10th August, 2010

Sue Kedgley MP & Hon Luamanuvao Winnie Laban

House of Representatives

Parliament Buildings

Dear Sue Kedgley MP & Hon Luamanuvao Winnie Laban

Thank you for the opportunity to give feedback into your inquiry on: 'Older New Zealanders – aged care and home based care.

Several members of the New Zealand Association of Occupational Therapists have provided comment on rest home care and I have summarised their feedback:

Some compelling stories indicated that rest home care took choice and control away from residents. For example:

> *Picture this (rest home)*:
>
> Everyday is the same - you have no choice but to be lined up along the wall in large chairs. The television is on, but you don't actually have a good view from your seat in the corner. You have no control over whether or not you want to watch television, let alone what programme to watch or how loud the sound is. If the television isn't on, sometimes there is loud music coming from somewhere which you think the staff might enjoy, because you certainly don't. Day after day after day… oh, until Thursdays, for bingo or crossword time. Then it is time for tea, "dear".

We have observed some care facilities that are very well managed. In our opinion, the best run institutions (big or small) are those managed by leaders who are both very professional and caring of both residents and staff. These managers role model good practice and lead others to likewise provide consistently high emotional and physical care and support, and also recognise the rest home is the residents' home.

Working in partnership might include:

- Ensuring that the basics (medications, personal hygiene, helping with eating etc) are done as much as possible at the residents' pace, and carried out to a consistently high standard.
- Encouraging independence and functional activities as much as possible even though this may take more time: such as walking; feeding oneself and performing basic self cares.
- Providing choice where possible, and encouraging self decision making.
- Accessing community organisations to assist with training. For example, if one or more residents had a particular disability, a field worker might be approached to do an in-service both about the disability in general, and to discuss ways to increase understanding and improve care for the resident(s) concerned.
- Including all staff (e.g. including the kitchen staff) in their in-service training – recognising that how you treat people is important for everyone to learn, and also that nutrition/appetising food is as important as other aspects of care.
- Genuinely welcoming family members, and understanding the dynamics when some are trying to micro-manage the care of their loved one in the rest home.
- Greeting every resident as they pass through the home, and encouraging their staff to engage in conversations with residents.

- Trying to offer a range of experiences for residents – both formal and informal activities – where possible by engaging members of the local community to be involved.

Thus the emphasis in rest home care needs to consider:

- hiring the best possible management team
- hiring staff in all positions who genuinely like and care about older people
- investing in continuous 'on the job' training for all staff and ensure training includes more on how to interact positively and meaningfully with all residents
- ensuring that care plans for each resident should include a number of ways in which residents can occupy themselves in meaningful ways that they have chosen for themselves. Options include access to a garden, gardening, craft work, workshops, scrapbooking, or any activity that is of interest and meaningful to them, alongside the more usual in-door bowls, bingo and news review groups.
- engaging with the local community – individuals and groups who can help to engage residents in occupations

Some members made particular comment about people with dementia and wanted to see an:

- increase in 'enjoyment in the moment' activity which is important for their quality of life such as outings into the community
- investment in the *Spark of Life approach* for people with dementia see: http://www.dementiacareaustralia.com/index.php/the-spark-of-life-approach.html

> One member said: '*The Spark of Life is definitely having an effect on residents and staff at our facility. All our staff have become involved and they can see it gives them new skills and positive ways of working with each other.'*

Above all the environment should always reflect that this is the home of the residents. In our homes we get up and have breakfast at different times of day, have days when we choose to be active and sociable, and days when we prefer to spend more time by ourselves, and sometimes we choose to have wine with dinner or a beer with our friends. The physical environment should reflect the age, culture, interests and memories of the residents - not just in their own rooms, but in the communal rooms as well - whether they are in a rest home, hospital or dementia care setting. **The best managed institutions are those that continually strive to achieve the sort of care and environment that the staff would want to receive themselves in a few years!**

In addition please find attached a detailed single submission as regards an occupational therapist's perspective on home care for older people.

Please get in touch should you wish any further details.

Yours sincerely

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Note: Excellent book to read "Making residential care feel more like home" by Jeff Garland. Winslow Press 1991.

HOME BASED CARE

The experiences of one occupational therapist who has visited adults, and particularly older people, in their homes for several years.

1. The System is confusing for people.

Who Pays?

There is short term urgent care for people who have recently been hospitalised, and longer term care for people under both the Ministry of Health system, and the ACC. I have experienced people being referred back and forth between agencies because of indecision as to who should take responsibility for the person's care. In the meantime, the person is waiting for any sort of care.

There needs to be one system and point of access for everyone.

Who does the work?

Many people I have visited in my role as a field worker have been confused. They have difficulty understanding why they have to repeat their story to:

- The person referring them for help (e.g. GP's practice nurse, field worker of their age/disability organisation)
- The Needs Assessor – if Min. of Health, but sometimes an ACC case manager instead or as well
- The representative from the service provider who is going to allocate the worker
- The worker who comes to visit. This can sometimes be several workers a week if the person has high needs for assistance.
- If the initial worker was funded and allocated by the ACC, this whole system appears to be repeated in transferring a client with ongoing age related needs back to the Ministry of Health.

All of this has taken another week or two or six, during which time it is assumed that there are family members capable of providing these services. People rarely ask, “how will you eat, get dressed or toileted?” in the meantime.

This system needs to be streamlined.

A temporary service which can be implemented on Day One if required needs to be available. (cheaper than residential care, or the person falling again and ending up in the public hospital).

Who pays how much for the Carer/Spouse to get a Break?

People are often only asked about their need for a break when they first apply for help. At this point this may not be an issue – or the carer does not realise it will be an issue. The annual reviews of needs often do not cover what is not already being provided. That is, people who currently receive 2 hours for personal care may get asked if that is sufficient. They often do not seem to be asked about whether the carer needs a break. When they are asked, the system is not clearly explained.

Carer Support is not adequate.

My understanding is that if the ‘client’ is assessed as being **‘rest home’ level**, they are entitled to make use of the Carer Support scheme. This is a nominal daily rate of money they can give to a friend or relative to provide care so their main caregiver (e.g. spouse) can have a few hours off.

Many people I have visited have no-one they can turn to for this service. Their only option is for their loved one to go into a rest home for a few days. But Carer Support only pays a nominal amount of the cost, which is out of the question for many people.

However, if the loved one required **hospital level** care, they would be entitled to Respite Care, which pays the full cost of the residential break.

If you are 80 years old, supporting your spouse, you need a break even if the level of care required is rest home level. As the carer, the spouse has usually had to take on

the full responsibility for all the household decisions, all the meal preparation, dealing with finances and trades people, and maybe getting up at night each time their spouse does to ensure their safety en route to the bathroom. They get exhausted and need help. Most do not want their spouse to go to a rest home, but lack of informal supports means there is little alternative. If they cannot afford residential care, they just plod on, and the exhaustion accumulates until the whole family system breaks down.

There needs to be home based options for people to stay at home with the Carer Support scheme (e.g. a list of available and trained 'in the home' carers). If a person needs to use residential care for their Carer Support, the level of remuneration should be 'the going rate' for rest home care.

2. The Standard of Home Care is Unpredictable

Despite all the money that has been spent recently on home based care workers, the standard of training and quality of service is still very dependent on the individual worker. I have found no consistency in any service provider agency so far.

People who have a 'good' worker comment on the fact that the person:

- Arrives and leaves at the scheduled time
- Is honest and careful – client's belongings do not go missing or get broken.
- Treats the client like a functioning adult – not talked down to, or told what to do by the worker.
- Listens to the client's requests, even if they change from day to day (not everyone wants everything done the same way every time).
- Asks, learns and remembers (or writes down). This is important. The client often gets frustrated at having to tell the worker repeatedly how they prefer the bed to be made, which cleaning products to use where, and how to use and empty a vacuum cleaner.
- With personal care, the worker is capable, caring and efficient so that embarrassment is kept to the minimum. If necessary, the worker has been

trained in how to safely move the client, use a hoist etc to ensure the client feels and is safe.

- Does not burden the client with the worker's own health and family problems.
- Many clients have told me that they were unsure about having a worker from a different culture to their own. Over time though, they have decided that this has not been an issue, provided the worker does all the above. The one exception is if food preparation has been required.
- If food preparation is required, the worker needs knowledge and experience in preparing similar food to the client's preferences. And the ability to use a cooker or microwave. Even if both client and worker are of the same culture this can be an issue. This is not being fussy. Appetising, familiar food is an essential ingredient to maintaining health and well-being.

I still find many people who comment that their worker does the opposite to the above. Sometimes they are too afraid to complain (or to allow me to). Other times, they have complained, and the worker has been replaced. However, the next worker has been no better.

A good service provider is one which ensures every worker has the personal integrity and communication skills listed above, and which carries out the practical training of the worker – and does not leave it to the client to train every new worker.

3. ACC

There was a time when the ACC system was more generous and concerned with providing total care as compared to the Ministry of Health system. This now appears to have been reversed for some people.

There does not appear to be a full service to older people in the way there is for people under the Ministry of Health system. I have experienced older clients having received no inquiry from ACC into their needs, even though they have placed a claim following a fall. A similar referral in the health system would lead to a needs assessment in person, which could then lead to services such as home help, referral to the occupational therapist for safety equipment throughout the house, and/or

physiotherapist for assessment of safe mobilisation etc. Despite the Falls Prevention campaign, there does not seem to be any system in ACC for flagging the ongoing risk of older people once they have had a fall. Older people need personal contact to be made by a well-trained, experienced assessor, not just a line on a letter advising them to contact the agency if they need help.

4. Funding of Allied Health Services

When older people are referred to needs assessors, they often have chronic health needs which can affect their safety. The assessors regularly make referrals to occupational therapists (for safety in shower, in getting out of bed or off chairs etc), physiotherapists (for safety in mobilising around the house), speech-language therapist (particularly for assessment of the person's safety in swallowing and for communication), and district nurses for continence issues which can also affect skin integrity. In all cases the need for assistance has been established, and there are personal safety issues involved. Yet for some of the allied health services throughout the country, the funding allocated does not allow for an urgent service to be provided by the allied health workers. It is difficult to imagine dialling 111 and waiting several weeks or months for an ambulance to arrive. Yet that is how long some people are waiting to be contacted by allied health practitioners. Although these services do prioritise their waiting lists, there are still potential safety issues in people waiting so long to be assessed and provided with safety supports by the professional expert.

If we value people remaining in their own homes, we need to ensure allied health services are given the funding required to provide a timely and safe support service.

Conclusion

We are very fortunate to be living in a country that provides home based services to its citizens. What we have in place would be the envy of many people around the world. But with some more thought about what it is like to be on the receiving end, the system could be even better.