

Carers need our support

Address at the launch of the
Taskforce on Care Costs 2007 Report
*“The hidden face of care: combining work and caring responsibilities
for the aged and people with a disability”*

Brian Babington, Chief Executive, Families Australia
Melbourne, 16 November 2007

Families Australia is delighted to have been part of this project, in keeping with its role of seeking to promote the interests of families in all their diversity.

Families Australia undertook the qualitative part of the Taskforce on Care Costs (TOCC) project and ran five focus groups in Sydney, Melbourne and Wollongong, as well as a roundtable meeting, in conjunction with Carers Australia, for CEOs of many national not-for-profit organisations which work in the ageing, disability and related fields.

The focus groups brought together people who are in or are likely to be in caring roles. People might have been caring for an ageing parent with diabetes, or a child with autism, or a young adult with an intellectual disability – so many situations were represented in the gatherings.

In a moment I'll share a few specific stories that came from this work, but before that I wanted to tell you something of the overall experience of listening to the stories of 50 or 60 people who provide primary care for either an ageing relative or a family member with a disability, or sometimes both.

What I heard most frequently was the enormous load carried by the vast majority of these carers – a truly 24/7 life – and the difficulty they had in having their needs heard and in finding good, reliable and affordable support systems.

A frequent and common theme was the importance and incredible value of having a workplace that understood their needs and could respond flexibly and consistently. People truly valued it when their employer responded helpfully, and that can only be good for broader morale.

They were often frustrated on the other hand by the segmentation of, and gaps in, government services not only within the same levels of government but between them.

Many were exhausted; all were looking for more help, especially to help them stay in the workforce while continuing to provide care.

And they all had ideas about ways to improve the situation – you'll see lots of their comments in the report.

Above all, they look for greater recognition of their role both in the workplace and the community generally; they seek greater access to flexible work practices and greater consistency in implementation by managers within organisations; and they look for better access to and quality of aged and disability services.

It is invidious to select from among the views but two that stood out to me were:

Most people want support - not to be carried – to stay in the work force. I felt I was being penalised for having a daughter with a disability. I was forced out of workforce into poverty. There is no child care for children with autism; the boss doesn't understand that. You need income, superannuation, investment for the future. The relationship break-up rate is huge.

I keep seeing women forced out of the workforce, living in poverty. Explaining to others is hard. It's limiting for the kids – they don't get into sports teams and have no birthday parties. It's hard work caring and enriching kid's lives. You have to source your own information. It's like a second job which is huge and hidden.

Thank you.