Latrobe Community Health Service
…Better health, Better lifestyles, Stronger communities…

SUBMISSION

DATE: 20 May 2010

TO: SENATE COMMUNITY AFFAIRS REFERENCES COMMITTEE

REFERENCE: **INQUIRY INTO PLANNING OPTIONS AND SERVICES FOR PEOPLE AGEING WITH A DISABILITY**

FROM: Latrobe Community Health Service

This document provides information for the consideration of the Senate Community Affairs References Committee which is focusing on the terms of reference below:

> *Access to planning options and services for people with a disability to ensure their continued quality of life as they and their carers age, and to identify any inadequacies in the choice and funding of planning options currently available to people ageing with a disability and their carers.*

Latrobe Community Health Service (LCHS) delivers services across the Gippsland region in Victoria. Services include primary and community health programs, community support services, aged care assessment, case management for people with disabilities and the frail aged, Commonwealth respite and Carelink. LCHS has 8 office locations throughout the Gippsland region, with locations in 5 of the 6 local government areas.

The LCHS Vision is:
Better Health, Better Lifestyle, Stronger Communities, which is supported by the objectives of the Strategic Plan (2007-2012):
- A Healthy Population
- Quality Services
- Community our Greatest Asset
- Excellence in Knowledge Management.

The LCHS organisational purpose is: To enable people to Live Healthier, Live Better, Live Longer.

Summary
The following points feature in this submission:
- Navigation of the service system, including jargon and paper work presents a challenge for service users.
- Insufficient appropriate respite and accommodation options, particularly in rural locations.
- Demand management based on urgency rather than advance planning.
- Workforce issues relating to availability of skilled staff.
- Insufficient numbers of and waitlists for current services.
- Gaps relating to age group and services that accommodate families and couples.
- The number and type of assessments required to access service needs refinement.
- Early or earlier intervention in planning would work well if the system supported it.

Staff who have provided feedback for this submission work in the following programs:

- Commonwealth Respite and Carelink Centre
- Aged Care Assessment Service (ACAS)
- Community Aged Care Packages (CACP), Extended Aged Care at Home (EACH), HACC and Disability Services, case management and planning.

Team members were asked to comment on six questions related to the Terms of Reference. The questions and team member responses are tabled below.

1. What specific problems have you seen confront some one with a disability who is ageing?

- Lack of respite and permanent accommodation options. Many clients have to wait too long to access planning services and to obtain funding to support with respite / accommodation.
- Difficulty accessing funding to modify accommodation to ensure it is safe as people with a disability age.

- Perception in the public hospital system that elderly people are "clogging beds." Resultant lack of dignified treatment and disenfranchisement.

- Insufficient CACP, EACH and EACH D packages with long wait lists for these services once assessed by ACAS. When someone is referred to ACAS for a package they usually require increased services at that time.
- Dislocation from supports/friends/family. Even more difficult for those with intellectual disability.
- Lack of age appropriate residential support for people who reach the point of not being able to care for themselves at home or have care needs that are no longer able to be met with available services.

- Carer issues associated with ageing, such as onset of dementia for Carer. Also physical decline and finding it increasingly difficult to continue the caring duties.
- Extreme difficulty accessing respite services in their local rural area.
- Ineligible to access local aged care facilities as they are ineligible for assessment by the aged care assessment service (< 65 years).
- Often clients require far more services to be provided to them in their home than their funding packages will allow.
- There is always a shortage of personal care and homecare staff.

- Unable to live independently. When the Carer is taken ill or has to go into hospital, it is very upsetting for the adult person with a disability to cope with the situation, change and daily living arrangements at the same time.
- Difficult to identify and deal with increasing medical issues, particularly for those with an intellectual disability who cannot express how they feel in a way that can be understood.
- Lack of respite facilities. Lack of required skills to complete forms to access services. The complicated and fragmented funding system which is difficult to understand.

2. What system/service barriers are there for people with a disability to plan for the future?

- One of the barriers is the waiting time to access services and workers who can support with future planning. Also it would be more beneficial if planning could begin as early as possible so that all options are explored; things are put in place and sorted rather than being organised in a rushed and reactive way when a crisis occurs.

- Lack of packages of care to permit home-based care.
- Lack of facilities to cover those "in between years" before aged care residential care is truly appropriate.

- People not understanding what is available in the community to assist them.
- Lack of advocates and support workers to assist with planning.
- Lack of appropriate residential supports especially in regional areas.
- People often have ageing carer who has need for support also. System largely doesn't allow for people to be located together if not able to be supported at home.
- Funding, skills development opportunities
- Clients are only able to apply for services when they need them and can demonstrate urgent need for services. This means they cannot plan for the future. When clients can demonstrate an urgent need for services they then have to apply for them and wait for a lengthy time on a waitlist.
- People get confused with the jargon and paperwork.
- Lack of flexibility on where people can live or what type of accommodation they reside in.
- Have to wait years for funding for home modifications etc.
- The complicated and unsympathetic bureaucracy of Centrelink and the fragmented health system which requires a Case Manager or other professional to navigate.

3. What system/service barriers are there for people with a disability to access appropriate services as they age?

- Mix of available information so not limiting options or being overwhelming and confusing.
- Isolation and distance for those who live rurally.
- Uncertainty of funding tied to current government policy.
- Confusion as to services and providers with ongoing multiple assessment by each agency.
- Some people have reported that they do not want to know about services available until they are ready to use them.
- People with a disability age faster and require services earlier. Placing them in the aged care sector is not the best solution for appropriate care.
- Lack of home based supports with sufficient flexibility & level of service to meet individual needs.
- Lack of appropriate residential supports.
- Lack of understanding of disability issues in the more mainstream services.
- Insufficient funding available from DHS.
- People are often confused by the seemingly vast array of service system providers and service system terminology.
- People often believe that once they have been assessed as being eligible for a service that they will automatically and immediately receive that service. This is rarely the case.
- Many people I have worked with have become bitter and frustrated by their dealing with the service system. This may have been their experience over decades of trying to obtain the help/ equipment/funding that they need. Many people give up altogether and cease to bother requesting services.
- There are few independent living facilities in country Victoria for young adults with disabilities. People like to be close to their family and social networks.
- There are no special wings within Ageing facilities, in the Gippsland region, that cater for young adults with disabilities.
- The fragmented health system which is very difficult to navigate.
- The slow response of the disability services sector in providing funding. For example, the wait list for an individualised support package can be up to 2 years with substantial paperwork to be completed.

4. If you know of one, please provide an example of a positive system/service response that best ensured quality of life for the person ageing (and their carer).

- Carer Services (Commonwealth Respite & Carelink Centre) is a flexible and holistic program that provides outreach to clients and links clients in to services needed now and possibly in the future. The needs of the clients and their carers are fully assessed and support provided is tailored to meet the needs of the individual.
- Availability of EACH for married couple with relatively short waiting time to enable ongoing home-based care as compared to residential entry.
- I am aware of a situation where two members of one family were located with in a low care facility in Gippsland. Following the use of current referral protocols and not being able to establish more appropriate accommodation - both were accommodated together.
- Service provided a mix of social interaction and skill development for the person with a disability to resource them better to accept services into the future when required.
- The positive examples I can think of are the small things that sometimes we are able to assist with; this might be the provision of advocacy or emotional support. It seems that the larger needs are often unmet.
- Providing someone with enough services and equipment to allow them to remain living as independently as possible for as long as possible. Having a joke with them and making them feel human and valued. Case Managers are able to provide a lot of assistance with service access.

5. Based on your experience with people with a disability who are ageing and their carers, what do you think would assist with planning and service access?

- Earlier intervention, not just when a crisis occurs, is required so that there is time for those involved to think things through and feel supported / secure in their decisions.
- Additional flexible respite options are needed to meet different needs.
- More self directed planning by providing people with the means to be more involved with decision making.
- Greater consultation.
  Availability needs to match approval.
  End to multiple assessing.
- Promotion of services available and then more funding /lobbying for increased amount of services for the target group.
- Appropriate care within the disability sector.
- Aging in place within the sector with their peers.
- An increase in the level of funding attached to supportive services and allowing these to be flexible enough to meet the needs of each individual occupying the same address.
- Some program guidelines prohibit providing the 'same service' to the same address - even if it is for different people in the family unit.
- Ability to plan with funding attached well before crisis hits. Funding to set up assistance for the Carer before they can no longer cope.
- More funding and respite facilities.
- General daily living skills and budgeting prior to moving a person into a facility or independent living would be an improvement on current services.
- Counselling for all family members to assist with the move could make the transition easier.
- Starting the planning process when the person with a disability is still at school so they experience the feeling of becoming independent once they reach age 18 like others their age. This would also help prepare families.

- An easy to access system that provides timely human contact with comprehensive and simple information on what services are available and how to access them.

6. Please provide other comment relevant to the Inquiry topic

- There are many wonderful services and service providers out in the community already. We need to continue to support and enhance these services through increased funding, further development and also continue to raise community awareness.

- Still need to streamline assessment so that each agency does not duplicate assessment which is often tiring / confusing for both client and carers.

- Increase the value of the CACP, EACH D and EACH as at this point in time, the packages are not enough to safely keep, in many cases, people at home. This is not in line with the policy agenda to lessen the amount of people going into aged care facilities.

- Young people with a disability placed in nursing homes; there needs to be places within the disability sector? I had to approve a 52 year old for an aged care facility. We need to do better as a society in the care of people with disabilities.

- Access to packages tailored at older parents and the person they care for. This group may need more support to plan for ageing without the worry.

- People with a disability need to be able to access respite in their own local area. They need to be able to access respite in a timely manner. As carers are ageing they in turn are more likely to experience medical emergencies of their own and require additional services for their family.

- Some Carers are reluctant to relinquish the care of an adult child with a disability which also becomes a barrier for services to be put in place.

- There needs to be many more supported accommodation facilities from low, medium to high needs people so there's a choice, and better training for staff that assist run and supervise these facilities.

- The whole system is bulky and complicated. There are many agencies providing services and funding but some of these are duplicated and many clients and families do not know where or how to access them.

- Poor communication between service providers and departments complicates the access to services.

- Some services are unsympathetic to the clients which discourages them from seeking help.

- Duplicating forms and information across multiple services is very frustrating for the clients.