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30th July 2004

The Secretary  
Senate Community Affairs References Committee  
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Parliament House  
Canberra ACT 2600

**Submission to Senate Community Affairs Reference Committee  
Inquiry into Aged Care**

This submission has been made by Angus Witherby. It predominantly addresses the term of reference "C"; the appropriateness of young people with disabilities being accommodated in residential aged care facilities. As part of this, the issue of complaints processes is also raised.

I have had some experience with the aged care system through my parents-in-law and my own grandparents, as well as with a young person in an aged care facility. From my observations of the quality of the system, this is highly variable. The system is under significant strain in terms of staffing levels, particularly in terms of the ability to attract and hold permanent staff. Extensive use is currently being made in many parts of the system of sessional staff, many of whom have very poor English. To be blunt, pay rates are unacceptably low. We are facing a system in crisis, and one that is increasingly failing to meet the needs of a range of people who require ongoing high-level care, irrespective of their age. Despite increased efforts to manage people in their homes, and, in the case of people with disabilities, to support their better integration into the community through group homes and the like, there remains a growing core of people who either permanently, or as part of a rehabilitation process, require ongoing high-level care, for considerable periods.

In many respects this is a broader societal issue. We are still placing people with disabilities and aged people "out of the way" in a way that fails to genuinely integrate them with the broader community. There are exceptions, but these are relatively rare. For example, aged care in the Armidale district NSW has a number of facilities where people may progress from fully independent living through to a nursing home within the one institution, with the institutions being easily accessible to the central area of the town. People can receive the level of support they need, whilst maintaining continuity in social connections and interactions. Perhaps the best example I know is McMaugh Gardens, run by Uralla Shire Council. I have had recent experience of this facility, where my mother-in-law lived until recently, and it is staffed by long-term permanent staff,

most of whom are local and know the residents well, and who go out of their way to provide a high-quality stimulating and interesting living environment along with very high levels of ongoing focus to individual needs. This is how it can be done, within an institutional setting.

My experience with a younger person with a disability living in an aged care facility relates to Fiona, currently resident at Leighton Lodge in Turrumurra, Sydney NSW. This is a much less happy experience. Fiona suffered substantial brain injury in a car crash some four years ago. Initial responses by the public health system in NSW were good, including the brain injury unit at Royal North Shore Hospital. Significant issues arose, however, in terms of her longer-term residential situation and, just as importantly, her rehabilitation.

Certainly immediately post-accident Fiona's prognosis was not good. She was in a coma and not able to breathe independently. Good quality acute-care management led to substantial improvement. She awoke, gained independent breathing, and over time gradually rebuilt important skills including voluntary movement, and speech. She has also been able to start taking food by mouth. The prognosis for continued recovery is reasonably good, however it has been of major concern to me that her recovery has been actively hindered by her location in an aged care facility. The facility seems merely interested in what I would describe as "basic care" (after a fashion) and taking the money. There are problems with this basic care. She was frequently left wet and soiled for extended periods, she has been found distressed, sitting in her chair, in a darkened room unable to eat her meal, which was cold. I believe that the medical regime at times was more to do with drugging her for easy management than genuinely assisting her recovery. I believe some critical health issues are being inadequately monitored and treated such as sores and the like.

A number of complaints have been made by her guardians to relevant state and federal bodies. This has been an appalling experience. Jurisdiction remains unclear. Where complaints have fallen within jurisdiction, there are no means or mechanisms to ensure that recommendations arising from the complaints process (which in this case usually find in favour of the complainants) are actually implemented. The processes are incredibly time-consuming, and expensive in terms of emotional and physical resources. At the end of the day, these processes are a sham. You go through "a process" and then nothing happens. There is nowhere else to go, and no one is interested. Agencies appear more focused on complaint "throughput" than complaint resolution.

Yet here we have someone who has the potential to be rehabilitated and leave the aged care system, freeing up resources for others. There has, however, been no active engagement by the aged care facility with Fiona's guardians in terms of her ongoing rehabilitation. Providing her with the ongoing stimulation and interaction that she so badly needs to feel part of society has proved extremely difficult. The aged care facility is somewhat out of the way, but is the

only facility available. Fiona has no interaction that I have observed with other residents, noting that her own behaviours have been reported at times as being challenging (I have not personally observed any particularly challenging behaviours from her). Nevertheless, I believe that many of the behavioural problems she has experienced are a direct result of the inappropriate treatment and isolation she has experienced within an aged care facility. For example, despite repeated requests and Fiona's known wishes, she was repeatedly showered by male staff.

The aged care facility is not really interested in her rehabilitation. Some individual staff are kind and supportive, however the time they are able to spend with her is minimal, and is generally associated with functional tasks such as feeding and bathing. Even the most basic of support issues seems difficult. Providing her with access to a television remote control from an overhead frame has proved hard. Even providing the basic window on the world of television, together with the ability to control her own access has been a major struggle.

The Facility has neither the time, resources or staff to undertake rehabilitation. They do not see that they are funded to do so, either. In fact from their own management perspective, I suspect she is much easier to deal with, being currently unable to walk, then she would be with further rehabilitation although I believe she has the physical capacity to recover many critical skills, such as walking.

Whilst various professional services are being utilised to assist in Fiona's rehabilitation the core issue of social engagement and a meaningful social life remains untouched. There is only so much that can be done through volunteers and friends visiting. There is an urgent need for people such as Fiona, to be located where they can receive comprehensive support - care, social interaction and rehabilitation -all under one roof. I do not see how this can be effectively managed within facilities orientated towards aged care. Apart from anything else, they are not basically orientated towards people getting better and leaving.

Noting that a growing number of younger people do require "institutional level" support, it seems to me that there is a very clear case for specialist facilities to address this growing societal need - a need which is becoming much stronger as people with disabilities live longer, often outliving their carers. These facilities need to be located where they are accessible to family and friends, and need to be integrated as far as possible within the broader community. We do not, however, need a repeat of the deinstitutionalisation farce that occurred in NSW following the Richmond Report where people were basically left to fend for themselves outside any adequate support structure.

I find it completely appalling and totally unacceptable that a young person such as Fiona with good prospects cannot receive the support from society that she deserves, to enable her once more to take an active role in society. I feel at

present she simply perceived as a burden. She is not. She is a person with thoughts, feelings and emotions. She is aware of what is going on, increasingly so as her short-term memory improves. She is in hell.

We are at a watershed as a society. Have we room for compassion? Are we willing to stop and look at the appalling human costs of our institutionalised systems? More and more people are "falling through the cracks". We need a complete re-think of the system and our approach to it. We need to integrate not isolate. We need to become a whole society again rather than splintered fragments, each in its own world.

I would be happy to attend the hearings, if the Committee felt this would be of benefit.

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