

Submission No. 1245

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(Inq into better support for carers)

; Merrian

MC 218104

Legislative Assembly

I too am a carer concerned of what is going to happen to my son Brendon who is 13 has Autism with a severe intellectual disability

Where is he going to end up when I am too old and frail to look after him????

I am a committee member of The Sutherland Shire Disability Accommodation Action Group We need Supported Accommodation in the Sutherland Shire NOW

As I Said Brendon is 13 he has no speech, is not toilet trained and has limited understanding he is 172cm tall which is at least 10cm taller than me and weighs 70kg We have had our fair share of crisis with Brendon's challenging, and on many occasions volatile behaviour where he is self-injurious by hitting himself and head butting to the point where he bruises himself.

Brendon is mobile and has to be supervised all the time as he steals food and drinks from our pantry; he also has been known to consume things such as Listerine, shaving cream and other non-edible products from the bathroom.

Trying to keep the family unit together is a constant struggle. My husband Garry is a self employed plumber and is very busy with his work

Therefore I am the sole carer of Brendon.

Garry finds it hard to cope. Because of Brendon's age I am not likely to receive supported accommodation for years to come, until he is at least 18, when I will be 50 years old and he will be a grown man.

WE NEED TO PLAN FOR THE FUTURE

Unlike others, I'm not prepared to leave my child at respite or the local police station as other carers have resorted to, because of the fact that caring for their child has become impossible, I wish to receive supported accommodation before this happens.

DADHAC has a so-called register of need but our family does not fit the criteria I AM ANGRY and frustrated to the brink of despair that the carers of adolescent special needs children did not receive any additional funding in the 2008 federal budget. The \$600 Bonus will again go no-where. Brendon has to have medication to calm him down and to help him sleep. 3 of his tablets are on the PBS \$5. The other medication is \$121 a month and so the money goes towards that alone.

We would like a small cluster model of supported accommodation; which is a small block of villas fully staffed and maybe a communal dining room with rooms for medical, occupational therapy, and speech pathology etc.

We would like the cluster tiered for respite so the transition would not be so traumatic for our children.

The utmost important thing is we want it in our local community, the Sutherland Shire.

Merrian