ACH Group
Leading Choices for Older People

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Aged Care & Housing Group Inc.
ABN 99 437 071 895

16 August 2010

Inquiry into Long Term Care and Support
Productivity Commission
GPO Box 1428
CANBERRA CITY
ACT 2601

Dear Sir/Madam

Attached please find the ACH Group submission to the Productivity Commission Inquiry into Long Term Care and Support commissioned by the Australian Government.

We thank the Commission for the opportunity to make a submission to the Inquiry.

Mike Rungie
Chief Executive Officer
ACH Group

Long Term Care and Support

Productivity Commission Inquiry into Disability Long Term Care and Support

ACH GROUP Submission

August 2010

SUBMISSION TO THE PRODUCTVIVITY COMMISSION INQUIRY INTO LONG-TERM DISABILITY CARE AND SUPPORT

Introduction

ACH Group is a not-for-profit organisation, established in 1952, which provides health, housing, community and residential services to older people in South Australia and Victoria. ACH Group also provides support to parents older parents of adult children with a disability and to many people aged from about 45 t0 65 (particularly people with neurological conditions such as early onset dementia).

ACH Group supports South Australians to maintain their independence as they age and to continue to have rich and fulfilling lives, even in the presence of significant disability and ill health.

ACH Group has a long history of values based care which has evolved into a focus on "good lives". Older people tell us that a good life has 7 elements –

1. A good life is unique. No life has ever been lived before and it won't be lived again.
2. A good life is "mine" – each person is their own boss and makes their own decisions – good and bad.
3. A good life is optimistic – it has a sense of future.
4. A good life includes interests and passions like sport, art, music, faith, eating and drinking, volunteer work etc.
5. A good life also includes everyday things – it is much more than just things to do. We eat, we clean, we pay bills, we make lists, we look after a neighbour, we cope with grief and disappointment, we choose priorities for time, we work, we socialize etc.
6. A good life is companionable – it involves other people.
7. A good life is as healthy as it can be.

   Each of these elements has resonance with the overarching philosophies that emerge from the Disability Movement.

The simultaneous Productivity Commission Inquiry into Aged Care provides a unique and rare opportunity to develop these two vital support systems to work collaboratively and constructively.

ACH Group is a leading "not for profit" provider of aged care services in South Australia. ACH Group -

- Has contact with approximately 46,000 Australians every year through its residential, health, community and housing services.
- Provides disability and respite services to people with lifelong disabilities who are ageing and to older carers of people with disability.

- Operates over 1300 aged care packages of care with people in their homes
- Manages 7 Residential Aged Care Services that have over 500 places
- Provides housing to over 800 older people
- Provides restorative, therapy and health maintenance services to around 5,000 older people, including through a specialist residential transition care facility
- Assists over 7,000 older people to stay at home by undertaking minor home modification and maintenance services
- Supports over 23,000 veterans in several states and territories through the Veterans Home Care program.
- Employs over 1600 staff
- Works with over 800 volunteers
- Supports many older people with dementia/other neurological conditions and their families and carers through our specialist dementia services
- Delivers palliative care to many older people each year
- Supports a number of older people from CALD communities (including Italian, Dutch, Cambodian, Indo-Chinese and Polish)
- Supports older Aboriginal people, including through a specialist state wide Aboriginal respite and social support service.

As an aged care provider, ACH Group has worked for more than a decade to improve services at the interface between disability and aged care, to better support the good lives of several groups of people who are currently disadvantaged –

- People with a lifelong or longstanding disability who are ageing and who may need to access services from both systems
- People with degenerative conditions, such as Multiple Sclerosis, motor neurone disease, Huntington's Disease and early onset dementia. While the condition is often detected earlier, the reliance on higher level care often coincides with the third age of life.
- Older carers of sons and daughters with a disability.

Positive Ageing

Our interest in the Disability Care and Support Inquiry results from our work to facilitate positive transitions to old age for people with disabilities and their older carers, often in an environment of stand off between disability and aged care. The achievement of old age by many with disability who might previously have not survived is a new and positive pressure on a service system often seems disjointed and obstructive. This shifting demographic emphasizes the importance of a positive interface between the ageing and disability sectors and, more importantly, a view of people first and systems and services second.

Most older people do not draw on the aged care system until they reach their so-called "fourth" age[1]. The average age of people receiving our aged care services is about 82.

In spite of this, there is considerable fiscal pressure for people with a disability to start inappropriately accessing aged care (for example aged day centres). Most Day Centres (for example) are not appropriate models of care and we would suggest models with more valuable roles such as work and mixing with people their own age and interests.

People with lifelong or longstanding disability have one of the poorest health profiles in Australia, with high levels of obesity and smoking, low involvement in exercise and high rates of co-morbid physical and mental conditions for example. They have also very often had a life time of low income and reach their third age with diminishing informal networks and involvements as their primary carers age and their employment ends.

Despite this, there is very little support or expectation that people with disabilities will need support to live positively, to plan ahead and to meet their third age needs. These needs include -

- positive health management and the prevention and management of chronic disease
- retirement planning, including assistance in managing major life transitions, developing meaningful leisure options and community roles
- lifestyle support
- caring for older parents
- income security and financial counselling, and
- accommodation that suits a retirement lifestyle.
- working

[1] Retirement from participation in the workforce is usually regarded as defining the beginning of the Third Age, and while there is less agreement about the definition of entry to the Fourth Age, some demographers have identified age 85 as the entry criterion for membership in the group of the oldest old. The Fourth Age: A Period of Psychological Mortality? Dr. Habil. Jacqui Smith, Berlin. 2000

Consumer Choice and Control

As a large, private not for profit aged care organisation with experience in the frequently fragile interface of ageing and disability services we believe that the current system to support people with disability and their families is flawed and will increasingly be unable to meet people's lifetime needs. There is also insufficient capacity for people with disabilities and their families to exercise choice about the services they use and have control over the financial resources available to them.

There is also a pronounced lack of coordination and consistency within the current system illustrated through:

- Having access to one program restricted inappropriately because of receiving support from another
- Incomplete links between services provided by different levels of government
- Access to individualized funding
- Lack of support and capacity to plan ahead for older carers.
- Access to individualized funding/consumer directed care for both carers and for people with disabilities who are ageing
- Lack of suitable models of work, socializing and other appropriate and valued roles for people – particularly those aged 40+ with degenerative neurological conditions
- The need for a consumer directed care/personalized budget scheme which would overcome the problems faced by people with profound disabilities who currently cannot access the assistance they require under the plethora of piecemeal arrangements that exist at a local, State and Federal level).

ACH Group supports a scheme, funded on a no-fault, entitlement basis, and proposes that it should include –

- Capacity for people with disability to have access to an equitable level of support wherever they live
- Bundled funding for each individual, able to be directed at the support that most suits needs
- The elimination of the current inefficiencies of funding being distributed to service types which may or may not be of most value for the person with the disability

Capacity for each person with a disability to select their managing agent (including the option to self manage), and to transfer freely from one to another as preferred, much as one might change telecommunications providers. In its submission to the Productivity Commission on the Care of Older Australians ACH Group suggested a similar scheme

Interface between disability and aged care

An important part of the ACH Group interest in disability (despite being an aged care provider) was our desire to improve the interface between the aged care and disability systems.

People experiencing conditions such as neurodegenerative conditions (eg Multiple Sclerosis, motor neuron disease, Huntington's Chorea), early onset dementia (eg Korsakov's, AIDS related) or Acquired Brain Injury often get caught in a bind when seeking services as they age. While the condition is often detected earlier, the reliance on higher level care often coincides with turning 60 or thereabouts and so they enter the nether world between the aged care system, which characterises them as younger people with a disability and the disability system which sees them as "old" and therefore eligible for aged care! These people ought not to be funded against an aged care paradigm – rather one that reflects where they might be at their age and stage in life. - having Dementia does not make you old!

Likewise, people with long standing disabilities often struggle to access the aged care support that would assist their pursuit of a good life. Despite the fact that people with disabilities who are older are part of the eligible constituency of both disability and aged care services, there is a real risk that the underfunded disability sector will buck pass to the equally poorly resourced aged care sector, and *vice versa*. This is not just a funding issue but an issue around inappropriate paradigms of care and support.

For many older people with disabilities a partnership between particular disability support and aged care is essential. For example, it is estimated that about 70% of the 1,000 South Australians who communicate through sign language are aged over about 55, with many in their 80's. For these people, better practice aged care will be provided by signing care workers (or, less optimally, in the presence of interpreters), an approach which is not yet available. In the absence of such support these older people will become very isolated much as culturally and linguistically diverse (CALD) older people do in the absence of culturally appropriate support.

The boundary between the aged care and disability systems is murky, with neither system meeting the real needs of people who are experiencing many of the same transitions that the mainstream community experience in third age, without the same support.

With the growing interface between disability services and aged care services these barriers are noted particularly though not exclusively in the areas of -

- Opportunities for older carers to access flexible, regular and personalized respite
- Access to aged packaged care (CACP's, EACH) and to HACC services for people with disabilities aged 55 to 65.

Scope of Disability Support

With regard to eligibility for entitlements we urge the Commission to include disabilities which are currently not acknowledged or inadequately acknowledged, including autism, language disorders, learning deficits, and various neurological conditions.

Any system too will need to facilitate life transitions, including into old age, such that the person experiences continuity, certainty and a capacity to control their own choices.

Eligibility should acknowledge the high rates of co-morbid physical and mental health issues experienced by people with intellectual disability such as schizophrenia, depression, anxiety and post traumatic stress disorder.

While we note that the terms of reference "cover people with disabilities not acquired as part of the natural process of ageing", some conditions such as dementia and deafness, are often viewed as age related despite sometimes being experienced well before age 65. This currently results in a stand off between the disability and aged care systems about which system should fund and serve them and often leaves the individual without services or receiving services that are far from optimal.

Indeed currently a person with early inset dementia can very often only be supported in the aged care system which assumes that the person does not have a dependent family, is physically frail, and is able to supply a bond and daily care fees if they need a residential care option – particularly when supporting a younger person (i.e. less than 65 years of age) with a disability in a Residential Aged Care setting is completely the wrong paradigm of care.