

1 July 2008

AOC 29/7/08

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

Dear Secretary

Thank you for this opportunity to make a submission to the House of Representatives Standing Committee on Family, Community, Housing and Youth's Inquiry into better support for Carers.

I care for my 6 year old daughter who has both a congenital muscular disorder of unknown aetiology and mild autism. I initially had planned to return to work as a financial management consultant when my daughter turned 9 months of age, unfortunately her condition has prevented this to date.

I feel my role is to provide Ella with access to the best services available to allow her to have opportunities in life commensurate with her 'normal' peers and maximise her chances of being a successful contributing member of society in her adult years.

I see the two main problems facing our family as the:

1. financial burden on our family in accessing those services
2. availability of allied health services in Canberra.

Ella's disability has caused our family considerable financial hardship. Although we have received the Carer's Allowance since May 2006, there is considerable shortfall between the allowance and the gap payment we make for Ella's therapy and medical services and the Medicare and Private Health Insurance rebates. We estimate that in the financial year ending 30 June 2007, the medial costs for our family were as follows:

Medicare Levy	\$ 2,096.89
Medibank Private premium	\$ 2,213.10
Out of pocket Medicare expenses	\$ 1,078.81
Out of pocket MBP expenses	\$ 3,178.05
Prescription expenses	\$ 1,636.93
Non claimable reports	\$ 610.00
Total	\$ 10,813.78

This cost is after accessing all safety net, mental health and enhanced primary care initiatives available to Ella.

We were fortunate to live in Washington DC from the time Ella was 6 months old until she reached 4 years of age. The difference in services available there are in stark contrast to those offered in Canberra. When she was 13 months old, she underwent a comprehensive assessment by a specialist team of speech, occupational and physical therapists. As a result of this assessment, she underwent occupational and physical therapy sessions 4 times a week, delivered in our house, at a total cost to us of \$8.00 a session, the remainder being provided by the District of Columbia government.

This program continued until she was 3 years of age, at which point we employed the same therapists privately, with 80% of the cost refundable under our CIGNA health insurance scheme.

In contrast Ella is currently receives 1 private occupational therapy session every fortnight due to a shortage of therapists in the ACT. Ella will have her first Therapy ACT provided occupational therapy session for 2008 in July. Her previous occupational therapist from Therapy ACT saw Ella 3 only times in 2007, I was told the therapist had a case load of 96 patients and only worked 3 days a week.

We receive a rebate of \$31.5 from Medibank Private for each private occupational therapy session (costing \$80), to a maximum rebate value of \$400 per annum.

Given the level of financial support the government provides to the private health insurance industry, the government should be in a position to demand that those patients with chronic health needs are able to access a greater level of rebate from private health insurers. This level should at the very least be equal to the rebates available through Medicare under the enhanced primary care and mental health initiatives.

The new autism intervention is a welcome development, but more could be done by government in the form of rebates for essential allied health services for those children over the age of 6. Twenty services over 6 years is a mere fraction of those required to ensure my daughter becomes a functioning member of society.

Since our daughter was born with her disability, we have devoted a considerable amount of time, money and foregone salary as part of efforts to give her the best start in life possible, and the best chance of being a normal contributing member of society. Inevitably when a family is affected by a disability there will be a substantial cost to the family, but the question with the move to home based care over the last thirty years is whether Australian society has the balance correct between the burden assumed by the family unit and that born by society as a whole. While I would never swap home based care for institutionalization of our daughter, never the less, there is scope for society to do more in terms of supporting those families that bear the burden of integrating their children with disabilities into our community.

Thank you for the opportunity to make this submission and for taking my views into consideration.

Yours sincerely

Nicola