

27th January, 2015

Committee Secretary
Senate Standing Committees on Community Affairs
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Re: *The adequacy of existing residential care arrangements available for young people with severe physical, mental or intellectual disabilities in Australia

Dear Secretary,

I wish to make the following submission based on my personal experience of caring for two young adult daughters with an acquired brain injury from infant stroke. They both have complex medical, mental health and physical issues which I believe puts them in the above category* of young people with a disability.

As parents we were continually aware that as our daughters grew older and into young adulthood and further into adulthood there would be obstacles surrounding moving into their own accommodation. We were not prepared for the onslaught of major medical, mental health and physical issues that transpired in their twenties given their recovery from infant stroke had been something of a miracle whereby they enjoyed a relatively healthy childhood.

Given that both our daughters had differing personalities and medical issues the discussion surrounding their own accommodation was not easy. The younger daughter put her name on the NSW Housing list for accommodation when she was 21 years of age but the older daughter wanted to remain living with her father and myself, forever. In terms of our younger daughter, we tried on two occasions to obtain suitable accommodation of her own via NSW Housing. The paperwork was not only repetitive but was 'lost' on both occasions. Of course it came to a point where it just became the 'too hard basket' and momentum was lost. We did on many occasions look for other accommodation in the private rental market, however, nothing was affordable, suitable or safe.

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What changed for us was that in 2005 a group of local parents formed a parent group to advocate for suitable accommodation for young adults with a disability in our area. In 2012 our parent group was asked to be part of a NSW government initiative to be part of a 'pilot' group in obtaining suitable, sustainable, close to services accommodation.

We agreed and our group received funding from the NSW government in 2012 to assist us with the

above accommodation task. A housing agency came on board and our young adult children received an 'individual' funding package to assist us in their ongoing management. This 'individual' funding gave us not only freedom to choose service providers but flexibility in terms of how and when the monies could be used.

From 2012 to 2014 advocacy for our youngest daughter who still wanted to try independent living was more than intense, it was a two year period of negotiating with NSW Housing and St. George Community Housing for 'suitable' housing options given her ongoing medical, mental health and vulnerability issues. It took a lot of assessments, saying "no" to the above housing bodies on two offers of unsuitable accommodation. It took further assessments (many) and several letters to our local MP and two letters to the NSW Minister for Disabilities till Nadia was offered a suitable option to take up. From our perspective there appeared to be a general lack of understanding of disability across the board from the above housing agencies which strongly impaired the 'negotiations' about 'suitable accommodation' not just 'accommodation'!!

As for our eldest daughter who still wishes to reside with her parents remains part of the above 'pilot' group for accommodation which will be a purpose built villa model in our local area. Given she does not wish to move away from home we looked at other 'options', for example; moving to a retirement village with her with the view that upon our death she could remain living in the village till her death. However, after many phone calls and visits to retirement villages to discuss this option, nothing to date has been positive. This option is not for everyone but it would suit our family. This particular option is currently operating in some Victorian retirement villages.

Having said all of the above, it has been a long journey finding suitable and sustainable accommodation for our daughters. It has been abundantly clear for many years that the sector is in a dire need of a frank conversation with relevant agencies, advocates and clients about how we can best meet these accommodation needs. This conversation will not happen unless there is proactive leadership from government, housing bodies, NGO's, Health, purpose built facilities and others who are involved in accommodation for persons with a disability, in particular, those with severe, complex, and often progressive disabilities.

Some of the questions that need to be asked of relevant agencies prior to being allocated, future funding are.....

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*are you ready for change?,

*have you changed over the years?, if yes, can it be demonstrated?

*are your staff trained in disability?, have you disability specific 'case workers'/case managers?

*do you consult with families/advocates when properties become available re; suitability?,

*have you or are you currently working with other housing agencies, retirement villages, over 55's complexes, health facilities, aged care facilities etc in an effort to try something different and innovative?

If the answers to any or all of the above are 'no' then we really have a gigantic task ahead of us all.

We need to start the ball rolling on 'inclusiveness' and doing business differently.

Thank you for this opportunity.

Yours sincerely,

Rhonda Danylenko