

June 27<sup>th</sup> 2008

Committee Secretary

Standing Committee on Family, Community, Housing & Youth

P.O. Box 6021

House of Representatives

Parliament House Canberra ACT 6000

Dear Secretary,

I am the mother of a daughter with cerebral palsy resulting in severe & multiple disabilities. She is totally dependent on my husband & I for every aspect of her life. We do receive a few hours break Mon - Fri whilst Karyn attends a Day Activity Programme. These few hours are very precious to us to attend to our own healthcare appointments, other family demands & to be involved in some community activity.

We can't be fully involved in these due to time constraints when Karyn is due home again & it is now a 2-person lift for many moves within the home. At times we have felt we were judged because we were not committed to giving more time & help. Unless someone has been involved personally with 24hr care they do not appreciate the demands on our time for feeding Karyn, personal care & medical care. Even some of our closer friends & family don't fully understand.

Over the years this has proved to be socially isolating where we have been excluded, possibly due to peoples' perceived difficulty to cope with a wheelchair in their homes or over a meal when we have to feed Karyn. Although we have had occasional in-home help we

constantly have problems finding competent, caring help who will continue with us for a period. Constant change is extremely unsettling for Karyn who likes an unchanging routine.

From our experience the whole area of support workers is under-valued & therefore underpaid, which in turn doesn't attract workers to stay in the field, especially those who are the most suitable. So often this has ended with us physically carrying the load without any relief. We are now aged  $77\frac{1}{2}$  +  $68\frac{1}{2}$  yrs & finding it increasingly more difficult.

Our biggest concern is what happens to our daughter when we can no longer cope. It has been our desire to care for her at home as long as possible but should something happen to either of us the other could not cope alone. We know the huge demand for supported accommodation makes it impossible to plan effectively ahead. This causes us a lot of stress. We would really love to be able to plan for the future with a preferred service provider & in a home within a reasonable range to us, enabling us in future years to be able to visit nearby & not across the other side of the city.

We have been linked with the Spastic Centres of S.A. for 30 yrs & we feel that they are the ones who know us & other families to suitably match young people to live together. We have had so few choices along Karyn's life journey & we'd really appreciate that this huge step in all of our lives would be one of choice.

Thank you for considering my views as part of your inquiry. I look forward to reviewing any recommendations you make to improve life for Carers in Aust.

Yours Sincerely