Senate Community Affairs References Committee
Inquiry into aged care

Submission on:

- The appropriateness of young people with disabilities being accommodated in residential aged care facilities

- The extent to which residents with special needs, such as dementia, mental illness or specific conditions are met under current funding arrangements.

Summary of submission:

The following submission outlines the current strain of young people in nursing homes and the effect it has not only on the disabled but their carers and families respectively. This submission focuses on my intellectually sister Melissa's move to the care of her teenage sister, to the eventual placement in an aged care facility. Outlined is the constant struggle to attain an appropriate placement to cater for a young person with an intellectual disability – the emotional and financial burden along with the 'abandonment' felt by the Governments lack of intervention.

I write my submission on behalf of my intellectually disabled sister and myself.

In 1999 our mother passed away suddenly and unexpectantly of heart failure. She was just 44 years of age. She left two daughters, myself aged 19 and my intellectually disabled sister, Melissa aged 26. Mum had been Melissa's sole carer and had dedicated her life to ensuring Melissa's disability did not stop her from living a happy, healthy and dignifying existence. Living in a rented home with no financial net to fall on and no extended family support, mum's death resulted in myself stepping up to take the responsibility of Melissa. I dropped out of the Bachelor of Nursing course I was studying at University to begin working as a carer in an aged care facility to enable me to provide for myself and my new dependant, Melissa.

Melissa attended Knoxbrooke ATSS from 9-4 during the day giving me the opportunity to work during those hours. A case manager was secured to help guide and obtain services available to Melissa. This included 2 hours of care from an outside agency per day to assist Melissa with her personal care after Knoxbrooke. I was also entitled to a meagre 2 weeks respite per year. This may seem like my load was lightened – not so. After the outside carer finished her 2 hours it was up to me for the rest of the night to 'entertain' Melissa, prepare an evening meal, get her ready for bed and have a restless night myself as she woke often asking for mum. There was no care available on weekends. Please remember I am only 19 at this time.

Melissa had been placed on the Emergency needs register for accommodation through the DHS and I was advised my 'caring' would be temporary. Melissa would be placed in a CRU as soon as a place came up. Three years passed…

At 22 the realisation that I would always be caring for Melissa set in. The small respite allowance I received was no longer a 'help', it was a god send. I was beginning to struggle financially and emotionally. The only family support I received was from my osteoporosis, arthritic Aunt. She was able to take Melissa for a night occasionally when it got too much, but with her debilitating health she was unable and not expected to do this often.

Carers don't just sit and ensure the person they are looking after is 'supervised'. They cook, clean, bathe, toilet, counsel, support, entertain, teach. There are many more responsibilities that are carried out in the daily life of a carer. Who care's for the carer? Attending to Melissa's every need ensured I was no longer Amy – I was Amy, Melissa's carer. I no longer

looked toward my future but that of my sister. I resisted with all my might but finally the feelings of resentment began to take over. I began to resent my sister for the life we were living. Living hand to mouth and barely making ends meet. I felt complacency had set in term of Melissa's placement on the needs registry. I was never updated and when I made the odd enquiry I was offered 'respite' in the form of people coming to the house for an hour and teaching Melissa how to use the telephone!

I began to fall into deep depression and felt our situation was hopeless. I couldn't see the light at the end of the tunnel and remember driving home one day in the pouring rain behind a truck and wondering 'what would happen if I didn't brake at the red light?' That was the moment I realised I was not helping Melissa feeling this way. I had seen a Doctor and was put on Anti- depressants immediately. Due to my state, I had a meeting with DHS regarding placement for Melissa. I was no longer able to 'wait' like I had the last three years or so. The response was unfortunately one I had come to expect. Option 1 was to keep her and continue as we had the last three years. Option 2 was the leave her at her Respite facility. Relinquish care and not pick her up. She could be placed in various short term facilities until a placement came up – she wouldn't be able to attend Knoxbrooke (a daily routine that had become her reason to smile) I would have no contact and no 'say' in her life. Option 2 was never going to happen although I considered it.
I went home in tears. The option of placing Melissa in an SRS was offered. A temporary placement while she remained on the urgency list. Similar to a hostel I was told they catered for disabled. Having worked in the aged care industry, I took comfort in the fact they had to adhere to 'standards' and that Melissa would have her personal care, meals and laundry attended to. She would also be able to attend Knoxbrooke. At my 'wits' end…I took this option.

Melissa is now 31 and is still in her SRS. She was one of 43 people aged between 30-39 in 2004 living in an aged residential facility in Victoria. (Dept. health and ageing, 2004) Mislead to believe it catered for people like my sister; she resides in a 'nursing home'. After Melissa was placed I was able to get back on my feet and have been trying to get an appropriate placement for her ever since. Melissa sits among the aged. Her 'spark' for life has gone – she has no friends there and no one able to communicate effectively with her. The facility is catered for the aged, she does not go on 'outings', there are no activities. Her personal appearance is neglected due to the number of beds and shortage of staff. A small thing to you or I, but Melissa loves a bath. For the latter reason she cannot have this simple luxury. Being an aged care facility, there are no appropriate disposal units to cater for her Menstrual Cycle. A simple plastic bag in her room is used. To cater

for the amount of 'residents' tea and coffee are pre made in a large jug with the milk already added. A sight you or I would balk at – A daily standard Melissa has had to live with. Melissa is isolated and feels 'abandoned'. She recently surprised me with her understanding by saying "I need to get out – everyone is old – no one talks to me". My heart breaks over and over when I go to see her. I know where she will be – sitting on her own.

The figures say there are 6000 others like Melissa living an undignifying and 'abandoned' life.(ypinh website) I say undignifying because these are young people – young people who deserve to live in surroundings that suit their age. They are entitled to have appropriate care to match their age. The disabled are the vulnerable of our community yet we cannot provide appropriate accommodation to suit their needs. They are left sitting amongst those who are, to be blunt…waiting to die.

Its costs $250 per week to keep Melissa in an aged care facility. She receives a Mobility allowance to pay for her transport to and from Knoxbrooke. With the funds left over from her meagre disability pension after paying housing fees she contributes to her Knoxbrooke fees. This leaves all but spare change for her. Should she with to purchase anything from a haircut to a movie ticket, she has to rely on funds from family.

An SRS in Ferntree Gully houses three other young people with a disability that attend her day placement. Although still an inappropriate placement, we enquired to this facility as the staff were more 'aware' of the needs of the young disabled having three in residence? At $350 per week, we had to walk away and break the news to Melissa that she would have to return to her facility. There is n0 subsidy for the disabled to live in aged care facilities. Although many attend day placements and are away from the facility for the most part of the day, the fee remains the same.

My only wish in life is to see my sister live the health, happy and dignifying life she once had. She has gone unheard for too long and its time she was listened to. Every life is precious and hers is no exception. Her innocence and vulnerability should be reason to 'save' her from a listless, grey existence. Please help me to see her smile again.

RECOMMENDATIONS:

- Appropriate housing for the disabled needs to be emplaced
- Adequate communication between Government bodies and carers/family needs to be enforced. Carers should be updated on their dependants 'status'. As it stands, many feel swept under the rug and abandoned by a body which is emplaced to assist them.
- Aged care facilities and staff should be trained to cater for the disabled. This issue will not be resolved overnight. It is imperative that those who are currently residing in aged care facilities are having their emotional, physical, socia and spiritual needs met.
- Access to funding packages for those disabled living in aged care facilities should be attainable.
- There needs to be a light at the end of the tunnel for carers and families. Who will look after these precious individuals when we are gone? We have ensured care and housing is available to the aging community, now its time to care for the disabled.

Yours sincerely,

Amy Seadon

References

Department of Health and Ageing – Investing in Australia's Aged Care, review of pricing arrangements in Residential Aged Care, 2004

Young People in Nursing Homes – www.ypinh.org.au