

Submission No. 453

(Inq into better support for carers)

A.O.C. 2/7/08

Sent: Thursday, 26 June 2008 3:42 PM
To: Committee, FCHY (REPS)
Subject: FW: Inquiry into better care for our carers

From: Paul
Sent: Thursday, 26 June 2008 2:40 PM
To: Committee, Reps (REPS)
Subject: Inquiry into better care for our carers

25 June 2008

Clerk Assistant (Committees)
Inquiry into better care for our carers
House of Representatives Standing Committee on Family, Community, Housing and Youth
Parliament House
Canberra ACT 2600

Inquiry into better care for our carers

We are the parents of a 22 year old man with multiple disabilities (cerebral palsy, cortical blindness, severe developmental delay, epilepsy, etc). Adrian needs full time support to dress, feed, shower, entertain, etc. Basically he is unable to initiate or perform any tasks for himself. Adrian currently lives at home with us. The state and federal funded services we currently receive are as follows:

1. FFS and IFS funding of about \$22,000 for in-home respite. After paying insurance this is buys us about 1100 hours of support.
2. Adrian is on the maximum rate of Post Schools Options funding. This enables him to attend the Rocky Bay Getabout program on three days a week for about 5.5 hours per day.
3. Two nights a week Adrian is in out-of-home respite.
4. In addition we get assistance to shower Adrian on two nights a week and he attends a Saturday entertainment program once or twice a month for 3-4 hours each time.

Despite this level of support we are still required to spend approximately 40 hours per week caring for our son. This involves personal care, getting Adrian up in the morning and putting him to bed at night, taking him to respite, entertaining (eg swimming, tricycle rides, wheelchair rides), etc. This is

27/06/2008

in addition to arranging doctor's appointments, standing in when caregivers are not available, managing caregivers, laundry, etc.

We are both aged 56 and would like to be doing what others of our generation are doing i.e. visiting grandchildren, going on holiday when and for as long as we want and generally being free to act on impulses. However, as you can imagine Adrian has had a significant impact on our lives, our lifestyle and our future. Some of these impacts include:

1. At the point of writing this Adrian had a bowel motion in his pants. We were both trying to work at the time. It took us at least 20 minutes each to clean up. Another load of washing. More mess on the carpet.
2. We are both unable to take up full time employment as it is too stressful for the parent at home to manage Adrian full time. This means that, compared to a normal family, we find it difficult to maintain a steady income, to generate an income similar to that we would potentially earned if unencumbered, to find jobs that are intellectually challenging and rewarding, and to find jobs with normal benefits such as superannuation payments and long service leave.
3. We are always "on duty". It doesn't matter what we are doing we always have Adrian's interests and demands to consider and we cannot fully relax when he is around. If trying to do something for ourselves (whether working or relaxing) we are affected by his noise in the background, have to respond to his calls and needs, and feel guilty that we are not doing something with him, even though we might have spent the previous 4 hours entertaining him.
4. We cannot be spontaneous. We cannot make quick decisions about activities. If we want to go out we always have to ensure that Adrian is taken care of, wait till the caregiver arrives, and be home at the agreed time.
5. It is difficult for us to do things together - especially holidays. These have to be planned months in advance as respite facilities are quickly booked out. Once booked there is no option to change dates for any reason.
6. We cannot plan our future. For several years we have unsuccessfully sought Accommodation Support Funding. Under current arrangements it would seem we have minimal chance of getting any assistance for a considerable period. We are unable to establish when or if we will ever get funding.

Practical steps that could be taken to reduce the stress on our lives, and to improve Adrian's quality of life, include:

1. Being given a clear indication of when Adrian could expect to receive accommodation support that would enable him to live independently. Even if we don't agree with the advice we receive at least we can then plan the rest of our lives according to it.
2. Provide financial support for us after retirement. As noted our earning potential, and ability to contribute towards our superannuation, has been significantly reduced as a result of our inability to take up full time employment at a level commensurate with our skills, qualifications and experience. Recognition of this by providing additional financial support in retirement would be appreciated.
3. Provision of additional out-of-home respite facilities, especially for holidays. This would enable us to have holidays together, something we can rarely do, and / or be more spontaneous when holiday options come up.

We trust that the inquiry will take these concerns into account and will recommend changes that will enable our family, as well as the many thousands of families in similar circumstances, to lead more normal and fulfilling lives.

Paul and Erica

27/06/2008