

Senate Community Affairs Reference Committee

community.affairs.sen@aph.gov.au

Dear Sir,

RE: **ENQUIRY INTO PLANNING OPTIONS AND SERVICES FOR PEOPLE AGEING WITH A DISABILITY**

I am writing to you as the parent of a child with Down Syndrome. I am 70 years of age and my wife is 64 years. Both of us continue to work part time because of the financial constraints.

Our son [REDACTED] is 29 years of age has Down Syndrome and Type 1 Diabetes which requires him to receive blood sugar tests 4 to 5 times a day and insulin injections 2 times a day. In addition it is necessary to monitor his food intake and level of activity.

For some 6 years now our son [REDACTED] has lived with 2 "housemates" in a small semi-detached house we purchased in [REDACTED]. The arrangements with the housemates are that they live in the house rent free on the basis that they provide services that are required for [REDACTED] in so far as his day to day living and monitoring his diabetes.

[REDACTED] attends an activity centre at [REDACTED] during week days and has been pursuing this routine for approximately 2 years. Prior to that a number of attempts were made to have [REDACTED] trained for an employment position, but on each occasion this was not successful due to a variety of factors including [REDACTED]'s difficulty in maintaining attention for the task at hand.

On Friday evening [REDACTED] is picked up by myself or my wife and spends the weekend with us and is taken back to the house on Sunday evening. This arrangement is necessary because of the extent of the care provided by the housemates and the financial arrangements with them only cover the period from Sunday evening through to Friday evening. Therefore it has been necessary for myself and my wife to care for [REDACTED] during the weekends and we continue to do so.

The cost of maintaining the house where [REDACTED] lives is considerable. [REDACTED] receives a pension and is able to contribute something to rent, however, there is no other income as the house mates do not pay rent in exchange for them caring for [REDACTED]. In addition

we have to maintain the property and cover the cost of all outgoings including replacement of equipment, furniture etc.

Last year I was treated for cancer with considerable chemotherapy. This placed a great strain on my wife. I am now in remission. Recently, [REDACTED] complained of a swelling on his scrotum. This had to be investigated with an ultra sound and consultation with an urologist. Medical attention is an ongoing issue for [REDACTED] and requires a considerable amount of time and energy to manage his care needs. Most of these arrangements are attended to by [REDACTED]'s mother, however, at this moment my wife has been obliged to visit our daughter in the UK for a month. In addition to managing the needs of [REDACTED], I continue to work part time.

The accommodation arrangements for [REDACTED] are beneficial for him and his need to have some independence. However, should I cease work or die, then the accommodation arrangements will need to be terminated as it would not be possible to maintain the cost of these arrangements. We are concerned therefore as to what might be available for [REDACTED]'s living arrangements particularly to satisfy his need for some independence and also particularly for him to be able to maintain contact with his peers and involvement in the activities which he has been pursuing for some time.

My wife and I would be prepared to sell the house at [REDACTED] where [REDACTED] lives and apply the proceeds to some accommodation that [REDACTED] might be guaranteed that would be satisfying for him and secure him for the rest of his life. Apart from accommodation needs there is clearly a considerable need for care for [REDACTED] that would need to continue.

In the course of your deliberations as to planning options I ask that you consider what type of accommodation and care arrangements might be made for our son in the future.

Yours faithfully