SENATE COMMUNITY AFFAIRS
REFERENCE COMMITTEE INQUIRY INTO AGED CARE

Karingal Inc.
Geelong, Victoria

Submission in response to Senate Inquiry Terms of Reference (c):
"The inappropriateness of young people with disabilities
being accommodated in residential aged care facilities."

July 2004

For further information, contact: Dr. Brian Donovan,
Karingal Inc.,
Level 1, 4 James St.
Geelong, Vic 3220
Phone: (03) 5229 2583
Email: bfdonovan@karingal.org.au

Disturbing plight

Young people in nursing homes is one of the more disturbing aspects of the broader plight of people with disabilities whose basic needs are not being met. The lack of leadership by all levels of government to genuinely collaborate to provide suitable accommodation and appropriate supports makes so much of Australia's excellent policies and legislation ring hollow.

In reporting the story of Vicky Smith, *The Herald Sun* of 21st May 2004 stated:

> A spokeswoman for federal Community Services Minister Kay Patterson said under a national agreement, it was the state's responsibility to provide appropriate housing for disabled people. But Ms Smith's plight was "recognised as an issue".
>
> A spokeswoman for Victorian Community Services Minister Sherryl Garbutt said: "The State Government believes it is inappropriate for young people with disabilities to be living in aged-care facilities."

This highlights a buck-passing mentality by both the Federal and Victorian Governments that does not serve the interests of citizens with disabilities.

The ABC program *Australia Talks Back* on 20th April 2004 highlighted the plight of a young West Australian man who's right to receive one-on-one care in his own home rather than a nursing home was recognised by the District Court. There are young people however for whom nursing care, apart from being a matter of choice, is also inadequate as well as inappropriate. A story below gives the instance of one family in Geelong endeavouring to support their son in spite of governments' inaction to collaborate for even overnight respite. Minister Bishop's response at the time of the ABC program was that "the Commonwealth was already doing more than it was required to do." This did not demonstrate a compassion, much less commitment, to the disturbing plight of the 6000 young people in nursing homes and those families who endeavour to provide the support themselves.

Karingal view

Karingal Inc. is a community organisation founded over 50 years ago in Geelong by parents of people with a disability. The founding was prompted by the lack of opportunities for people with a disability and lack of support for them and their families to live in the community.

Karingal clients and families, staff and the Board of Management are concerned the form of institutionalisation that governments are condoning with young people inappropriately accommodated in nursing homes. The effects of this have been well documented over the past decade, but without the political will of government to work in partnership to address this intolerable situation, vulnerable people and their families are left to cope as best they can.

This submission gives a glimpse into the lives of three of our clients. They, and so many others, have been severely impacted by governments' apparent reticence to provide the leadership and support consistent with their objectives. The first story is told by a mother crying out for support for her 21 year son but finding government constructed blocks. The second story is of a woman who lived nearly 10 years in a nursing home. The third (based on the notes of a community support worker) is of a mother with a neurological disease forced into a nursing home and separation from her dependent child because of inadequate respite support.

Crying out for help

My biggest fear is what happens to my son if anything happens to me. I am a 46 year old mother. He is 21 years old now. He was 17 when he got sever hypoxic brain injury while he was depressed.

I am really tired. My husband and I are both worn out over this past 3½ years. My son is only 21. He needs the stimulation of young people. He loves older people but he is not old.

He had to be assessed by ACAT (Aged Care Assessment Team) because there was no one else to assess him.

> ***"I went home with my son and cried my eyes out and never went back."***

I have just had to hand back 63 days of respite care (Federally funded) because there was no suitable place in Geelong for him to go. We are crying out for Home First hours (State funded) to be topped up so we can have active night duty because he has severe sleep apnia. But the Federal and State Governments do not have their acts together.

It broke my heart going through the nursing home process with my 21 year old son. We were shown a mixed room – a man in his 90's in one corner, an elderly lady with dementia in another, and my son was to be put in the other corner.

I went home with my son and cried my eyes out and never went back. So we have never had respite yet.

Existing in a nursing home

I lived in a nursing home from 1988 to 1997 following a skin graft. I had been in hospital for 10 months and needed to be reassessed prior to discharge into the community. I ended up living at a nursing home for 9½ years. I was 50 when I went in there. I had to share with elderly people who were incontinent and had dementia.

The facility was regimented with meals at strict times, extremely small and inadequate portions (e.g. 1/3 of a banana and a bowl of soup was a meal, or one party pie and some pieces of fruit). Whilst I was in the nursing home I had four broken bones.

The whole place was set up for the elderly, not younger people. The footpaths were too narrow for people with wheelchairs and on one occasion I fell off the footpath in my chair. Getting someone to help me get back into my chair was a real drama – the gardeners who were there were not allowed to help. The registered nurse who attended told the SEN to help me stand up. She didn't appear to understand I was paralysed and what that meant.

The whole place didn't seem to understand the needs and wants of paraplegics. It wasn't set up for them or young people at all. It was necessary for me to be up at 4 am to attend to my own bowel regime. I needed to be up that early so that I had time for a shower after the bowel regime, both before breakfast. I had to use the bathroom after an elderly man who used to go to the shower with his colostomy dressing off, therefore sometimes this caused quite a faecal mess.

"The whole place didn't seem to understand the needs and wants of paraplegics."

Other young people came in for respite regularly. One young girl had cerebral palsy. When she had the misfortune to spasm out of her chair she had to crawl to find someone to come and assist her to her chair. The staff had no idea of how to look after them. I remember it was necessary for me to turn my own mattress approximately every three weeks. This used to take me about 1½ hours. The staff said I had to do it because they wouldn't - it would hurt their backs.

During that time I totally lost my independence. I was scared to live in the community. I remember if I had visitors I had to boil the kettle and make the drinks in the toilet/bathroom area. There was no other place to do it. One day I remember being in the dining area - I thought I've got to get out of here or I'll die in here.

I actually feel bad telling about this. I wish I could forget about it, that it ever happened.

Sense of hopelessness

A woman in her early 40's who has a neurological disease has been forced recently to take accommodation in a nursing home. She has a child of early primary school age.

For almost 3 years she has lived in a respite house, supported by day programs. Funding was provided through a State HomeFirst Individual package. With funds required being in excess of the 34 hours allowed in the package, there was insufficient to provide ongoing support.

The impact on her and her child have been profound:

- Her child can no longer access her as he previously was able. (This had been each week spending a full day with his mother, also having a dinner together on some evenings and at times stayed overnight.)
- Her child is able to visit but can't stay with her.
- She is no longer able to walk to the local shops, buy her personal items, have a coffee and do her own banking as she had done. Her money is now sent to the nursing home office where she collects it.
- She is now unable to keep her clothes with her as there was not enough space. She was advised there were 'store' clothes available.
- She was placed in a shared room with an elderly lady who was dying. She was there when the lady's grieving family was spending their last moments with their family member. It was she who alerted staff when the lady died a few days later.
- Her appearance has deteriorated as staff do not have time to support her.

Her condition was reviewed by a specialist just before she moved to the nursing home. He stated that her good health and reduced rate of progression of her illness were in part attributable to the quality of support she was receiving. Appropriate accommodation, social interaction and as much control as possible over her own life, are vital to her wellbeing.

> ***"She was placed in a shared room with an elderly lady who was dying."***

What is needed

The most significant need is the political will by Federal and State Governments to work cooperatively to address the plight of young people in nursing homes and the families, at huge personal and emotional costs that are generally unsustainable, who are trying to keep their sons and daughters out of nursing homes. If this will is directed at working with people with disabilities and their families, we will find more creative approaches. The Mobile Attendant Care Service (MACS) in Queensland is an example of what is possible. This highly relevant and flexible service, imagined and created by people with disabilities, provides night time support for those needing personal care assistance throughout the night while living in their own home. It has enabled people to enjoy a lifestyle in the community that most people take for granted.

Our clients and families who are experiencing, or have experienced, living in nursing homes noted the following as what they need. They do not seem to be huge demands given the spirit and letter of Federal and State legislation:

- Some respite to cope with the overwhelming tiredness
- Compassion
- Dignity and respect
- Flexibility rather than inflexible arrangements and attitudes

- Some choice
- Some stimulation
- Be treated as a valued individual

People described their loss of sense of humour, loss of self belief, loss of autonomy even in the smallest things, and loss of dignity. In their place came a paralysing depression and hopelessness.

We believe that this Senate Inquiry provides another opportunity to ‘get things right’ for the many people who are not in a position to ‘right matters for themselves’.