiatives announced in the 2008 Federal Budget to assist carers, including: the expanded eligibility for the Carer Payment; the new assessment process for Carer Payment (child); the one-off Carer Adjustment Payment; an easier transition from Carer Payment (child) to Carer Payment (adult); and the carer bonus payments and extension of Utilities Allowance and Telephone Allowance.

In addition to financial measures, carers need additional assistance—in the variety of ways outlined below—to support their ability to care for their family member with disability.

#### ***Understanding disability***

Carers benefit from being given assistance to develop the skills to recognise, understand and manage the nature and complexities of a disability, particularly when the person they care for has complex medical and other support needs. They need access to ongoing and consistent training, education, information and resources.

Governments need to improve and simplify access to information, and develop additional specialist information resources for carers with specific needs, in particular those who are men, have a disability, are young or are from Indigenous or culturally and linguistically diverse backgrounds.

#### ***Increased provision of disability support services***

The current limited access to supported accommodation and day programs, expressed in part by the heavy demand on respite programs, is a particularly

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<sup>7</sup> Taskforce on Care Costs,

[http://www.tocc.org.au/media/Final\\_TOCC\\_2007\\_Report\\_The\\_Hidden\\_Face\\_of\\_Care\\_16\\_Nov\\_2007.pdf](http://www.tocc.org.au/media/Final_TOCC_2007_Report_The_Hidden_Face_of_Care_16_Nov_2007.pdf)

important issue for governments to address. Providers of accommodation support are concerned about the lack of housing options available to assist people to live away from their family. They are also concerned about the number of people with disability who are left permanently in respite services when carers feel they are unable to continue their role.

### ***Respite***

Many carers consider respite to be an important source of support. Most children become increasingly independent as they grow and develop their own friends and interests. This is frequently not the case for people with disability, where their need for constant and continuing care can place enormous pressure on carers. Respite gives carers a break from their daily routine, and the opportunity to relax, revitalise and build up the personal resources necessary to resume their caring role. Respite services can be in-the-home even when the carer is there, out-of-home, and support for family outings or get-togethers.

Respite, however, should also provide positive outcomes for the person with disability, and facilitate the development of new friends and offer new experiences. Services should be structured with this in mind, as the quality of the support being provided to the person with disability is as important as the break it is providing for the carer. The importance of this cannot be overestimated.

While the Australian Government's recently announced funding for 10,000 extra respite places is very welcome, many families will continue to struggle to obtain adequate access to respite—greater access to regular support services is required.

### ***Continence aids***

Extending the Commonwealth Continence Aids Assistance Scheme (CAAS) to include children aged 4 years who have a permanent disability and experience daily incontinence would be a positive step to relieving the caring and financial pressures on families with a child with disability.

In a welcome initiative, last year CAAS was extended to include children and young people aged 5 to 16 years. It remains a concern, however, that families of children aged 4 years are unable to benefit from the Scheme. A child with disability who is incontinent at 5 years will have been incontinent at 4 years (very few children without disability are incontinent at that age).

The Children's Hospital at Westmead has identified that almost 20 per cent of 4 to 6 year olds are incontinent at some stage but only 3 per cent are incontinent twice or more in a week. In addition, they estimate that the number of children aged 4 years who are incontinent daily is less than 1 per cent of all children<sup>8</sup>. The family of a child with disability aged 4 years who uses continence aids when attending pre-school and during daytime activities would benefit greatly if assisted by CAAS (their current expenditure on continence aids could be as high as \$3,000 annually).

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<sup>8</sup> [http://www.chw.edu.au/parents/factsheets/daytime\\_wetting.htm](http://www.chw.edu.au/parents/factsheets/daytime_wetting.htm) viewed 30 June 2008.

### ***Vehicle modification***

Many people are unable to meet the cost of modifying vehicles to enable the safe transportation of a person with disability. Currently, only two States have vehicle modification subsidy schemes: Western Australia and Victoria. The Australian Government should work with State and Territory governments and non-government organisations to develop and implement a national vehicle modification subsidy scheme.

Often wheelchair manufacturers will not certify their equipment for travelling in vehicles and instead ask that people be transferred to a seat, an action that could be difficult to achieve and unsafe for the individual. Consistent national guidelines for the authorisation of vehicle modifications and the requirements for wheelchairs would significantly help avoid the knowledge gaps in vehicle suppliers and modifiers, wheelchair manufacturers and even government bodies (including wheelchair funding schemes and transport departments). Adopting measures to ensure that people in wheelchairs have an appropriate level of safety in vehicles should be a priority.

The development of a national vehicle subsidy scheme should be accompanied by the updating of the Australian vehicle modification standards to reflect current international standards.

### ***Investment in assistive technology***

Some people with disability need access to aids and equipment to develop mobility, communication and other skills. The announcement, on 30 May 2008, by Federal, State and Territory Disability Ministers of the intention to develop a nationally consistent approach to the provision of aids and equipment is most welcome.

This initiative should also include a focus on the provision of assistive technology for communication to children and young people with a disability. Such provision will make a significant difference in their ability to learn and to make their wishes known.

### ***Family relationship advice***

The Family Relationship Services Program provides, among other things, mediation and counselling to assist families with a member with disability to make decisions about future care arrangements, resolve conflicts and discuss concerns and issues<sup>9</sup>. It is important that the Australian Government's recent announcement of additional funding of \$277 million also benefits families who have a family member with disability. Their need for support around decision-making is important.

### ***Access to future planning services and support***

With the increased longevity of many people with disability, there is an urgent need for families to consider future support arrangements for their family member with disability. Older carers, in particular, need support to undertake this future planning task—involving legal, financial, housing and support, and psychosocial decisions—which can be emotionally difficult and administratively complex.

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<sup>9</sup> [http://www.frsa.org.au/UserFiles/FRSP\\_Carers.pdf](http://www.frsa.org.au/UserFiles/FRSP_Carers.pdf) viewed 30 June 2008.

While the booklet developed by the Department of Families, Housing, Community Services and Indigenous Affairs, *Planning for the future: people with disability*, provides useful advice to assist families make arrangements, some require additional informed support and have difficulty in identifying such assistance.

The historical practice of primarily directing government funds in response to crisis situations fails to give due recognition to the need for future planning. Older carers need:

- encouragement and support to undertake future planning;
- handing-over options: that is, substantial care packages and a range of accommodation and support options to assist them to withdraw from their primary care role; and
- flexible consumer and carer-driven services and supports.

The key elements of any future planning initiatives ought to include:

- a dual focus that ensures the needs and desires of the person with disability, as well as those of the carers and other family members, are included in planning processes;
- engagement with the service system; and
- both future and emergency planning.

As the key aim of future planning is often to facilitate transition to alternative accommodation and support arrangements when the person with disability is no longer able to live with the family, it is important to encourage early engagement with the disability service system that will ultimately have a role in providing support.

Some carers, particularly those who have not used the service system, will need to establish confidence in the ability of services to provide quality support for their family members. They may require time to build this trust. Consideration should be given gradually to building the range of services accessed by the person with disability, including:

- in-home support;
- community access and participation (which may include transport assistance);
- day programs;
- leisure and holiday services; and
- respite.

Planning should also consider options that would be available for the provision of emergency care, whether it is for a temporary period until the family can return to usual support arrangements or an interim period while alternative arrangements are sought.

***Improving the supports available to young carers***

NDS acknowledges that the specific needs of young carers (who may still be completing schooling or education) deserve to be recognised and supported. These supports have been identified as<sup>10</sup>:

- provision of information about their rights and the services available;
- schools which are more understanding and provide greater options for young carers to reach their full potential;
- homework assistance programs;
- career counselling that is tailored to their situation;
- provision for out-of-school learning and assessment;
- provision for leave or time-out from school without penalty;
- more flexible timetabling and scholarship programs;
- flexible work environments and targeted transition to work and return to work programs;
- provision of regular, flexible and coordinated respite; and
- services focusing on young carers from CALD backgrounds, including Indigenous Australians.

Responding to the needs of these young carers is important to their future options, their well-being and their willingness and ability to provide care and support.

***Research***

Government investment into disability research is poor; research into how to improve the support provided to carers of people with disability is no exception. Considerable investment in research into all aspects of disability, including into the pressures experienced by carers and how better to support carers in their role, is required as a matter of urgency.

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<sup>10</sup> *It's About Time: Women, men, work and family – final paper 2007* HREOC, ch.8  
[http://www.humanrights.gov.au/sex\\_discrimination/its\\_about\\_time/](http://www.humanrights.gov.au/sex_discrimination/its_about_time/)



## **About National Disability Services**

**National Disability Services** is the peak industry body for non-government disability services. Its purpose is to promote and advance services for people with disability. Its Australia-wide membership includes 630 not-for-profit organisations, which support people with all forms of disability. Its members collectively provide the full range of disability services—from accommodation support, respite and therapy to community access and employment. NDS provides information and networking opportunities to its members and policy advice to State, Territory and Federal governments.