Submission No. 775
(Inq into better support for carers)
Acc 15/7/08

Jann

27th June 2008

Committee Secretary
Standing Committee on Family, Community, Housing and Youth
PO Box 6021
House of Representatives
Parliament House
CANBERRA ACT 2600

Dear Secretary,
I wish to make a submission to the House of Representatives Standing Committee on Family, Community, Housing and Youth's Inquiry into Better Support for Carers.

As you are seeking to better understand the situation for carers, I am writing to describe my former caring role for my son with a disability, and how beneficial **supported accommodation** has been for myself and for him.

For the benefit of the reader, this document is in 2 parts:
PART 1 - My Former Caring Role, and PART 2 - My Current Caring Role.

As requested, the following **summarises** my submission.

What would have helped me in my caring role?

- an assurance that supported accommodation would be available by a certain age
- superannuation in recognition of the value of my unpaid caring role
- before and after school care for a teenager with disabilities
- certainty of respite allocation and greater provision of planned respite

To summarise the beneficial Carer outcomes of supported accommodation:

- carer well-being improved
- carer health improved
- carer socially connected to friends and family
- personal relationship possible
- carer participation in extended family
- paid employment bringing financial stability, satisfaction, social interaction, superannuation
- tax paying productive employee adding value to workplace
- government dollars not spent on respite services or social security benefits (recognising supported accommodation has its own cost)

Background:

- my son who is now 23 years old, has very high support needs.
- I was his primary Carer for 18 years and in our family situation that responsibility was almost entirely carried out by myself, his mother.
- my husband and I separated when our son was 12 (later divorced) resulting in me single-handedly rearing our two teenage daughters and our son with a disability. My former husband resides overseas.

<u>PART 1</u> - My Former Caring Role: While my caring role for my son gave me a sense of fulfilment and was with love, it was a role I did not choose. It dominated my life and determined a bleak outlook in the areas of social interaction, family engagement, financial stability, and employment opportunity.

Personal well-being:

I once calculated that the face-to-face time spent with my son - excluding school and respite hours - totalled 60 hours in a typical week. I was time poor, as I was nearly always on duty supervising his whereabouts and safety, and attending to his needs.

Care included:

- every aspect of personal care including continence care
- mealtime assistance & supervision (he is at risk of choking)
- mobility support - he has a falls risk and sustained several bone fractures
- safety - ensuring locked doors and yard gates as he has no sense of traffic danger
- supervision - keeping him out of the fridge, pantry, toilet, etc. and away from programmable devices such as the TV remote & cordless phone.
- co-ordinating & attending medical & dental appointments
- co-ordinating respite care
- working closely with school teachers
- transport
- all domestic tasks of shopping, laundry (daily), cooking, cleaning
- advocacy - I challenged the Department of Family & Community Services at the Administrative Appeals Tribunal re. their decision not to allow Carer Payment (Child) for the care of my son. These days the department recognises the supervisory care required for some young people with complex care needs.
  Over a period of 5 years I sought opportunities and advocated for funding for my son to move into a group home.

I believed my job of caring to be of a high standard and with value, so my feelings about myself were for the most part favourable. I sometimes felt trapped in my situation and quite exhausted, and according to my GP had symptoms of stress. However, as a sole carer there was no option but to continue.

Social interaction:

I relied heavily on respite services for a break and a "taste" of the relatively carefree life that others enjoyed. There could be no spontaneity - social engagements had to be planned well in advance and "fit" respite availability. For some years I used my respite hours to visit and entertain my mother with dementia in a nursing home.

Consequently, my caring role did not allow even for contemplation of a new personal relationship.

Family engagement:

My son is one of three children. Throughout their lives his siblings were relegated to waiting for parental attention, or missing out, as their brother's care needs necessarily took precedence.
While my ageing parents were alive, I needed to juggle my caring responsibility for my son while finding time to visit my parents, and support them as they became unwell and frail.

Financial stability:

I was able to manage financially with Centrelink benefits because I was fortunately not paying rent or a mortgage. There was little left over for discretionary spending.
As I had not been in paid employment for over two decades, I worried that if my son were to receive supported accommodation funding sometime in the future, I would not be able to earn a sufficient income to support myself. Additionally when I reached retirement age I would not have superannuation to supplement an age pension.

Employment opportunity:

My son's very high support needs essentially prevented me from participating in the paid workforce. I would have liked to work part-time but the issues of no before/after school care services for a teenager with significant disabilities prevented any likelihood of that.
Work outside the home had the potential to provide income, a sense of achievement, social interaction, superannuation, and a break from the caring role, but it was not possible. I felt a sense of loss that my training as a biologist and my Science degree were not being utilised.

PART 2 - My Current Caring Role:

What changed?

Four years ago I was notified that my son had "top priority" if I still wished for him to move out of the family home at the age of 18 ½. I accepted the rare offer and my son transitioned to a group home with 4 other young men all with very high support needs.

I now see myself as a 'secondary' carer as I:

- have frequent contact with the group home management and staff assisting with issue resolution and decision making, and brainstorm strategies to make his life a good one.
- have frequent contact with his day program providers involving planning, care and decision-making
- provide emotional support
- oversee his finances
- oversee and usually attend medical and health appointments,
- purchase and repair clothing

On average I take him out twice a week for several hours each time, and arrange for a paid worker to provide some recreation away from the group home.

Along with these dramatic changes in my caring role, came changes to my personal well-being, my social interaction, my family engagement, and the opportunity for paid work (before it was too late!).

I no longer experienced symptoms of stress and exhaustion - I could "breathe easy" without the constant vigilant supervision, and get adequate sleep. Without the constraints of my previous socially isolating caring role, I met a man and now several years later we have married.
My daughter has given birth to baby boy, and I can fulfil the grandmotherly role of visits and occasional help - something that would not have been possible when I was my son's primary carer.

The offer of supported accommodation came when I was 55 years old. I needed to find employment that would provide an income to support me for 10 years. After 4 months of volunteering in an aged care facility I was offered and accepted work at $13/hour. A year later I was successful in applying for a position with the local Area Health Service in a job that utilised my tertiary education and paid twice as much per hour!

Soon after my son's transition from the family home to his group home, I consulted a counsellor skilled in carer issues....she explained that in the past I was mostly "doing" for my son, and just a little "being" his mother. Now that he lived in the group home independently from me and I was not providing the primary care and all that entailed, I was now mostly "being" his mother with just a little "doing". That put my sense of loss and guilt in some perspective!

As for my son, he has developed into a young man who has independence from his mother, who has increased his living skills, and who has a broader engagement with a range of people. Like many of his typical peers, he too does not live in the family home with "the oldies".

Thank you for reading my submission - it is intended to highlight the benefits of sharing the care. I look forward to reviewing any recommendations you make to improve life for carers.

Yours sincerely, Jann