

13th July 2004

SUBMISSION

To the Senate Community Affairs References Committee

On the Aged care Inquiry.

Terms of Reference (c) The appropriateness of young people with disabilities being accommodated in residential aged care facilities and the extent to which residents with special needs, such as dementia, mental illness of specific conditions are met under current funding arrangements.

INTRODUCTION

This submission is from:

Ms. Gayl Foy

The Secretary
Senate Community Affairs References Committee
Suite S1 59
Parliament House
CANBERRA ACT 2600

Dear Secretary,

I am writing on behalf of my daughter, Amber Foy. Amber is 29 years old and was born with Cerebral Palsy and an intellectual disability. Amber has been living in an Aged Care Facility for 6 years.

Amber is a vibrant young woman who enjoys rock music and socialising with her friends at the Adult, Training, Learning and Support (Atlas) program and also in the community.

Amber is not a person to sit around doing nothing, she loves life and wants to be on the go all the time. She loves going to dances, putting on her good clothes, make up and having her hair done. She has a wonderful sense of humour and often has her family and friends laughing with her. She can be mischievously funny in her own little ways.

Amber has a very outgoing personality and will join in anything that looks like fun. She loves going shopping, out for morning teas and meeting with other people in this small community. Most of the people in Casino know Amber as she grew up here and is very well regarded for the strength that she has shown through her very hard and turbulent 29 years.

In 1998, when Amber was 24 years old, my own deteriorating health meant that I could no longer care for Amber at home. I looked around for supported accommodation in Casino so that Amber could continue to live near her family and friends. But there was none, and despite countless requests for assistance, it seemed that the accommodation and support Amber needed was not going to be forthcoming.

Amber hates living in the Aged Care Facility and I hated putting her there. It breaks my heart to see her there and I feel that I have thrown her life onto the rubbish heap.

Amber currently lives with approximately 80 elderly/frail and dementia and dying residents. No one talks to her because they think that because she cannot talk, she does not understand.

In the 6 years Amber has lived in the Aged Care Facility, she has had to cope with numerous elderly people dying and has also seen bodies taken from the rooms by the Funeral Directors.

Amber may be physically and intellectually disabled, but she is able to understand that someone has died. This is an extremely stressful experience at anytime. None of us expect to have to cope with numerous deaths over the course of our lives.

I go to see Amber 2 to 3 times a week and when I go to see her she is always in a fetal position in a water chair, amongst the elderly residents. No one is talking, there is no music playing and no staff is to be seen. The staff does not have the time to sit her up properly. This complete lack of any stimulation has been devastating to Amber and has seen her become more depressed and withdrawn over the 6 years she has been in the nursing home.

Staffing levels in the Aged Care Facility may be consistent with care for people in the end stages of life, but they are nowhere near to being adequate for the different and more intense needs of young people with complex care needs. As one example, the staff does not have the time to position Amber properly in her chair and I often arrive to find her slumped over and nearly ready to slide out onto the floor.

Others and myself have arrived to visit Amber only to find her in her room with the door shut because she has been too noisy and upsetting the elderly residents.

Amber loves the time she spends in the community with people her own age. But the opportunities for her to do this from the nursing home are almost non-existent. Were it not for the Atlas Program that Amber attends 4 half days a week, she would have no contact with people her own age or with the broader community that she is a part of. I had to fight extremely hard to get Amber this opportunity and she simply loves going out of the Aged Care facility into the community and the stimulation that being with others her own age brings. Her obvious enjoyment has been documented in videos and diaries by Atlas program staff and they have also noted in the same diaries that Amber gets extremely upset when they take her back to the Aged Care Facility.

As a young person with generally different interests, Amber is a square peg in a round hole in the Aged Care Facility. She has been told to “*shut up*” and that “*She was a naughty girl*” by some of the elderly residents.

Clearly an Aged Care Facility is no place for a young person like Amber or any other young person.

Amber also has no choice about aspects of her daily life that the rest of us take for granted. She is given her dinner at about 5pm and then put to bed at approximately 6pm when the elderly residents are in bed. This represents a complete loss of the dignity and independence every young Australian has a right to expect. Amber wants to be able to choose what she would like to eat or drink or what time she goes to bed and also what she wants to wear.

Amber cannot have those options because an Aged care Facility is an Institution, run to a timetable and without the facilities or the funding needed to support the more intense need for rehabilitation, community access and social and emotional support that every young person has. The staff have no extra time for a young disabled person who has very different needs to those of the elderly people the Aged Care Facility was designed for, and for whom it receives a set level of funding that was never intended for the support of a young person in need of rehabilitation.

While her basic physical needs are being looked after, her emotional and social needs are not. Amber is now suffering from clinical depression and who wouldn't be, with people older than your own grandmother as your housemates.

Because the support she needs does not exist, Ambers' health is now at risk. The only therapy she receives is the very occasional 5-minute walk along the verandah on a walking frame. Because her muscles are not exercised, the muscles in her legs are deteriorating. If this continues, added costs for medical care and possibly hospitalization will be incurred. But with the appropriate physiotherapy, this could be avoided.

Amber does not require any clinical care. Her only medications are tablets that are given morning and night. She has high support needs, all of which could be met in a supported accommodation home.

Yet because of staff and timetable "expediciencies", Amber is given medication on a certain day every week so that her bowels will work the next day. If they don't, she is given a suppository to make sure that they do.

Amber has lost every vestige of her privacy and dignity. She is showered by both female and male staff and is never asked for her consent or whether this is agreeable to her.

Aged care Facilities are designed and funded to look after frail/ elderly Australians who are nearing the end of their life. They are quite simply the wrong place for young people who are at the beginnings of theirs.

Amber is one of several young people in the Casino area in the same predicament. Not all are in Aged Care Facilities.....YET! But unless something is done to provide extra supported accommodation homes and support that they need, these young people will end up in an Aged Care Facility, like Amber, isolated from friends and community members. Their rights and dignity will be taken from them. Their life choices will also be denied. Young disabled Australians deserve better than this and they should receive the accommodation and support that they require, outside of an Aged Care Facility.

Amber was re-assessed by the NSW Aged Care Assessment Team in September 2003 at my request. They recommended that Amber be given access to a high support home, but according to the NSW Department of Ageing, Disability and Home Care (DADHC), Amber is already

“accommodated” and is not a priority!!! DADHC agrees that Ambers’ accommodation in an Aged Care Facility is inappropriate!

Amber does not want to live the next 60 years of her life in an Aged Care Facility. She deserves a life worth living and the chance to be part of the community again.

SUMMARY

I have enclosed with this submission a short video of Amber. The first part was taken at the Aged Care Facility, where she is residing. The second part was taken at the ATLAS program, which Amber thoroughly enjoys. You can see clearly the difference in Ambers’ personality when she is with her peers and enjoying life outside of the Aged Care Facility.

Governments are meant to safeguard Human rights and encourage full citizenship. Both Federal and State Governments must work together to provide the proper supports necessary for disabled people to live and participate in the community.

Amber is a citizen of this country but is denied such basic human rights as inclusion in the community and the chance to contribute to society.

Every disabled person deserves to have their basic human rights to live and participate in the community. They are being denied their rights and are also being overlooked by both Federal and State Governments.

I would like to see Amber, who has been living in an Aged Care Facility for 6 years with the frail/elderly, dementia and dying residents, relocated into a more appropriate supported accommodation home as soon as possible and be given the opportunity to live her life to its’ full potential.

I would be happy to meet with the Committee to speak in more detail about Ambers’ inappropriate accommodation in an Aged Care Facility.

Yours sincerely

Gayl Foy