

6th March 2015



The Committee Secretary
Senate Standing Committees on Community Affairs
PO Box 6100
Parliament House
Canberra ACT 2600

Background to the current issue:

'Young people in nursing homes' are people under the age of 65 living in aged care facilities.

Characterised by disabilities acquired largely as a result of catastrophic injury or through progressive neurological diseases, these young people require service responses from not just one arm of the service system, but multiple, including health, disability and sometimes aged care, amongst others. These people expect to access the rehabilitation needed to restore health and independence; and to live in the community **as other able bodied young people do.**

Approximately 6500 young Australians with disability presently occupy a not insignificant 5% of residential aged care beds.

When a young person is placed in aged care they discover that their disability funding gets taken away. The nursing home is either seen to be now wholly responsible for all of the care and support, or disability services do not have the funds to add 'extra' support. Unfortunately however, **aged care is funded for older people in the end stages of life.**

Older people require much less 'active' support than a young person with a complex disability, and the nursing home is not equipped to provide vital "extras" such as additional staff to assist with clinical needs, rehabilitation therapists and community access.

If a young person enters aged care without additional input and funding from Disability, they will be treated like an older person; often left in bed for most of the day while they wait for 'their turn' to get up; with insufficiently trained staff to monitor health, little to no rehabilitative therapy, and no communication with people their own age.

Every day of every week, a young Australian with acquired disabilities is placed in an aged-care nursing home because there is nowhere else for them to go.

Like us all, these young people and their families shared an expectation that the **system would be there** to support them when they needed it. But it was not.

This is a set of circumstances that sees young disabled Australians with complex support needs falling through the system's cracks to end up in aged-care facilities that were never designed to support them, are **not funded to do so**, and lack staff trained in the disparate support needs of the acquired disabilities these young people have.

Rather than expecting a young person to accommodate the setting, whether or not it suits their needs, the development of individually targeted accommodation and support responses enables the delivery of lives of **meaning and dignity** in both the short and long term.

Being young is about having a lifetime ahead of you, yet aged care is designed for someone who is at the end of their life. The realities of aged care mean a young person will share a residence where the average age is 83 and the average life expectancy is just three years

Our Client's Story:

Our Client had a fall at the Acquired Brain Injury unit in 2010 and sustained a broken ankle. She was transferred to a home for the aged after her discharge from the Hospital.

██████████ is in ██████████, a one and a half hour drive from ██████████ and our client had no supports, family or friends in ██████████

Our client was **47 years old** at this time.

IAT have been advocating for this young woman for 3 years to have her returned to supported accommodation in the community as has been her constant cry.

Our client clearly articulates she does not like living at ██████████ as she cannot access the community due to her reliance on a wheelchair, use the local swimming pool or access the local shops due to poor access for wheelchairs.

This young and vibrant woman was never given rehabilitation following her fall and broken ankle due to not being able to access the physiotherapist on site. She has been immobile since 2010***from a broken ankle.***

This month our client sustained another fall and was transferred eventually to ██████████ Hospital. Following complex surgery on a severely broken leg she was once more transported back to ██████████. A recent and unannounced visit from us revealed the following:

1. Our client now occupies a room away from the Nurse's station whereas previously our client's room was located closer to the nurse's station.
2. Our client's door is closed and client lying in bed with only a shirt and continence aids on while male workers clean her room.
3. Client has received no visitors.
4. The Support Services funded to provide care have not been to see the client
5. Client is bed bound for 6 weeks, bathed in bed and left to soil her bed as they cannot hoist her out of bed. There is no interaction or stimulation provided.
6. Client reports verbal abuse by staff and being pushed from her bed, told to "shut up and grow up" when crying out in pain as her knees buckle and she snaps her leg.
7. Client not given pain relief following the incident.
8. Client not given pain relief when discharged from ██████████ Hospital.
9. Client not able to access fresh air and sunshine as staff too busy.

10. Neither the Client, or their Guardian, or their Advocate has been given a discharge summary with any mention of necessary rehabilitation.
11. [REDACTED] Home has not reported the incident to the Client's guardian.

This could be you, your daughter, your sister.....

Would you accept being treated like this woman?

Would you stand by and not expect total quality care for your loved one?

The Office of the Public Guardian is currently appointed in matters of health and supposedly working to protect the rights and interests of this incredibly vulnerable young woman.

The general principles under which this Office performs its duties include:

- presumption of capacity
 - same human rights
 - individual value
 - valued role as member of society
 - participation in community life
 - encouragement of self-reliance
 - maximum participation, minimal limitations and substituted judgment
 - maintenance of existing supportive relationships
 - maintenance of environment and values
 - power should be exercised in a way that is appropriate to the circumstances
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- Where is the basic human right to choose where she resides?
 - How is placing a young person into an Aged Care facility meeting her basic human rights?
 - How is denying her access to rehabilitation meeting her basic human rights?
 - How can she be empowered to be a valued member of society when she is left lying in her own waste until staff have time to assist her?

- How is the Office of the Public Guardian encouraging and supporting her to perform social roles valued in society when she is even unable to leave her bed or her room and interact with other residents?
- How is the Office of the Public Guardian encouraging and supporting her to live a life in the general community, and to take part in activities?
- How is the Office of the Public Guardian encouraging and supporting our client to achieve her maximum physical, social, emotional and intellectual potential, and to become as self-reliant as practicable when she has been left without basic care and dignity in an aged care facility?

The Office of the Public Guardian has knowledge of our concerns – The Office of the Public Guardian is **negligent** in their duty of care to our client.

The Department of Communities, Child Safety and Disability Services helps people with a disability and their families to access the support and services they need as they move through the different stages of their life. The Human Services Quality Framework (HSQF) is the Department of Communities, Child Safety and Disability Services' new quality assurance framework and is based on the following principles.

- Respecting human rights — services are planned and delivered in a manner that respects the individual's human rights, in keeping with the United Nations Universal Declaration of Human Rights.
- Social inclusion — services are planned and delivered to promote opportunities for people to be included in their community.
- Participation — people using services are included in decision-making about the service they receive.
- Choice — people using services are provided with the opportunity for choice regarding the service they receive and where and how they receive it, within available resources.

Clearly our client's basic human rights are not being upheld when she is left to exist in isolation and excluded from her community surrounded by the elderly, dying and infirm, cared for by staff both over worked and not trained in assisting young people with disability.

Clearly this client's basic human right to dignity and quality care appropriate to her needs is being ignored.

The Department of Communities, Child Safety and Disability Services is aware of our client's situation and yet.....**fails to act**, blaming lack of funding or any available alternative options for this client.

The Department of Social Services claims to have as its mission: To improve the lifetime wellbeing of people and families in Australia and operates under the National Standards for Disability Services. According to these standards

- You should be allowed to take part in all of the decisions about your life.
- You should receive good quality services.
- You have the right to be treated fairly, just like everyone else.
- You have the right to take part in your community.
- You can decide when and how you do this.
- And you can decide when and how you have contact with your family and friends.

What part does our client play in having a choice over the service she receives, how it is received, where it is delivered and in what manner it is delivered to her?

How is this young woman encouraged to remain connected to her community?

Who is monitoring the services provided to our client?

Why does it take an unannounced visit from her advocate to reveal conditions of such horrific neglect?

Who is there for this young woman? Whose duty is it to ensure she can maintain some dignity and be valued as a person of worth?

For too long our client has been left to barely exist in a failing aged care facility that has led to a marked deterioration in her physical, emotional and spiritual health.

Our client, once active, vibrant involved in her local community, lies bedridden, immobile in her own waste until staff find the time to clean her up.

Where is the dignity? Where are her human rights?

We are no longer prepared to allow this situation to continue, tired of cries of "It's not our role" or "There isnt funding attached for that"....

We believe that what is happening for our client is not unique; unfortunately....it is in the public's interest to become aware of this situation and the failings of our systems to care for one of the more vulnerable members of our community and therefore:

1. We respectfully request that our client is immediately removed from this aged care facility, given access to proper health care and rehabilitation that every human being has a right to, regardless of whether they can speak up and demand it.
2. If the many departments and people trusted with her care and protection are not able to offer an alternative from this situation of abuse and neglect, we are prepared to ensure that the public becomes aware of the mistrust placed in those charged with the care of our most vulnerable members in our society.
3. If there is no response that ensures our client's access to rehabilitation and her community, we will be forced to inform the public what does and can happen when the services charged with someone's care and guardianship is remiss in their duties.
4. Independent Advocacy will contact a number of media outlets to do this within 10 working days of this letter, the **20th March 2015.**

To this end, we have forwarded this correspondence to those we believe can reach out and give our client the life she is **entitled** to lead.

Thank you and on behalf of our client.....please don't leave her to die...An **immediate** investigation is required.

Kylie-maree Beller
Manager
Independent Advocacy Townsville