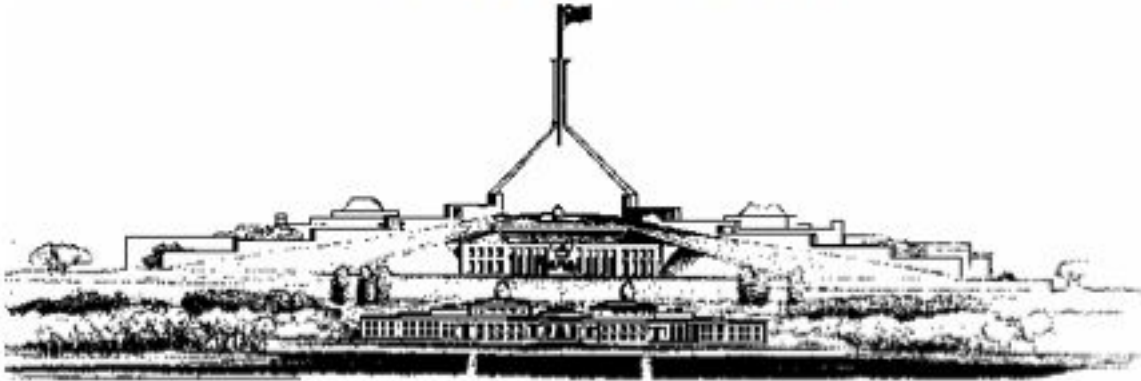




COMMONWEALTH OF AUSTRALIA

PARLIAMENTARY DEBATES



**THE SENATE**  
**ADJOURNMENT**

**Respite**

**SPEECH**

**Thursday, 9 August 2007**

BY AUTHORITY OF THE SENATE

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## SPEECH

**Date** Thursday, 9 August 2007  
**Page** 140  
**Questioner**  
**Source** Senate  
**Type** Speech

**Database** Senate Hansard  
**Proof** No  
**Responder**  
**Speaker** Boyce, Sen Sue (LP, Queensland, Government)  
**In Main Committee** No

**Senator BOYCE** (Queensland) (7.03 pm)—Tonight I want to talk about the topic of respite, in the sense that the term is currently used to describe the support given to families who care for a person with a disability. According to the Oxford dictionary, ‘respite’ means ‘a short period of rest or relief from something difficult’. There is no doubt that full-time, unremitting care for a person with a disability can be something difficult. Many families undertake extraordinary workloads, with very little support. A recent report from Carers Australia showed that on average the carers of people with mental illness spent an average of 104 hours a week in the care and monitoring of that person. One mother commented:

It’s so undignified asking for help. I virtually had to slash my wrists and drop blood all over their desks before the administration would give me respite.

And, chillingly, there are parents who, in desperation, have done worse.

I am proud that our government has recognised the needs of these families, with funding of \$1.8 billion for respite and accommodation services. But now that the public call for tenders for provision of these respite services under this funding has been made, I would like to urge all those in the disability sector to rethink respite. In fact, I think it is time we found a whole new term for it. The term ‘respite’ describes a one-way street—a break from—not a mutual opportunity for productive and enjoyable time apart for all the parties involved.

Every member of any functional family group needs respite from the other members of that group. No matter how dearly we care for those we live with, almost none of us could cope with 24 hours a day, seven days a week together. For some families, respite means dad’s Saturday golf, and it is not just respite for dad. And then there is work, school and many different sporting and recreation activities that constitute a normal life. But in most families these opportunities for respite are wound into the fabric of everyday life. They are chosen freely by the participants because the individual enjoys them and finds them productive.

So it is not in fact the respite itself that any of us need. What we all need are opportunities for product-

ive and enjoyable stimulation, relaxation, rest or recovery. It is only within the disability and aged sector that respite is generally seen as the answer to that need. There is a danger, when we characterise respite for families that include a person with a disability as a break away from the person with a disability, that we ignore or discount the needs of that person with a disability. There is a danger, when we view the person with a disability only as a burden, that the person with a disability is placed into a program, any program.

Research shows that very few families—and even fewer people with a disability—are happy with the respite service opportunities that are currently available. In my view, this is because the respite opportunities are generally inflexible and completely at odds with that idea of respite as part of a normal life or of normal routines. At present, most respite services offered are in day centres or overnight care for varying periods, and sometimes, occasionally, in-home assistance is available. In many cases, these services are just a temporary fix. They do nothing to improve the overall lives or quality of life of families or the individuals within them. Families may get a break from the physical care of the person with a disability, but that is all. Their concern, even guilt, about leaving their loved one in an unfamiliar environment where their needs and wishes are often poorly understood certainly does not provide mental rest and recovery for the family. On the flip side, many people with a disability view respite as punitive. A week or so in a strange and stressful environment often means the person returns home more stressed than when they left, and the circle and the need for respite within the family starts all over again.

I would like to turn around the way we view respite for people with a disability and their families. Respite must be normalised. By that I mean that, instead of formalising respite by taking the person with a disability out of the family and into a structured, inflexible program or service, we need to look at how other families achieve respite from each other—the Saturday afternoon golf and so forth that I was talking about before. We need to bring respite into the family, to weave respite into normal everyday life for families that include a person with a disability—just like other families do. Most families do not see the natural breaks that they have from each other as respite because they have functioning and supported

lives. For families caring for a person with a disability there may well be very little support. Families can live very isolated lives, but the provision of respite services does nothing to assist this. Taking the person with a disability away does not diminish their social isolation within their local community and it brings nothing new into the lives of the families and the parents.

I truly appreciate that there are many families desperately in need of support in their full-time care of a loved one with a disability. But respite, as the term is currently understood, is not the answer. The answer is to build opportunities for rest, recovery and stimulation into the everyday lives of these families. And this is not best done in a bricks and mortar respite centre away from the local community and away from the family home for slabs of time. It is best done by supporting the rhythms of everyday life, of ordinary life—perhaps someone who can assist at mealtimes, perhaps someone to come to the house to offer art or music classes while the rest of the family go about what they would like to do, perhaps someone to accompany the family on holidays so everyone gets a break.

Currently, much respite simply helps dysfunctional families to remain dysfunctional: they are not quite in crisis, but they are on the verge of it. If we continue to provide respite by making it a fix that goes outside the network, outside the family and which does nothing to help build social relationships and community relationships for these families and for these people, then we just continue this cycle. We do nothing to improve the lives of the person with a disability; we do nothing to improve the community connections and the relationships of the other family members within this situation. To me, the more normal we can make respite services, the better and more long-lasting the benefits for families will be. I encourage any organisation—I particularly encourage smaller organisations—to consider applying to offer the respite services under the government round of funding that is currently available. But I would ask them to look at this in terms of how you might bring respite into a family's life, not take a person out of the family to offer them respite. We can make some big advances in improving overall lives, not just having little fixes that improve things for that instant but do not improve things overall.