

Submission No. 786

(Inq into better support for carers)

MC
15/7/08



Developmental Disability Council of WA

Working for people with intellectual and other developmental disabilities

Submission to the House of Representatives

**Standing Committee on Family, Community,
Housing & Youth**

Inquiry into Better Support for Carers

July 2008

INTRODUCTION

This submission by the Developmental Disability Council of WA (DDC) places before the Standing Committee on Family, Community, Housing & Youth a summary of the key issues that we believe need addressing if we, as a community, are to offer Better Support to Carers.

DDC is a not for profit, community organisation speaking up for people with developmental disability, their families and the organisations that work for them. DDC works to promote and safeguard the rights of people with developmental disability and their families and to ensure they are provided the supports and services they need.

DDC is the WA State Agency member for the National Council on Intellectual Disability (NCID), the national association representing people with intellectual disability and their families in Australia.

SUBMISSION

Introduction

DDC acknowledges with gratitude the work and commitment of the politicians who have brought this critical issue to the attention of the Standing Committee and we thank the Standing Committee for conducting this Inquiry.

We expect that you will hear first hand from many families about their lives and issues. Families are in the best position to convey this knowledge and they do so most compellingly. DDC will not attempt to present these issues in this submission.

DDC is also acutely aware of the large body of information that already exists on carers, including that collected by the 2007 Senate Standing Committee on Community Affairs Inquiry into the Funding and Operation of the CSTDA. DDC prepared two submissions to this Inquiry, one on our own behalf and one for the Disability Coalition of Western Australia. Both these submissions are pertinent to this current Inquiry.

Given the above, it is our intention that this submission will be short and succinct. Our views are drawn directly from our experience with people with developmental disability and their families, but many apply equally as well to the broad population of 'carers' and the people they care for.

Firstly, we will present the key point we would like to emphasise, which is relevant to all Terms of Reference, and then briefly address each Term of Reference specifically.

Key Point

The key to offering 'Better Support for Carers' in Australia today is to offer 'better support to the people they care for'.
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People who are unable to fully care for themselves need assistance to do so. Families and friends, on the whole, provide this assistance. This they do lovingly and willingly. The overwhelming priority for family 'carers' is the well being of their family members. The outstanding impression one is left with after speaking with families is the lengths to which they will go to ensure their family member has a good life.

When the support services that people with disability need are not available in a timely, appropriate and dignified manner, the primary consequences are that they miss out on opportunities that they need, that are available to others and that most people would expect are available to all, and families are called on to 'fill the gaps'.

In Australia in 2008, most people would expect that both children and adults with a disability have access to the therapy they need to overcome or minimise their disability, that children have the opportunity to go to their local school as do other children, that adults receive the help they need to get a job and earn a living and that they receive the support they need to leave the family home and live an independent adult life. Most people would similarly expect that families caring for people with a disability would receive the respite they need to support them in their caring roles. The reality is that, for thousands of Australians with disability and their families, contrary to Disability Principles and Standards and the recommendations of very many Reports and Studies over many years, these opportunities, services and supports are not available.

Despite this situation being highlighted by people with disability, families and supporters over many years, it has been left to spiral into an ever deepening crisis, causing extreme disadvantage, difficulty and despair for thousands of people with disability and their families.

The most appropriate and effective way to offer 'Better Support for Carers' is to offer the support and opportunities the people they care for need. This support must take into account the needs and wishes of both the person with a disability and the family, leaving both with the same choices and opportunities as are available to other members of our community.

Term of Reference 1: The role and contribution of carers in society and how this should be recognised.

The role and contribution carers make to our community, through caring about and for the wellbeing of others, are of immeasurable moral and social value.

This contribution should be recognised by providing carers with dignity and choice. Carers should be able to lead lives of dignity, receiving needed support for themselves and the person they care for in a timely, flexible and appropriate manner. Carers should also have the opportunity for choice – choice regarding their caring role and choice regarding other priorities in their lives, including the wellbeing of other children, their marriage and financial security.

It is often quoted that the contribution carers make to our community saves our governments, (and thereby taxpayers), billions of dollars annually. As long as the supports and services that carers and the people they care for are not available, a compelling case can be put that carers are being exploited.

While providing needed supports and services for carers and the people they care for will come at a cost, so too does not providing these supports and services. It is debateable which will cost the most.

For carers struggling to manage 24 hours a day, seven days a week, 365 days a year, without the supports and services they and their family members need, the usual recognition of nice words and gestures rings hollow. The time for glossy pamphlets, committees, inquiries, standards, conferences, awards etc has well and truly passed. It is time for action – and this Inquiry offers hope that this may happen.

Term of Reference 2: The barriers to social and economic participation for carers, with a particular focus on helping carers to find and/or retain employment.

The primary barrier to social and economic participation for carers is the lack of adequate, appropriate, timely and flexible support for the people they care for.

If these supports and services were available, including alternative care to enable carers to have the time and energy to work and participate in social activities, carers would have the same access to social and economic participation as anyone else.

Term of Reference 3: The practical measures required to better support carers, including key priorities for action.

- The next CSTDA should fully address the recommendations of the 2007 Senate Inquiry into the CSTDA, and be informed by the estimate of unmet need presented by the AIHW Report into Current and Future Demand for Specialist Disability Services, June 2007.
- The government should, as a matter of urgency, research options for adequately funding disability support services in Australia. Options include a National Disability Insurance Scheme as proposed at the 20/20 Summit. Another possibility canvassed by some is a social care levy such as medicare. The systems already operating in other countries should be referred to and drawn from eg Germany, Japan, New Zealand and Scandinavian countries.
- A commitment should be made to the provision of the supports and services that people with disability and the people who care for them need.

Term of Reference 4: Strategies to assist carers to access the same range of opportunities and choices as the wider community, including strategies to increase the capacity for carers to make choices within their caring roles, transition into and out of caring, and effectively plan for the future.

If carers and the people they care for had access to timely, adequate, responsive and flexible supports and services, both would have access to the above opportunities and choices.

DDC has been advocating for a government commitment to the planning and funding required to ensure the availability of the support and services that people with disability and their families need since 1994.

Over the past 14 years, it has become increasingly apparent that it is not a matter of money, it is a matter of priority and political will.

If Australia cannot see fit to ensure that people with a disability and their carers get the support they need to lead a decent life in this time of record prosperity, when will this happen?

DDC urges this Inquiry to tackle this issue head on.

We thank the Committee for the opportunity to contribute.

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