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Submission No. 662

(Inq into better support for carers)

AOC 10/7/08

Committee Secretary  
Standing Committee on Family, Community, Housing and Youth  
PO Box 6021  
House of Representatives  
Parliament House  
CANBERRA ACT 2600

## **RE: Inquiry into Better Support for Carers**

The Disability Council of NSW welcomes the opportunity to make a submission to the House of Representatives Standing Committee on Family, Community, Housing and Youth's *Inquiry into Better Support for Carers*. This issue is complex and will attract many, varied opinions and strategies to consider. We hope our contribution through this submission adds constructively to the debates that will ensue.

### *About the Disability Council of NSW*

The Disability Council was established under the terms of Section 16 of the Community Welfare Act 1987 to advise Government in NSW on issues affecting people with disability and their families. We also give advice to the Australian Government on the effect of policy on people with disability living in NSW. Council members are appointed by the NSW Governor on the recommendation of the Minister for Disability Services. Members are selected because of their experience of disability, their understanding of issues, their knowledge of service delivery and their ability to reflect and advise on policy. The majority of Council members are people with disability.

Our Council has a statutory duty to give the best possible advice on matters relating to people with disability and their families. Our primary obligation is give advice that promotes the interests, welfare and social inclusion of people with disability within a rights-based framework of domestic (State and Commonwealth) and international Law.

We do so with a deep commitment to building better relationships between people with disability, their families and friends, the communities within which they live and work and the broader society of Australian social, economic and cultural life. We seek holistic solutions to common problems.

### Preliminary comments

We acknowledge the vital role played by carers in the lives of people with disability who require support to live ordinary and, we hope, fulfilling lives.

We understand the complexity of the relationships between people with disability and family members / friends and associates who provide unpaid personal assistance and much-needed support of many types.

We recognise that within those complex personal relationships both parties have needs and rights that must be addressed.

People with disability have formal rights to live free from disability discrimination and with access to formal services. Carers, who have no less important (but distinct and separate) needs from people with disability, currently have fewer formal rights than the people to whom they may provide unpaid assistance and support as carers. That anomaly should be rectified.

### Legislative Context

While it is clear that the Disability Discrimination Act provides some formal protection to carers from indirect discrimination (by association with people with disability), there is currently no rights based framework in Australia to protect their interests or meet the role-related needs of carers. Legal rights of the type we mean exist for carers in other countries, such as the UK. We believe that there should be formal recognition of carers rights and needs within Australian law.

We note, however, the set of legal instruments that do / will form the basis the rights and service access framework for people with disability in NSW. These rights are replicated in every State and Territory:

- The United Nations Convention on the Rights of Persons with Disabilities, with particular regard to;
  - Article 7: the rights of children with disability;
  - Article 16: the right of people with disability to freedom from exploitation, violence and abuse;
  - Article 19: the right to live independently and be included in the community;
  - Article 23: respect for home and the family;
  - Article 26: rights to habilitation and rehabilitation;
  - Article 28: rights to an adequate standard of living and social protection; and
  - Article 30: the right of participation in cultural life, recreation, leisure and sport.
  
- The Commonwealth of Australia's Disability Services Act 1986 with particular regard to the following Objects in section 3.(1):

- (b) *to assist persons with disabilities to receive services necessary to enable them to work towards full participation as members of the community;*
- (c) *to promote services provided to persons with disabilities that:*
  - i. *assist persons with disabilities to integrate in the community, and complement services available generally to persons in the community;*
  - ii. *assist persons with disabilities to achieve positive outcomes, such as increased independence, employment opportunities and integration in the community; and*
  - iii. *are provided in ways that promote in the community a positive image of persons with disabilities and enhance their self-esteem;*
- (d) *to ensure that the outcomes achieved by persons with disabilities by the provision of services for them are taken into account in the granting of financial assistance for the provision of such services;*
- (e) *to encourage innovation in the provision of services for persons with disabilities; and*
- (f) *to assist in achieving positive outcomes, such as increased independence, employment opportunities and integration in the community, for persons with disabilities who are of working age by the provision of comprehensive rehabilitation services.*

○ **The NSW Disability Services Act 1993 with particular regard to Section 3: Objects**

*The objects of this Act are:*

- (a) *to ensure the provision of services necessary to enable persons with disabilities to achieve their maximum potential as members of the community, and*
- (b) *to ensure the provision of services that:*
  - (i) *further the integration of persons with disabilities in the community and complement services available generally to such persons in the community, and*
  - (ii) *enable persons with disabilities to achieve positive outcomes, such as increased independence, employment opportunities and integration in the community, and*
  - (iii) *are provided in ways that promote in the community a positive image of persons with disabilities and enhance their self-esteem, and*
- (c) *to ensure that the outcomes achieved by persons with disabilities by the provision of services for them are taken into account in the granting of financial assistance for the provision of such services, and*
- (d) *to encourage innovation in the provision of services for persons with disabilities, and*

- (e) *to achieve positive outcomes, such as increased independence, employment opportunities and integration in the community, for persons with disabilities, and*
  - (f) *to ensure that designated services for persons with disabilities are developed and reviewed on a periodic basis through the use of forward plans.*
- o The Commonwealth of Australia's Disability Discrimination Act 1992.

### **The importance of carers to people with disability**

The Disability Council of NSW agrees with the observation by Dr Jeff Harmer in his Foreword to The Nature and Impact of Caring for Family Members with a Disability in Australia<sup>1</sup> that

*"Family carers make an invaluable contribution to the care and wellbeing of people who need assistance due to disability, severe medical conditions or ageing. This contribution also provides enormous benefits for the Australian community."*

We concur with the views of the Premier of NSW, The Hon Morris Iemma MP, who wrote in the NSW Carers Action Plan 2007 – 2012<sup>2</sup> that:

*"Better support for families and carers has significant long-term benefits for the whole community, not just those being cared for."*

We endorse the additional comments by the NSW Premier that:

*"... carers need care too. They need to know they are not alone. That their service is valued by the community. And that practical help is available to make their journey that little bit easier."*

*The NSW Carers Action Plan outlines the NSW Government's five-year commitment to do these things.*

*Our plan includes significant new support for those living with mental illness and physical disabilities, as well as expanding measures to support carers such as the NSW Carers Program."*

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<sup>1</sup> Australian Institute of Family Studies Research Report No. 16; 2008

<sup>2</sup> NSW Department of Health; 2007

### *The essential role played by formal service systems*

We believe that the NSW Premier's final point (above) is particularly perceptive. The development and provision of an adequate formal disability services system is fundamentally important to addressing the needs of people with disability and, therefore, meeting many of the concerns of carers.

Despite the continuous efforts of national and State governments to increase growth and development of services, however, we have not yet secured the comprehensive and flexible network we require. We illustrate this point with reference to a few key indicators of the challenges that still confront the entire community of Australians.

- The findings of Australian Institute of Family Studies record *"Almost half of the carers' families did not use any support services (47.9%)."*<sup>3</sup>
- In its analysis of need and demand for specialist disability services the Australian Institute for Health and Welfare<sup>4</sup> estimated the following levels of unmet demand for CSTDA funded services:
  - 23,800 people with a need for "accommodation and respite services";
  - 3,700 people with unmet need for "community access services";
  - At least 1,700 with unmet need for "employment services";The Institute notes that *"all three estimates of unmet demand are considered conservative."*
- The Senate Community Affairs Committee, commenting on the CSTDA in 2007, observed that:

*"The evidence of carers, who undertake so much of the caring, brought home this reality to the Committee. Many cases were cited of families and loved ones shouldering enormous responsibilities over decades caring for a person with a disability, with government or community assistance relieving that burden only slightly or not at all. The Committee acknowledges that families will always have a substantial responsibility towards the care of their disabled members, and that it may never be either desirable or economically feasible to shift that responsibility onto the community as a whole. At the same time, the Committee recognises that the weight of that responsibility on countless families is a crushing and unreasonable one, and that much greater community assistance in that task is urgently called for."*

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<sup>3</sup> Research Report 16; 2008

<sup>4</sup> Current and future demand for specialist disability services, AIHW; 2007

## *Meeting the Needs of People With Disability*

Fundamental to any new strategy that recognises the roles of carers and meets their needs are continuing and increased actions by all governments to review, enhance and develop support systems to meet the diverse needs of people with disability. In our view this includes (but is not limited to):

- Addressing unmet need for services for people with disability. This would relieve stress on and exhaustion of carers as they provide care and support. We acknowledge, of course, that there will always be a role played by carers. This is natural and desirable. Nevertheless, Government funded services should be enhanced, modernised and developed so as to benefit both people with disability and carers.
- Reducing waiting lists and times for services. Government should ensure there is adequate funding and operational capability to eliminate any need for carers to fill gap in service provision.
- Ensuring there is no unintended risk created for people with a disability when meeting carers' needs.
- Providing flexible services that are funded within government agencies as well as non government agencies. This ensures that both carers and people with disability can have full lives, which includes participating in social and work activities (as examples).
- Recognising that people with disability can and do contribute to family life as much as they receive support.
- Training of staff. Government should lead cross-sector strategies which complement the delivery of services by competent staff. This will mean that carers will not be required to re-do the work delivered at a less than adequate standard. It also avoids the necessity to put the person with a disability through a repeat steps to ensure adequate provision of a service.
- Reviewing funding of services according to quality, demand and service user assessments as part of a commitment to continuous quality improvement.
- Reviewing the provision of equipment eligibility criteria and timeframes for provision of this service. In some cases people with a disability are provided with a "make do" equipment item as a band aid measure until such time as funding is available to provide adequate equipment that meets the Australian Standard. "Make do" equipment that does not meet the Australian Standard should not be issued as this only adds stress upon the carer when there are operational difficulties with the equipment.

- Intervening at early stages of need with appropriate and timely options such as early intervention service provision.

**Responding sensitively to the expressed views of carer organisations**

Carers' organisations can and do represent the best interest of carers. When they do so, with as strong a commitment to the social inclusion and rights of people with disability as for their members, government must listen. We particularly commend the thoughtful agenda proposed by agencies such as Carers NSW and Carers Australia. We note the observations of the latter when it states:

*The primary issues for carers are:*

- *Financial security and income support*

*Caring responsibilities can not only restrict a carer's income earning capacity, but also incur extra costs for the household such as extra electricity, phone or transport costs, medications and special equipment. Carers Australia has constantly brought the high cost of care to the attention of Government and argued for more adequate and equitable income support measures through an improved and broadened Carer Payment and a substantially increased Carer Allowance to go some way to recompense carers for the actual costs of care. We also urge the Government to widen eligibility for the Carer Allowance to carers who are not living with the person they support but provide substantial regular assistance, as is the case for the Carer Payment.*

- *Workforce participation and flexibility*

*The majority of carers who are of workforce age report great difficulties in balancing their caring responsibilities with workforce participation. Carers also face considerable barriers in re-entering the workforce after their caring responsibilities decrease or cease. Carers Australia is advocating for;*

- *more flexible workplace options;*
- *affordable; quality alternative care arrangements, such as adult day care that is aligned to working hours; and*
- *improved transition to work programs for carers.*

*Recognising people's caring responsibilities and accommodating them in the workplace is beneficial both to the employer and the employee.*

- *Carer support services*

*For caring to be sustainable in the long term, carers must have ready and affordable access to quality support services including flexible respite care, counselling, 'hands on' skills development for their caring role, in-home services delivered on a regular basis by trained staff and residential care. Too often carers cope on a day-to-day basis until a crisis hits and then emergency help has to be found in difficult and stressful circumstances. If assistance was readily available on an ongoing basis this crisis response could be averted and caring responsibilities would be more sustainable."*

We submit to members of the Committee that there is an additional set of related issues, which emerge directly from the experiences of people with disability. These include (but are not limited to) the following.

### *Ageing Carers*

Carers are ageing as is the Australian population generally. Older carers will personally feel the impacts of ageing, some of which will result in the onset of disabling conditions. This in turn will impact upon the ability of older carers to provide continuing care within a traditional carers' model for family members with disability.

Similarly, we acknowledge concerns from ageing carers in relation to who will look after their sons and daughters when the carers die. People with disability dependent on such care feel no less anxiety around this matter than carers.

### *In-House Support*

The carer workload is often heavy and stressful, particularly when there are few or no supports available from formal services. Government and non-government service providers need to further actively promote services to maximise uptake. People with disability and carers need timely access to flexible, person-centred services that recognise and respond appropriately to the distinct but linked needs of the person with disability and the carer.

### *'Respite' Choices*

People with disability get no respite from their disabling conditions. Carers should not be trapped, however, in a forced caring relationship that gives them no respite from gaps in formal support services which State and Commonwealth Disability Service Acts assert should be available.

'Respite services' must, therefore, move beyond the traditional approaches of bricks and mortar facilities and beds. The goal should be to provide person-centred, individualised support to carers as well as people with disability to enhance the capability of family members to build and sustain normal family relationships. In all families, all family members need breaks from one another to 're-charge batteries'. We need to develop non-traditional, service options that result in respite as an outcome rather than a place to visit.

We urge all funders and providers to review all respite services. This includes accommodation, systems, processes, amenity of buildings, internal protocols, availability, choices. We need services that better meet the needs of clients.

The Disability Council is of the opinion that a person with a disability and their family should have available to them a number of choices with regard to respite. We believe that this is not only a person's fundamental right but will also alleviate a person with a disability and their family from accessing a service that is the only one that is available to them.



Any 'respite' solutions deemed to meet the needs of carers must, first and foremost, fit with the needs of people with a disability. We do not favour 'respite' solutions that are congregated or institutional in nature. They may place the person with a disability at risk and, therefore, cause further concern for the carer who is meant to be having a break.

### *Assessment of needs and Individualised and Direct-Funded Services*

We favour a statutory right for carers to receive a formal needs assessment of their circumstances as a carer. Carers would have a right to such a 'carer assessment' but it would not be mandatory.

We further believe, however, that a formal right to an assessment of needs should be enacted in law for people with disability. The existence of a needs assessment for a person with disability who is likely to receive support from families / friends or others in 'the informal network of care' would be a pre-requisite to exercising the right to a 'carer assessment'.

We stress two points. The 'carer assessment' would be an assessment of the support needed by the carer to sustain their well-being and capacity to continue in the caring role as a positive life-choice. Secondly, no 'carer assessment' could be considered complete unless the person with disability had separately had conducted with them their own needs assessment.

We would expect both forms of assessment to be individualised, person-centred and mutually consistent, within the context of sustaining and developing the capacity of families to operate as natural units.

We urge all Governments to further explore, develop and introduce widely throughout service systems individualised support packages for people with disability and for carers based on their respective needs assessments. We support the further allocation of funding directly to clients, third party service brokers and/or financial intermediaries to enable individuals to plan, secure and manage individualised services that fit best with their lifestyles.

### *Cultural diversity*

Australia is home to people from many cultural backgrounds and traditions. Indigenous Australians have well documented and highly specific cultural norms and expectations, which mainstream services have not been well-equipped to meet. Families from non-English speaking backgrounds often encounter additional barriers to accessing services.

Newly developed carer strategies must respond sensitively to the cultural diversity of Australia's carers. There will be differing views of the relationships between individuals, families and formal services. People from different cultural traditions will be more or less likely to seek assistance outside the family home. There may be varying perceptions of the respective roles of women and men when it comes to carer issues. Language may be an issue, however the issue extends beyond linguistics with carers from CALD background as they may not identify themselves as "carers". In many CALD

communities the care of a person with a disability is the responsibility of the family. There may or may not be extended family support available to share caring responsibilities.

The key to developing cultural competency is to ensure service planners and providers neither make nor act on assumptions. With this mind, we favour broader consultation with Culturally and Linguistically Diverse groups to encourage the formal service sector, including funders, planners and providers, to better understand, develop, promote and provide services which are available and which will assist carers from every cultural background to maintain their preferred lifestyle.

### **Budget implications**

The Disability Council acknowledges that there will be financial consequences of providing an improved support system for both carers and people with disability. However, Council believes that the improved quality of life, involvement in activities which promote social inclusion and improved health outcomes will reduce existing costly impacts on currently stretched health, disability and income support systems. We foresee greater opportunities for entry and return to the workforce by carers and people with disability with potential to increase tax income and reduce Government requirements to the current pattern of benefit payments.

On a specific point of detail; we favour the ending of discretionary, 'one-off' bonus payments to carers. Bonus payments should be mainstreamed as annualised, permanent components of welfare payment / income support reform. There should be enhancement of the payments regime for carers.

### **In conclusion**

As it considers the needs of carers in Australia and better ways to support carers, we urge the Family and Community Committee of the House of Representatives to ensure that any and all recommendations fit with existing statutory obligations to address the rights of people with disability. The Australian community will benefit fully only when the interests of both people with disability and carers are recognised and met.

It is not possible to recognise adequately the role and contribution of carers unless and until the community as a whole responds to and meets the needs of those who receive care.

We wish to remind Committee members that many carers are, themselves, people with disability. There is, from time to time, a perverse and unhelpful polarisation created in the minds of some people between the two groups. It is right and proper, of course, that the distinctive needs of individuals as carers or as people with disability are recognised and met. It is important to understand, however, that for a sizeable proportion of the group of people we seek to support better through parliamentary discussion and government action many individuals are both carer and person with disability.

Our own Council is a microcosm of the reality that people with disability can be and are carers. At least six members of our 15 member Council do now or have in the recent past acted as principal carers and / or guardians of people with disability. Three of those Council members have disability; three do not.

We utterly reject any hurtful and undignified representation of people with disability who receive care from family, friends or formal service systems as a "burden". We acknowledge that the vast majority of carers do not and have never perceived or portrayed those to whom they may provide caring assistance as burdensome. We note, however, that during the period leading to the National Election in late 2007 people with disability receiving formal and informal support were, on a small number of occasions, portrayed as being burdens on those who cared for them.

We contend that it serves the interests of no one – least of all carers and people with disability – if a 'burden mentality' were to be encouraged or developed. People with disability and carers both need an adequate, flexible, person-centred service system that builds the capacity of individuals.

This submission seeks to address complex and varied issues relative to the provision of better support for carers. To do so adequately, we believe it is necessary to offer comments on potential impacts of a reform agenda on people with disability. We hope to ensure, however, that the Standing Committee is in a position to make informed decisions about support for carers without negative or detrimental impacts upon people with disability.

The Disability Council of NSW would be pleased to provide further comments or clarify the above recommendations should it be required.

Should you require further assistance please telephone Angela Hardman, Senior Policy officer, Disability Council of NSW on 02 9211 2264.

Yours sincerely

A handwritten signature in cursive script, appearing to read 'Andrew Buchanan', written in dark ink.

Andrew Buchanan  
Chair  
Disability Council of NSW  
2 July 2008