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HCCA Submission to Productivity Commission Inquiry into Caring For Older Australians

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HCCA Background

Health Care Consumers' Association (HCCA) of the ACT was formed over 30 years ago to provide a voice for consumers on local health issues and now provides opportunities for health care consumers in the ACT to participate in all levels of health service planning, policy development and decision making at the local and national level.

The fundamental principle that HCCA looks for in the development of any strategy relating to health care systems is acknowledgement that the individual consumer is in the best position to be aware of their own health care needs. An essential role of the system is to support and empower consumers to take active steps to improve their own well-being. This is encapsulated in Declaration IV of the Alma-Ata Declaration: "The people have the right and duty to participate individually and collectively in the planning and implementation of their health care".

Too often discussions around human services are overwhelmed by the commercial needs of service providers. In any discussion regarding aged care the people using the services and their families must be the primary focus. In doing this it should be acknowledged that family members are important members of the care team of any older person living in residential care.

The Australian charter of health rights.

The Australian Charter of Healthcare Rights, which has been adopted by all Australian governments state and federal, should guide the provision of all health care in Australia including care for the aged. Briefly the charter states

<p>Access – I have a right to health care Safety – I have a right to receive safe and high quality care Respect – I have a right to be shown respect, dignity and consideration. Communication – I have a right to be informed about services, treatments, options and costs in a clear and open way. Participation – I have a right to be included in decisions and choices about my care. Privacy – I have a right to privacy and confidentiality of my personal information. Comment – I have a right to comment on my care and have my concerns addressed.</p>

The Productivity commission should bare these rights in mind when considering provision of services for the aged.

Aged care residents rights and responsibilities

As a minimum HCCA would like to see the charter of Residents Rights and Responsibilities used as a yardstick by which all aged care facilities are measured.

Below is the charter as published by the Department of Health and Aging.

A. Each resident of a residential care service has the right:

- to full and effective use of his or her personal, civil, legal and consumer rights;
- to quality care which is appropriate to his or her needs;
- to full information about his or her own state of health and about available treatments;
- to be treated with dignity and respect, and to live without exploitation, abuse or neglect;
- to live without discrimination or victimisation, and without being obliged to feel grateful to those providing his or her care and accommodation;
- to personal privacy;
- to live in a safe, secure and homelike environment, and to move freely both within and outside the residential care service without undue restriction;
- to be treated and accepted as an individual, and to have his or her individual preferences taken into account and treated with respect;
- to continue his or her cultural and religious practices and to retain the language of his or her choice, without discrimination;
- to select and maintain social and personal relationships with any other person without fear, criticism or restriction;
- to freedom of speech;
- to maintain his or her personal independence, which includes a recognition of personal responsibility for his or her own actions and choices, even though some actions may involve an element of risk which the resident has the right to accept, and that should then not be used to prevent or restrict those actions;
- to maintain control over, and to continue making decisions about, the personal aspects of his or her daily life, financial affairs and possessions;
- to be involved in the activities, associations and friendships of his or her choice, both within and outside the residential care service;
- to have access to services and activities which are available generally in the community;
- to be consulted on, and to choose to have input into, decisions about the living arrangements of the residential care service;
- to have access to information about his or her rights, care, accommodation, and any other information which relates to him or her personally;
- to complain and to take action to resolve disputes;
- to have access to advocates and other avenues of redress; and
- to be free from reprisal, or a well-founded fear of reprisal, in any form for taking action to enforce his or her rights.

B. Each resident of a residential care service has the responsibility:

- to respect the rights and needs of other people within the residential care service, and to respect the needs of the residential care service community as a whole;
- to respect the rights of staff and the proprietor to work in an environment which is free from harassment;
- to care for his or her own health and well-being, as far as he or she is capable; and

- to inform his or her medical practitioner, as far as he or she is able, about his or her relevant medical history and his or her current state of health.

Access to Information

As a community we have higher expectations in terms of choice, responsiveness, and flexibility in how we access health, community care and aged care services. These expectations need to be managed. One important element of this is ensuring that people have access to information on all types of services and accommodation types that can be used by people as they age in the community.

It needs to be recognized that aged care services are not totally the responsibility of health care providers. A team or case approach needs to be developed to allow appropriate services to be marshalled for individualised care. In other words a cross sector approach is critical.

Policy directions have moved to positive ageing and ageing in place. Both require a higher level of coordination of services to ensure that the range of community based services are in place to support older people in retirement communities and those living in their own homes. The Commonwealth Government has introduced a range of funding packages to enable this including the Home and Community Care (HACC) and Community Aged Care Packages (CACAP) packages as well as the dementia specific EACH and EACHD packages.

Navigating the System

As Australians live longer there is a higher proportion of the population who will be frail aged with more complex, high-care needs. There is also a higher proportion of older people living with co-morbidities which require management and access to health services. The current system is complex. Whether it be the maze of accessing an ACAT assessment, completing the 26 page Centrelink form, or trying to find providers of in home care, finding the information at the right time in order to make informed decisions is very difficult. Many are defeated by the challenge. We make choices about services without knowing how well they perform or whether they are appropriately located. Information is also difficult to find. Accurate, up to date and plain English Information needs to be centrally located and easily accessible.

Information and communication is essential to this. We need information that helps with decision making; this means taking into account one's health status, hobbies and interests, community and family connections and financial means as well as lifestyle preferences. Because information about services is so scant decisions about services are often made merely on how well presented a service or facility is, rather than on how the service meets needs or performs against standards. While appearances are an important element of service provision it is the quality of the services within the complex which determines outcomes.

The Care Quality Commission is the health and social care regulator for England. Their aim is to ensure better care for everyone in hospital, in a care home and at home. They have an online search so that consumers can find their local care

services and get an independent view of how well they are performing. We consider that there is a need for a similar agency in Australia.

TOR 2: regulatory and funding options for residential and community aged care

Funding Options

There has been increased consideration of giving individuals greater control over decisions relating to their care and the allocation of funds to select services. Some stakeholders in the sector are arguing for individuals eligible for assistance under the Aged Care Act 1997 to be able to choose what mix of services they receive and which accredited provider delivers the services and where they are received. This would certainly provide many with the opportunity to get their individual needs met. Before any such scheme were developed there needs to be extensive community engagement and discussion on the topic a discussion which explores what it means to age in place, what financial provision you need to make and what would be reasonable for the community to provide.

There needs to be careful checking and training, accreditation and registration of the service providers to ensure that vulnerable old people are not exploited.

Access to care

The answer for aged care services appears to be to build ever more high care residential aged care facilities, even though newspaper reports suggest that these facilities are the most miserable places in the community and that they are failing to meet the most basic needs of the residents. Yes residents are fed, but there is no choice and the food is “manufactured” off site; recreational activities are often inappropriate (juvenile) or silly (square dancing for wheelchair bound people) or people are left alone with no one to talk with.

It is time to look at overseas examples of aged care services where they no longer build large institutions where older people are hidden away with limited contact with outside world. In Australia access to home based service is an intricate maze where “the winners” of services are often those who are the most persistent. These people become ‘grateful’ for the meagre assistance and are too scared to ask for more. Information on services is difficult to find and has developed an air of mystery that can not be penetrated by people who are not part of the system. Information should be accessible in many formats and languages so that people can make a decision based on facts and needs not on desperation. Often the need to use aged care services comes at a time of crisis and people are expected to make decisions without full information about the range of services or a full understanding of the needs of the person who will use the services

Standards

We would like to see the development of quality indicators form the basis of a standards system for services for the aged in Australia

Quality standards have been developed for child care services, hospitals and community services but still there is no single comprehensive national system of accreditation for aged care services. The need for such a system is urgent; aged people are the most vulnerable people in our community. The Government, as the major player in this field, should be giving some attention to reviewing and developing new standards that are more robust than the current system that appears to favour providers at the expense of the users of the service, the residents of aged care facilities and the recipients of the services

TOR 4: Future workforce requirements of the aged care sector

Nurse practitioners

We are hopeful with access to the MBS and PBS from 1 November 2010 that nurse practitioners will be able to meet the primary care needs of many people living in residential aged care facilities. There are numerous facilities which are not visited by a medical practitioner, meaning that aged care residents are often transported to hospital for emergency departments for medical care which they could have received at their residential facility had there been a suitably trained practitioner (nurse or doctor) available to treat the individual. This situation is ridiculous, costly, traumatic and inefficient. We hope that Nurse Practitioners will fill this medical void.

New models of care

We would like to see an expansion of related health services, such as sub-acute care and respite services, community-based palliative care and primary health care services, to support older people living in their homes as those living in aged care facilities.

We support the Australian Nursing Federation campaign to have a mandatory qualified nurse to resident ratio and fair wages for aged care nurses. There is a mandatory carer to child ratio in place in the childcare sector, and we are of the view that there needs to be a qualified workforce to look after the needs of older people in care.

The introduction of transitional care services or step down facilities has resulted in people being able to return to their own homes and continue independent lives outside of institutional care. The less time that older people spend in acute care settings the more likely they are able to stay in their own homes. The loss of independence and self-confidence is huge and can be addressed with services that work towards keeping people out of hospital. These services do not necessarily have to be delivered by highly qualified clinicians but by a range of people with a variety of qualifications and experience. The other benefit of providing transitional care services is the reduced expenditure of health dollars and aged care dollars in building more and more institutions.

As well as increasing the number of nurses in residential aged care facilities (and ensuring through visits that this standard is met) it is important to review the other staff in these facilities. The number of personal carers needs to be increased so that

more direct and personal care can be given. For instance the reports from most services suggest that the carers do not have time to stop and talk and to recognise the resident as an individual. The personal carers need to have training in the types of services that they are delivering. The TAFE System has a number of different courses that should be mandatory for all staff working in the aged care sector. The child care sector is moving to all staff having formal and appropriate qualification, often at certificate level, before working that sector, so should aged care worker. This would mean that the staff working in aged care would need to have salaries that recognise their qualifications. It would provide opportunities for staff development and career paths in the sector. The current situation where people working in retail earn more than people working in aged care must change. Rewarding career paths need to be established and appropriate financial rewards available to those who choose to working aged care. Training and education can not be left to the individual aged care service providers but should have the scrutiny of an external nationally accredited provider.

More trained staff in the delivery of care services would also provide a group of people who would be able to deliver care services into individual homes or to clusters of people living in retirement villages or small unit developments that may not have the designation 'aged care housing' but older people may be aging in place in the community . The ACT has many of these clusters which have been built as public housing.

Access to allied health care and dental care

Community health services and support services like dental care, allied health services or mental health teams need to be accessible via affordable transport. The cost of this transport is often a barrier for consumers. We would like to see the development of mobile dental units similar to the mobile blood banks or immunisation vans which could go to areas of need and set up for a few days. This would eliminate the transport issue for many.

Respecting Patient Choices and Advance Care Directives

Advanced Care directives, including Respecting Patient Choices, should be promoted as a means of encouraging individuals and their families to plan for future possibilities. This would ensure the person and his/her family would have a better understanding of the choices which are available, when relating to end-of-life care. It is a means of assisting an individual to exercise his/her decision making process while they are still mentally, physically and emotionally able to do so.

Medicalisation of death

In a recent article entitled Diagnosis of Dying published in the Health Advocate, Professor Ken Hilman from the University of NSW he points out that death has become medicalised in much the same way that pregnancy and childbirth became medicalised in the 1950's and that:

...management of end-of-life in acute hospitals is often inappropriate and cruel. Nevertheless, there are pressures to place people at the natural end of

their life on a conveyor belt from their home to their hospital and from there into an ICU to spend their last days connected to machines when there is no hope of recovery.

We feel strongly that the Australian community wants and needs to have a robust conversation about this issue, and that control over decisions relating to the end of life needs to be returned to individuals and their families. This should be incorporated into a system of nationally accredited standards of care for the aged.

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