

Inquiry into better support for carers

On behalf of a local group of my constituents, 'Parents of Kids with Additional Needs', I wish to make a submission to the Standing Committee on Family, Community, Housing and Youth's inquiry into *better support for carers*.

At a meeting I attended with the group on 13 December 2007, a number of needs and concerns were expressed by these parents. Representations were immediately made to the Minister for Families Housing Community Services and Indigenous Affairs, to which a response has not yet been received.

At the meeting there were at least 20 parents, two of whom had twins with autism.

The group consists of parents with children aged from 0 -36 with a range of disabilities, some with autism, with the added complication of epilepsy or diabetes, Rhett's disease and spinal muscular atrophy, all requiring individually tailored, high level care, *constantly*.

These parents are full time carers of their children. They are **exhausted - emotionally, physically and financially**. They urgently require respite.

In Hamilton, the only existing respite facility consists of two adjoining houses. Each house can accommodate up to 4 people (one house is for adults and the other is for children) at a time, depending on the level of care required and carers available.

There is currently a waiting list for weekend respite.

In addition, Mulleraterong, the local adult disability services and support organisation, has approximately 50 (18 years and over) adult day time enrolments, and the Hamilton Special School (0 – 18years) has approximately 20 enrolments.

From this equation, there are at least 70 families or parents (many are single parents) in carer roles. Respite for these parents falls severely short of requirements in this region. Several of the parents live up to 50km from Hamilton and have conveyed the difficulties that isolation causes. The mobility allowance of \$68 per fortnight may cover one or two trips to Hamilton in petrol. There are no bus services for people who require these high levels of supervision in the region.

I have met with parents who admit to contemplating suicide, when faced with the challenge of trying to keep their families and marriages together, protect siblings from neglect and run a normal life.

These parents are at breaking point and they need respite urgently. They need a break, a rest, time off to focus on their other children and time to themselves, to have a life of their own.

One weekend per month does not cover the level of respite they need. For example, I met with one mother of an 18 year old male (Leigh) with autism who is still not toilet trained. She is physically exhausted from being woken every night to attend to her son's nappy change and if she does not attend he will possibly smear the contents of his nappy all over the walls of his bedroom.

.../cont'd

The Victorian Government claims that 'disability respite resources in 2007-2008 in Southern Grampians Shire (Wannon electorate) has the second largest component of resources for disability respite per population base for the Barwon-South Western region'.

This only leaves one thinking, what are services like in other regions?

For the purposes of this inquiry, respite services in this region fall dreadfully short of that which is required for the 'Parents of Kids with Additional Needs'. In addition, the group is aware of families with high needs kids moving to the Shire of Southern Grampians to access already limited services provided in this region.

Attached are the names and addresses of all the members of 'Parents of Kids with Additional Needs', who have registered their concerns as full time carers, to verify the claims in this submission.

In conclusion, I say again, more respite is urgently needed as many of these families are at crisis point.

A handwritten signature in cursive script, appearing to read 'David Hawker', is positioned above the printed name.

**THE HON DAVID HAWKER MP
FEDERAL MEMBER FOR WANNON**

3rd July 2008