

DOC 1717108

From: Sue
Sent: Wednesday, 2 July 2008 7:05 PM
To: Committee, FCHY (REPS)
Subject: what carers need

Submission No. 885
(Inq into better support for carers)

2nd July, 2008

Committee Secretary

Inquiry into Better Support for Carers

House of Representatives Standing Committee on Family,

Community, Housing and Youth

PO Box 6021

Parliament House

CANBERRA ACT 2600

I am a social worker, and have worked for many years with families who care for children with physical disabilities and High medical needs. As a SPECIALIST in this area, and witnessing the stress of families over the years, in both the financial constraints and the physical constraints in caring for thier children, I have been hoping to conduct some research into the additional costs of raising children with disabilities. I know that here have been attempts to look at this in the past, and put in the too hard basket.

However, the way that I think shoudl be expored is in the different FUNCTIONIONAL impairment. At present, a child who has cerebral palsy may be able to walk with frames and perhaps independently use a manual wheelchair, who will get the same financial assistance as the one who must use a power wheelchair and be fed, and use a communication device, and get the same assistance as childr with an intellectual disability who can be easlily amused, and has prospects, even of working later in life independently.

If you are going to interview people who might have a broad idea, and a log history of working with disabled children, There are we 5 who work within who have about 90 years between us of this specialised work. We work with children who have physical disabilities, children who have high medical needs, and provide a palliative care for children who are seriously ill. I can support a couple of parents to talk to you about thier life, thier injuries from looking after thier children, and their particular difficulties.

I have also looked at the British model of supporting families, which is referred to in the following (scroll down) request for funding to conduct research, in conjunction with Dr Paul Henman, who is a Uni of Queensland in the Social Work Department. He had previously been involved with attempts to find a scaling for different disabilities. however, it is my belief that this cannot be done, and that he focus must be on the functional impairment, and the notion that once a child is prescribed a power wheelchair that following from that is a need for home modifications and a suitably modified vehicle, so that the family can function as a family, and not be marginalised due to their child having a physical disability.

3/07/2008

And it distresses me to see parents and carers incurring life long injuries in their caring role, and children unable to access normal family activities: they might have their power wheelchair, but if their family cannot get them out into the community, it is all for nothing. There are 28 children here on the Central Coast who must be transported in their wheelchairs, only 3 are adequately transported in their family van. the rest, 25, would need an annual subsidy of \$16,000 (\$400,000.00) to be adequately and on a par, be able to travel, with their family, on outings.

Yours Sincerely
Sue |