

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

25 June 2008

Dear Secretary

I wish to make a submission to the House of Representatives Standing Committee on Family, Community, Housing and Youth's Inquiry into Better Support for Carers.

As Carers, I feel that the role played by my wife and I is not valued at all by the community at large, and is valued very little by the Government. I believe that this is a reflection of a society that really cares for little beyond its own needs and wants, and is prepared only to make token gestures when other peoples' needs are made high profile through some media story.

We are Carers for our own natural daughter, now aged almost 17. She has total disability in that she cannot communicate, she cannot feed herself and has all her food intake through a gastric peg, she is incontinent, and she cannot walk. In addition, she suffers seizures and requires regular medication to combat these. Because she is our daughter, and not fostered or adopted, we are at a disadvantage when it comes to resources being made available to us to help with her care. For example, many other families at her school are given vehicles with hoists to assist in transporting their foster children, but we do not qualify for this type of assistance.

We have very limited opportunities for a social life due to the lack of adequate resources available for child-minding, and even visiting friends with our daughter in tow is a major logistical exercise. Indeed, in summer our daughter is effectively house-bound as the 20 year-old vehicle we have to transport her has no air conditioning and tends to overheat on journeys of more than 10 kilometres.

While we are extremely disappointed with the lack of commitment from the Government to meeting the real needs of people with disabilities, we are grateful for the services provided by not-for-profit agencies, which help make our circumstances tolerable. However, the service levels available are fairly limited due to lack of funding and, as our daughter attains adulthood, the services become almost non-existent. This is a grave concern to us and we foresee our lives changing dramatically for the worse. Currently, our daughter is out-of-home for between 40-45 hours a week during school terms (including school bus travel time). Once she reaches 18 and leaves school, we are led to believe that sufficient funding will only be available for us to "purchase" about 15 hours activity time per week, and we will be required to arrange and pay for the travel out of our own pockets.

As a family, we are not in poverty by any means, but having a child with a disability is still a huge struggle, emotionally, physically and financially. We need assistance in having more external care available, assistance with transport needs and, generally, an acceptance of the role we play – it is not a job because we love our daughter unconditionally!

I think the Government can better help Carers by providing more funding for the disability sector to create more respite places, particularly for the post-school age group. The Government can also assist in other ways, for example by using its considerable purchasing power to provide discounted pricing in areas that are big drains on Carers' finances. This would make the purchase of special transport more affordable for families like us who may still not qualify for "free" vehicles. Further, instead of Carers having to seek assistance from agencies to buy incontinence items, or having to pay full price, the Government could make these available at greatly discounted rates, simply by using its purchasing power with manufacturers. This would not necessarily cost the Government any "real" money as it would recover costs from users.

By making a greater commitment to understanding Carers' needs and in providing much increased levels of funding, the Government will prove that it cares for its people. It will reflect that we have actually progressed as a society if we can provide adequate funding for those who cannot fend for themselves.

Thank you for taking my views into consideration as part of the Committee's Inquiry. I look forward to reviewing any recommendations you make to improve life for Carers, and their charges, in Australia.

Yours sincerely

Perry