

Submission to Senate Inquiry

“Adequacy of existing residential care arrangements available for young people with severe physical, mental or intellectual disabilities in Australia”

Name: Kirrily Hayward

Statement about sharing:

I am happy for my submission to be published

Signed:

Young disabled pin hopes on NDIS for housing



Kirrily Hayward. 'I feel that with the combination of both a disability and a recurring medical condition, I've just been pushed away'

RACHEL BAXENDALE

AN estimated 3500 people aged under 60 live in nursing homes despite 85 per cent of Australians believing there should be age-appropriate housing and support for people with disabilities.

A survey of 800 Australians also found that 90 per cent believe the issue should be addressed by government.

Geelong woman Kirrily Hayward, 26, is one of them. She and the Summer Foundation — the advocacy organisation for young people in nursing homes that commissioned the survey — hope the National Disability Insurance Scheme will help address the challenge of finding more appropriate accommodation for young people with disabilities.

Eighteen months ago, Ms Hayward, born with spina bifida, a birth defect, and who had both legs removed at 21, was forced to go into a nursing home after pressure sores on the stumps of her legs failed to heal, so she needed frequent medical attention.

She was living independently in a unit in the northern Geelong suburb of Norlane, and studying social work at university.

Ms Hayward said the emotional effect of being placed in a nursing home, where the average age of residents is 84, has had a negative impact on her ability to regain her physical health.

"I feel that with the combination of both a disability and a

recurring medical condition, I've just been pushed away in the hope I will recover," she said. "For a young person such as myself being in an aged-care facility, you're surrounded by people who are at the end-of-life stage and the care is all directed towards that.

"I've had great support in terms of nursing staff. It's more the environment. The activities, like bingo, are geared toward older generations and there's no one I can hang around with that's my age. It's very isolating.

"I'm a strong-willed person, but when you're constantly faced with situations that test that outside leather, such as frequently seeing people pass away, it can have an emotional impact.

"It had a huge impact on me to the point of depression."

Ms Hayward is being assessed under the NDIS, and hopes it will help her begin the process of getting into supported accommodation and eventually moving home independently.

Summer Foundation founder and chief executive Di Winkler said she believed the NDIS would help to provide the support and resources to enable young people with disabilities to find more age-appropriate accommodation.

"But the NDIS currently doesn't have the resources it needs to deliver the scale of housing required," Dr Winkler said.

"A large part of the problem is that there's not enough affordable and accessible housing for people living in nursing homes."

My name is Kirrily Hayward.

I have been living in an aged care facility for more than 2 years.

I have spina bifida, am a bilateral (double) trans-femoral amputee (upper leg) and a stage 4 pressure sore that resulted in my admission to the aged care facility.

I need

- Daily medical care to help with pressure care (make sure I have the right cushion, make sure the cushion is pumped up, make sure I am using proper care of the wound, dressing the wound, maintain my medication)
- Case management to manage funding, services and advocacy
- Support to manage any mental health issues particularly depression and psychosocial needs
- Physio and OT for correct supports and equipment for both inside and outside activities
- Physio to maintain overall strength and mobility so I can function within the community

The trigger for my admission to the aged care facility was not my spina bifida, not my amputations ... it was the stage 4 pressure sore that is currently being maintained but not improved with care from the aged care facility

I was living independently for a number of years. First living in a shared student house when I first began university in 2007. Afterwards, I moved into various rental properties. In 2012, I developed the pressure sore. I then went from acute care (hospital) to transition care (an aged care facility partly for rehabilitation and partly for recovery), then to another aged care facility where I now continue to reside.

My only source of income is the Disability Pension. I am currently looking for casual and/or part-time employment but am finding this very difficult. To a large extent, my difficulty in getting employment is due to the lack of flexibility that living in an aged care facility creates. I do have an NDIS package that I find is adequate in the most part. However, some areas such as transport, is still underfunded since I live in an aged care facility located in an area that lacks safe public transport access. This is not a problem for many of my co-residents since they don't need or want to go out but creates a lot of difficulties for young 27yr old woman such as me who still wants to be very active in her community.

Term of Reference (d) the appropriateness of the aged care system for care of young people with serious and/or permanent mental or physical disabilities

I have been living in an aged care facility for the last 2 and a bit years now. Before then, I was an energetic young Geelong woman living with spina bifida, studying at university, regularly going to the gym, travelling to Melbourne, rarely at home ... in other words living the typical life of any young person. Though I was already using a wheelchair, this did not stop me pushing the boundaries.

It was in 2012 that life for me took a turn for the worst, when I was struck down with a stage 4 pressure sore. After numerous surgeries and therapies to treat the condition, I was given a short list of aged care facilities and asked to choose where I would now move to. I say choice, but really there was only one place that had a bed so really I was given no choice at all.

As a young person living in this environment, I am constantly confronted with aged-care-related end-of-life circumstances, seeing things a young person in the prime of their life should not see. While living here, there have been many times that I have felt isolated, alone and misunderstood. It is very difficult to maintain friendships and relationships. And it is impossible to nurture new ones. While living here, my mental health deteriorated significantly. For many months, I shut myself off, spending most of my time in my room, not fitting in. Well, I didn't really. I was a 25yr old living with people who were 30-50yrs older than myself, some of whom had severe age-related illnesses. While the staff have been so fantastic and supportive here (I can not speak highly enough of the nursing home staff), the aged care facility remains a cold and clinical institution. This is not the place for a 27 year old woman.

Please view my digital story, a visual summary of my experience. Here is the link:

<https://www.youtube.com/watch?v=xAvuuLSYtJY>

Term of Reference (c) access to personal support and medical assistance for young people with disability

In the middle of 2012, I was struck by a recurring health condition, in the form of a stage 4 pressure sore that had broken down again. Pressure sores being one of the common perils associated with life in a wheelchair. I was to be hospitalised for 3 months, going through numerous therapies and surgical procedures to treat the condition. At the time, my lack of understanding of the reality of the situation led me to feel bullied and intimidated by the medical professionals charged with my care, who I thought were making me go through unnecessary and distressing procedures beyond what I thought was necessary,

I was to be then sent to a Transitional Care Placement (which is really an aged care facility) for my recovery and partial rehabilitation with a view to my going home afterwards. But, due to the wound not healing. During this time, it was made clear that I was not ready to make a return to independent living due to my physical and mental health state. I was then transferred to another aged care facility instead. I was given a choice of two aged care facilities but really I had no choice at all since one of the facilities (which was my choice due to location being more central) did not have a bed. That choice would have at least gotten me close to public transport that I could of used. But instead I was transferred to my current residential aged care facility.

I was later told that everyone who was involved in my care, were looking for supported accommodation opportunities. However, I was not involved in the process. Despite my difficulties adjusting to my health state at that time, I would have at least liked to have had some form of involvement/consultation in that process. It is my basic human right to self-determine and I feel that was denied to me. I do have more choice in choosing my living circumstances at present (though no where near that of a typical 27 year old) but I still feel that the medical/health professionals tend to act antagonistically towards my ultimate goal ... living independently like a typical 27 year old woman.

It was the stage 4 pressure sore that resulted in my admission to the aged care facility. It is the aged care facility that is maintaining the pressure sore, i.e., ensuring it doesn't get worse but not helping it heal. In other words, monitoring my condition but not improving it. How then can I expect to begin to live an independent life in the community?

My Ideal World

My ideal world would have the following elements:

- I could be living in coastal community, maybe In front of (or near) the beach
- I would be living a liberated life – having free choice, making my own decisions
- I would love the opportunity to have animals around me (ideally a dog as a pet (a fur kid ☺))
- I would be working (employed) in a situation combining my interests in fitness and human rights, activism and social justice
- Maybe live up north of Australia ... I love Darwin and Kakadu
- I would be able to travel
- Live in a small house that is wheelchair accessible
- I would have adequate and flexible supports that I would need to maintain my independence for general activities of daily living
- I would be able to choose what I eat, prepare it myself, at a time that suited me
- I would be able to do what I want to do, when I want to do it