NEW ZEALAND HOME HEALTH ASSOCIATION CONFERENCE:
15-17 OCTOBER 2007

DAY 2

"Towards a Preferred Future" – for people with a disability who are ageing

I hope it's apparent from what I had to say yesterday that my organization – and a number of our counterparts - is attempting to develop a range of services so that we can respond positively and appropriately to every person who develops ageing-related support and care needs.

As an over-riding policy objective – our **"preferred future"** if you like - I'm sure all of us would want to see a service system which is planned and resourced so that **every individual** can choose where they live and how they receive the care they may need.

Highly regulated systems like Australia (and NZ?) put their trust in government planning processes to get the balance right – the balance between residential care and community-based care, between city and country, between family-based care and professional service provision.

Some countries – like Germany, for example – resource the consumer and provide mechanisms for choice.

A quick summary of the Disability arrangements in Australia might be helpful at this point:

Funding and service delivery

Both the Commonwealth and the States have responsibility for funding different types of services for people with disability. In broad terms:

- ⇒ the Commonwealth Government has responsibility for the planning, policy setting and management of specialised **employment** assistance
- ⇒ state governments have responsibility for **accommodation support, community support, community access** and **respite**
- ⇒ support for advocacy and print disability is a shared responsibility

The different responsibilities are detailed in the Commonwealth State/Territory Disability Agreement (CSTDA) which sets out:

- ⇒ the administrative and funding arrangements
- ⇒ identified national policy priorities
- ⇒ financial commitments by the Commonwealth and State governments

Both levels of governments also fund some services directly, outside the Agreement.

Actual Disability services are provided by a mixture of government and non-government organisations, with differences occurring between the states/territories.

Current policy directions

Current policy priorities in the Agreement are to:

- ⇒ strengthen access to mainstream and generic services for people with disabilities
- ⇒ strengthen cross-government linkages
- ⇒ strengthen individuals and families
- ⇒ improve long-term strategies to respond to, and manage demand for, specialist disability services and
- ⇒ improve accountability, performance reporting and quality of specialist disability services.

The Commonwealth also signs **individual agreements with each state** which identify key issues. Current issues include:

- ⇒ flexibility between service provision by different levels of government
- ⇒ the situation of young people living in Australian Government funded residential aged care facilities and
- ⇒ issues facing people with a disability who are ageing.

People with disabilities are living longer than ever before and, as a consequence, are developing ageing-related care needs.

Ensuring they receive the support they are entitled to is presently beset by

- a lack of coordinated policy,
- service provider uncertainty about broadening their “core business”, and
- significant skills challenges -

Our experience is that the person with a disability who is also ageing may well find themselves the victim of a severe disconnection between the “silos” which should be providing coordinated support.

Our Aged Care Act, dating from 1997, while not specifying a minimum client age, is firmly directed towards the 65+ population (the potential for cost-shifting being a major reason for that), and…

Disability services are not funded to cope with the increasing needs and costs associated with ageing, let alone premature ageing. This makes it difficult for disability services to offer ageing-in-place for people with disabilities.

Most critically, ***aged care-specific services*** *and* ***disability-specific services*** *frequently lack the expertise to manage clients who have developed needs in both areas.*

What do I mean by this? Well…

- Will staff experienced in aged care be able to recognize and/or manage:
  - Cognitive complexities associated with a variety of intellectual disabilities
- Will the group home setting be able to identify and manage the onset of dementia? Or of heart disease?
- Is the disability provider resourced to meet changed social support/connection needs, often brought on by retirement of the client from their sheltered employment?

- Or what happens to the person who has lived in group housing for decades whose mobility and medication management now dictates high levels of support – is Rest Home or Hospital Continuing Care socially appropriate and will the staff there have the skills to understand the person's intellectual disability?

I'm not suggesting that these issues are not recognized by everyone in this room, but I **am** asking…

- Is the money available, and accessible, to deal with the increasing complexity?
- Are our disability and aged care staff trained to recognize and manage that increasing complexity?
- Is the right accommodation - the right buildings – in place, to meet the clinical and social needs of ageing clients?

So what is required?

- A genuine understanding - and articulation - of the ways in which individual clients' needs and preferences could and should be met better in the future. We need this articulation because the **political/policy arenas**, and the wider **service sector** which delivers services, **both** need to have a clear understanding of the drivers which lie behind the calls for change.
- An articulation of how the systems could be better aligned or integrated to produce those preferred outcomes; in other words, we have to be able to **describe** how the resources and associated accountabilities should be arranged. Governments do need to be seen as partners and helped to understand! Criticism without constructive, workable proposals almost always means bad policy!

- A service sector which is committed to playing **its** part in achieving those better outcomes (ie delivering)
- A service sector which has the **skills** to do it

Some obvious practical directions emerge from that outline of the challenges:

- Both **Consumer** and **Provider** peak organisations need to *maximize opportunities* for collaboration to identify ways and means of bringing about change, and to understand each other better. To publicly articulate what is needed…
- Ageing and Disability need to recognize that practical cooperation – **which need not cost anything** – can produce immediate benefits such as the creation of new pathways into services like respite and rehabilitation. It may be as easy as picking up the phone to a colleague, describing a particular client's need, and seeing whether that colleague's services might fit.
- We need to *identify and challenge* some of the barriers, which can include professional and provider territoriality, as well as Commonwealth/State boundaries and divisions between disability/ageing/acute programs and funding
- We need to *advocate* for service delivery to become consumer-based rather than program-based, so it services people, not bureaucracies, and we should frame future policies around resourcing the client and not the provider (there are precedents - eg German Long Term Care Insurance System model)
- The Ageing and Disability sectors need to be *planning **now*** how we are going to work together to skill our respective staff in the expertise which our colleagues have "on the other side of the fence" – we can find opportunities to work alongside each other, arrange staff exchanges/secondments, and open up our training programs to each other…

- We need to work at *better understanding and working with* the public **and private** housing sectors so that future care and support options are matched by housing options (bearing in mind that residential care facilities will play a diminishing role as a proportion of the aged care sector in the future.
- And we must take every opportunity to *demonstrate* - through publicly, and perhaps privately, funded initiatives – how things can be better done.

How can the system be changed? By **believing** that it can be done and by demonstrating how to do things better….

"Interlink" Care Packages

Helping Hand, in common with a number of other organizations around the country, operates a group of home care packages funded by some Australian Government innovation funding:

Our "Interlink" packages provide support to people with disabilities who are ageing and who live either in supported disability accommodation or in community accommodation. The support is in addition to that which is already provided by disability providers. The aim of these packages is to provide a new choice for people with disabilities who are ageing which will help them to stay at home longer.

Interlink Packages are different from aged care packages because they are delivered through a partnership arrangement between an aged care agency and a range of disability providers. Helping Hand, as the aged care provider, is able to use Commonwealth aged care funding

to complement the support and services provided by the disability agencies.

We do this by:

- Working alongside the disability agencies to add value to the client services that are already being delivered
- Sharing experiences from the sectors
- The Co-ordinator from Interlink and the Case Managers from the disability agencies developing a close working relationship which capitalises on the client focus in both sectors

We have learnt that:

- Working together works and it makes a difference to the clients
- Working together offers staff the chance for ongoing learning
- Similarities exist between aged care and disability support (eg values, focus on clients) but we are able to complement each other by our differences (eg different styles of working, our ability to access different sources of funding)
- The whole is greater than the sum of the parts

Can the system really be changed?

Sometimes it can be difficult to be confident about achieving system change, so it's been suggested I tell the story of how the Australian aged care system was substantially changed in the mid-90s…

In the early ‘90s, a new manager at Helping Hand looked at the then residential care arrangements which comprised Hostels for those requiring basic personal care support, and Nursing Homes which provided higher level care.

This new manager couldn’t understand why we had a system which uprooted people – as their frailty was increasing – by relocating them from the Hostel which had been their home perhaps for years and where they had the comfort of familiar surroundings, staff and neighbours, to a Nursing Home elsewhere on the same site (if they were lucky) or, more often, to another suburb…

So Helping Hand resolved to build a new care facility of 98 rooms utilizing 50 Hostel and 48 Nursing Home licences, in which people would be able to live regardless of which category applied to them. This would allow people coming in as “Hostel” residents to “age-in-place” with additional services being supplied to them as their care needs increased and they qualified as “Nursing Home”. It also provided the potential for couples, who may have been classified in different categories, to share together one of the double rooms planned for the purpose. Many of our counterparts in aged care were doubtful, citing higher building and operating costs (because Nursing Homes has more stringent fire requirements) and difficulty in managing numbers.

But with the support of some key senior staff in the Adelaide office of the Department of Health and Aged Care, the case was put to Canberra and agreement reached. Helping Hand invested about $8 million in the new facility and it opened in 1995. The Federal Budget of that year even included a specific funding stream to allow the pilot to operate, because the existing legislation didn’t allow Nursing Home funds to be expended other than in a facility designated as such.

In its first two years more than 60 groups of colleagues from around Australia – and many politicians – visited the facility, and the successful outcomes which it brought for residents contributed significantly to the framing of the 1997 Aged Care Act which enshrined ageing-in-place as a central principle.

So a well-thought-out pilot can change the system!

I was that new manager who couldn't understand why Hostel residents were compelled to move and lose everything that was familiar to them when they least needed it, and I tell the story today to underline the point that good service delivery thinking **can make a difference…**

END