

AOC 15/7/08

SUBMISSION TO PARLIAMENTARY INQUIRY

BETTER SUPPORT FOR CARES

Introduction

I'm Richard's Dad, and this is a good news story – about love and tenacity overcoming adversity.

In summary, my submission is that family Carers do not ask for much, and prefer to manage on their own. But when they do ask for help, they really mean it. They are at the end of their tether and need help immediately. If help is not forthcoming, they lose confidence, and a spiral of hopelessness kicks in.

The two key things that concern Carers the most are:-

- How can I get through today; and
- Who will care for my disabled family member when I'm gone.

Richard

Richard is 27 (born 1980) and was brain damaged at birth. He can't talk, read, write, or count. He has no street-sense, and no sense of danger. He is mobile, but can't dress, bath, or shave himself. He is toilet trained, but can't pour himself a drink, or take his medication. He has a mental age of probably a 3 or 4 year old.

On leaving school at 18, Richard has been fortunate in getting a day activity with Intework for 5 days per week. Richard and I are both happy with the level and type of support we receive.

Dad

I have professional as well as personal experience as a family carer for a person with a severe disability.

I am a lone supporting father, and Richard has lived with me for the last 16 years (since 1992). I am divorced, his mother having left for a better life without us, and there are no other children.

I am a Vietnam Veteran with post-graduate University qualifications. I spent some 30 years working in the State Public Service in Tasmania, Victoria, and Western Australia in the field of Human Services in an R&D role. I worked in the Disability Services area for some 15 years, and have been involved with NGO's for some 30 years. I was the Policy Officer for Australia's first Minister for Disability Services Hon Eric Ripper, from 1990 to 1992 (?), and was awarded an OAM for my community service in 2006.

I am now retired, and devote my time to caring for my son, and doing some voluntary work.

Since my retirement, I am or have been involved in:-

- Chairman of Intework, an NGO providing day activities for 700 Western Australians with disabilities;
- Member of Ministerial Think-Tank on Residential Services
- Member of a Research Advisory Committee for the Institute for Child Health;
- Mentor at the WA Police Academy;
- Member of the Ministerial Carer Advisory Council in WA.

Submission

The two key things that are foremost in family carers minds:-

- How can I get through today? and
- Who will care for my disabled family member when I'm gone?

Data from the Australian Bureau of Statistics 5-yearly survey of *Disability, Ageing & Carers* shows four key things:-

- The needs of people with disabilities are overwhelmingly met by Kith and Kin (70% by Kith & Kin; 24% by Agencies; 6% No one)
That is, Kith & Kin – not agencies - are the backbone of the system.
- The needs of people with disabilities are overwhelmingly met (From 75% to 96% depending on the domain in which support is required)
That is, the unmet needs are not a bottomless pit.
- Most Carers do not need any further support or assistance outside the Kith & Kin network
(48% no support needed; 29% support fully met; 23% unmet needs)
- Similarly with respite – most are happy to keep it in the family
(83% respite not needed; 35% respite needs fully met; 14% unmet respite needs)
That is, most don't need more respite or support

(NOTE:- My data is from an earlier survey, as I do not have ready access to the results of the latest survey. However, I doubt that there would be any major variation which would significantly affect the basic thrust of my argument.)

What does this mean?

It means that this is not an area where everyone wants to get their chop. Nor is it a bottomless pit. The overwhelming majority are doing it as best they can on their own within their own resources, and are happy to continue doing so for as long as they are able. I am one of the fortunate ones in this category at this time.

But it is devastating for those who have reached the end of their tether, and who can no longer do it on their own. It is tragic when their plea for help is rejected, and it is a betrayal of their commitment and dedication when there is not enough to go around.

By the time they ask for help, they have given it their all – they are running on “empty”. They need help and they need it immediately. They have borne the heartbreak and the physical, emotional and financial burden. They deserve our unstinting support. Immediately. I will expect no less when my time comes.

Charlie

10 July 2008