

Submission No. 1026

(Inq into better support for carers)

AOC 28/7/08

Sent: Tuesday, 1 July 2008 10:16 PM
To: Committee, FCHY (REPS)
Subject: Carers

My name is Merren
has a moderate intellectual disability works at a sheltered workshop. She has been on the "list" for accommodation since she was about 5 and I thought she would benefit from moving into supported accommodation when she turned 26. She is now 26 and I know that she would only be eligible for accommodation if there was a crisis, such as death of one or both parents or severe incapacity! Hopefully this is a fair way off for my husband and I although we are 63 and 60. When she was a baby, we made the choice to care for her at home and not put her into an institution, because we wanted to give her every opportunity, but now we find that other families who made the choice to institutionalize their babies have permanent accommodation, but those parents who have struggled to keep our children at home have also been penalised by being forced to keep them at home for ever!

My daughter who

I have a professional career but was only able to work one day per week while my daughter was at school and paid out more in childcare expenses than I ever earned. I continued to try to work because I dreamed of forwarding my career at some stage in the future. Now that she has left school, I have increased to 2 days per week but it is still a struggle and I have to have many days off to look after my daughter. I will never be able to fully work to my capacity or fulfil my career goals.

My husband and I have a very limited social life because any activity requires planning for care for our daughter. Of course this is expected for all children but not when they become adults! We use a DADHC respite cottage but it is very difficult to use it for a holiday because there is no care on weekdays and there is no transport to the sheltered workshop (although 5 years ago there was transport and we were able to access the cottage for holidays). We are only offered 2 or 3 days per month.

There is no way I can plan for the future because I see myself caring for our daughter for the rest of my life!