

PRIVATE MEMBERS' BUSINESS (Disability Support and Care) – 17th March 2008

Mrs VALE (Hughes) (8:25 PM) —I welcome the opportunity to speak on this issue and I am grateful to the member for Gilmore for raising this important matter before the House today. I am very pleased to note the warm response to and bipartisan support for this important motion. So urgent is the need in my electorate for supported accommodation that a group of parents concerned about the lack of services available in the Sutherland Shire formed a group called the Sutherland Shire Disability Accommodation Action Group back in 2005. One of the issues most raised on the occasion that the group was formed was the lack of supported accommodation for their adult children with intellectual disabilities. Sadly, we are now into the third month of 2008 and the issue still exists unresolved and untouched in the electorate of Hughes—and, I assume, in many other electorates across the nation.

In December 2006, this group became an incorporated association, with Mrs Judy Foord appointed as president and Mrs Kate Tye as secretary. Both these women are mothers of children with intellectual disabilities. The association has three main objectives: to obtain supported accommodation for family members located in their own area, to obtain accommodation that offers tiered layers of continuous care and to create a register of need. Alarming, the Sutherland Shire Disability Accommodation Action Group found that there was no planning for future accommodation needs. The group then facilitated a public meeting on 6 February 2007, which was attended by 95 parents and carers. The objectives of the group were published and a register of need was commenced, with 71 registrations received that day. Another 47 names have been added since, and there are more added on a weekly basis.

Perhaps the most important way of explaining the situation of people who have a serious disability within their family is to tell a personal story. I would like to recount one from a lady known as A.M. She writes:

Whenever I read about another mother killing her disabled child, I wonder whether it will come to that for me, and would I be able to do it? People do become desperate and overwhelmed. My disabled daughter 'S' has become my world and I, hers. And therein lies the problem.

She was born in 1978—induced for the doctor's convenience as he was going on holidays. She turned blue and stopped breathing. She had streptococcal pneumonia and was found to be 4-6 weeks premature. She spent a month in special care.

From about six months of age I knew there was something wrong. Then followed years of doctors and therapies until I finally had to admit you can't mend a broken brain.

Eventually, she attended a special school. Transport was provided but I needed to be there before and after school so full-time work was out of the question. One problem with going to school out of the local area was that she had no friends to play with and so all her time was spent with me.

Eventually I found a job with a small company run by a couple with children of their own. They were very flexible with hours and emergencies and phone calls. I brought 'S' to work with me on schools holidays.

In 1996 my marriage, like so many others involving disabled children, had come to the point where I took 'S' and left. I had calculated all eventualities before taking such a big step—or so I thought ... I was working for the small company and 'S' was travelling by train to her day-program and managing alone with a few phone calls, until I got home.

Six weeks later the small company collapsed. I quickly found a job with a big company—no flexibility, longer hours and NO phone calls. 'S' went on a 4-night ... camp for a break. When she returned, something was terribly wrong. She didn't sleep, muttered all night to someone, cried all day, got lost following 'voices' and didn't remember to eat or drink. Eventually she was diagnosed with schizophrenia brought on by her absolute terror in being apart from me. Even with hospitalisation and treatment the situation was horrendous. She was drugged, terrified, and either constantly crying or staring at the wall for hours. In the 30 minutes it took me to get to work each day there would be 10-12 phone messages awaiting for me with her just crying. She could not travel alone or stay at home alone. Finally, the company gave up; I was fired, and thus became her carer.

People sometimes think that carer equals no full time job, equals what a life. Well, imagine all you'd for very young children—dressing them, washing them, cleaning them after 'accidents' and then imagine doing it for a 28 year old woman, who won't learn to do more than she does now. Imagine never being able to go anywhere alone—not even to see a friend for a chat or a cup of coffee without your 'child' with you. Imagine listening to her cry all night because you have a cough and she fears you might die and leave her. Imagine lying awake every night worrying about what WILL happen to her. We do have respite, but only one day a month. And now, four years ago, I was diagnosed as having Parkinson's disease. My caring time is infinite. It will be the most difficult task to settle 'S' into a group home or similar accommodation. It must be done while I am here and able to help her cope.

I commend this important motion to the House.