

Menzies Centre for
**Health
Policy**



Caring for older Australians: Productivity Commission Submission

August 2010

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As Australian society ages, the number of people living with chronic illness will also rise. In 2006 chronic disease was estimated to make up 80% of the total burden of disease and consume two-thirds of health expenditure (1). Older Australians can expect to live longer, but their quality of life will depend on greater skills in preventing – or at least managing – long term illnesses.

Older people will need the resources of health literacy and confidence to successfully manage these challenges but the current picture is disturbing. The Australian Bureau of Statistics survey of adult health literacy in 2006 found that 83% of those aged 65 to 74 were below skill level 3: ‘the minimum required for individuals to meet the complex demands of everyday life’ (2). The ABS defined health literacy as an ‘ability to access and use health information ... a fundamental skill that allows people to make informed decisions and helps them to maintain their basic health’.

Health literacy is far more than knowing the meaning of medical terms and pharmaceutical regimes. It encompasses the confidence with which individuals engage with the health system and their ability to manage their illness and themselves with that illness – avoiding the stress and cost of repeated, avoidable hospitalizations.

This submission is informed by our research with people with chronic health problems, the Serious and Continuing Illness Policy and Practice Study (SCIPPS), a five year patient-focused study funded by the NHMRC and operating in Western Sydney and the Australian Capital Territory.

Our research identified failed linkages, if not actual blockages, between the health and aged care sectors as major obstacles to effective self management of chronic illness in the home and in the community. Self management depends upon an individual’s skills, capacity and active participation in treatment and related activities such as medication adherence, diet, exercise and managing mental health (3). It is vital to the care and management process of most chronic illness, including chronic heart failure, diabetes and chronic obstructive pulmonary disease - the three conditions that were the subject of our research. These disconnects in the system make it more difficult than necessary for older people with chronic illnesses to maintain independent living and so should be addressed as part of this inquiry.

Here we answer three questions raised in the Productivity Commission’s Issues Paper:

1. Are reforms required to more appropriately support carers and volunteers?
2. Should there be greater emphasis on consumer-directed care in the delivery of services and would this enable more older Australians to exercise their preference to live independently in their own homes for longer with appropriate care and support?
3. How well does the aged care system interface with the wider health and social sectors?

We propose the following recommendations:

- 1. Redefine the concept of need, inherent in the eligibility criteria, to improve access to services by clients with diverse needs and their families – this includes better access to support for family carers.**
- 2. Identify the support required to enhance older Australian’s capacity to determine for themselves and ask for services that best meet their needs and the system’s capacity to deal with the potential increase in demand for services.**
- 3. Identify the suite of services that best support older people with chronic illness and their carers to live at home longer.**
- 4. Improve the quality and consistency of data collection on community-based aged care services. This should be accompanied by a continuing program evaluating service quality to identify unmet needs within the system. This could be achieved by earmarking a proportion of program funding to research and evaluation.**
- 5. Improve the policy links between the government sectors involved in social welfare to get their acts together in supporting older and chronically ill Australians, especially those living in their own homes.**

(1) Are reforms required to more appropriately support carers and volunteers?

Time and again in our study we were amazed by the love and commitment of family carers for the patients we interviewed. One of our interviewees remarked, “Ninety percent of the care of people with chronic problems is provided outside the health and welfare services by family and friends!” Family carers provide distinctive support for patients with chronic problems enabling them to exercise a measure of personal control over their illness and engage in self management.

The informal care role is demanding in every respect - psychologically draining, socially isolating and often physically exhausting and is usually borne by people who are old themselves. The current policy structures result in inadequate access to the physical and emotional support and training required to perform well in this role for years – as is often required.

We recommend that your Inquiry define the gaps in policy that may be disadvantaging carers. For example, one key issue is that informal care policy is linked to an assessment of the care-recipient’s genuine need for care - based on their level of physical and cognitive disability, not the needs of the carer.

In SCIPPS we found that carers of people with chronic illness have distinct needs that arise from their care-giving role. We found that informal carers would benefit most from targeted skills-based programs that assist with the development of confidence and competence to carry out the following types of functions (4):

- assisting a care-recipient with self-care (e.g. bathing; using the toilet);
- obtaining health information;
- coping with role reversals;
- maintaining relationships with family and friends, including dealing with conflict resolution;
- advocating on behalf of a care-recipient in health care settings and;
- offering appropriate and useful levels of coaching and monitoring.

Family carers involved in assisting older Australians with self management of a chronic illness fall into serious policy gaps: we found that they have limited knowledge and access to the current services established to support informal care. The eligibility criteria for access to community support services should to be revised so that carers can be assessed based on their needs for assistance as well as the needs of care-recipients with complex chronic illnesses.

Recommendation 1: Redefine the concept of need, inherent in the eligibility criteria, to improve access to services by clients with diverse needs and their families– this includes better access to support for family carers.

(2) Should there be greater emphasis on consumer-directed care in the delivery of services and would this enable more older Australians to exercise their preference to live independently in their own homes for longer with appropriate care and support?

A greater emphasis on consumer directed care in the delivery of services could improve the flexibility and responsiveness of the aged care system. Such flexibility and responsiveness is currently lacking and this creates unnecessary barriers for chronically ill people who are trying to maintain independent living in the community. However, it must start from a recognition of the information asymmetries that are endemic to health and welfare policy – especially for the aged. These provide major barriers to the effective use of existing avenues of support. Current programs are confusing, eligibility criteria are often obscure and inconsistent. Assessment is often slow and has difficulties in adjusting to rapid changes in the conditions of the chronically ill.

People in SCIPPS discussed how difficult it was to balance the demands of their illness and everyday life. They felt that the services on offer were not well attuned to their particular needs and they were unaware of the range of community services that were potentially available to assist them (5). As a result, they struggled along without receiving the support they required. Such disconnects between individuals' actual needs and service provision and information about those services available create problems for self management. This can have serious consequences for patient outcomes and the support and resources required as a result. A greater emphasis in the system on consumer-directed care could address this issue.

Participants spoke of a need for services to enable them to better balance the demands of their illness and everyday life and thus maintain independent living in their homes for as long as possible. The following types of services were identified as the practical care and support required, but which were often difficult to access (5):

- home assistance for cooking, cleaning, gardening and grocery shopping;
- subsidised community transport schemes for travel to health care appointments, social activities and for running errands;
- assistance with medication management (e.g. picking up prescriptions, explaining dosages and support when side effects occur);
- flexible respite for informal carers and;
- coaching for lifestyle and risk-factor modifications (e.g. maintaining physical exercise, quitting smoking, eating healthy).

How might the system better support individuals to exercise a preference to live independently?

1. Individuals must have the knowhow and the confidence to identify their needs. This is linked to the concept of health literacy - The knowledge and skills required to understand and use information relating to health issues such as disease prevention and treatment and staying healthy and to navigate the health and welfare systems with confidence (2). Reforms to enhance consumer directed care must incorporate interventions to develop the capacity of older people to accurately identify their needs and access those services to meet those needs. Additionally the aged care system must also review its capacity to be responsive to more informed and 'demanding' patients and carers.
2. The suite of services that support independent living, particularly for individuals with complex chronic illness and co-morbidity and those who may have special needs, for example older Australians from culturally and linguistically diverse backgrounds (CALD) and Indigenous Australians, must be clearly defined. SCIPPS provides an important source of information on these practical support needs, as identified above.
3. The alignment between older people's actual needs and the range of aged care services currently available must be reviewed in parallel with the reform of the Home and Community Care (HACC) program - the most accessed aged care services. The mix of HACC services and providers differs dramatically between the States and Territories and there is little consistent and robust data to evaluate these contrasts. We don't know what is working well, for whom and why, and importantly - what's missing - across the jurisdictions and this limits opportunities for transferring lessons about the successes throughout the system. The COAG Reform Council report (2010) highlighted this problem of poor and consistent data across jurisdictions (6). Any moves to develop more standardized service models based on 'best practice' - a likely outcome of the Commonwealth Government's takeover of the HACC program - must be based on a better knowledge base about the alignment between client needs and services that are currently available.

Recommendation 2: Identify the support required to enhance older Australian's capacity to determine for themselves and ask for services that best meet their needs and the system's capacity to deal with the potential increase in demand for services.

Recommendation 3: Identify the suite of services that best support older people with chronic illness and their carers to live at home longer.

Recommendation 4: Improve the quality and consistency of data collection on community-based aged care services. This should be accompanied by a continuing program evaluating service quality to identify unmet needs within the system. This could be achieved by earmarking a proportion of program funding to research and evaluation.

(3) How well does the aged care system interface with the wider health and social sectors?

The aged pension and associated subsidy and concession programs are frequently insufficient for older people and their families to maintain an acceptable standard of living. This becomes more difficult if a chronic illness - or more usually several – is added to the picture. The home care and life-style modifications required as part of most self management plans and the costs of transport are expensive, adding to the out of pocket costs associated with medical services. Self-funded retirees are often saddled with huge out of pocket costs for their care as they are not covered by Health Care Cards or other social security arrangements.

The participants in SCIPPS echoed concerns about the negative impact that their illness had on their household's finances. They frequently reported an inability to pay for the necessities required for the management of their illness and often had to make sacrificial choices between paying medical expenses and basic living expenses (7). They reported using the following strategies, in some cases on a regular basis, in order to deal with the competing demands on their very limited resources (7-8):

- limiting discretionary spending;
- cutting back on more expensive, healthier foods;
- reducing participation in regular exercise programs;
- missing medical appointments;
- not filling prescriptions;
- borrowing money from friends and family;
- depleting savings and;
- selling other assets.

These coping strategies not only compromise the care and management of their conditions, but also make it more difficult to maintain independent living. While many people reported prioritising expenditure on essential treatment, it meant making compromises in other areas that were important to their quality of life and connection to the community (8). Importantly, while concessions and subsidised services are enshrined in the social security system in Australia, we found that possession of a Pensioner Concession Card, Commonwealth Senior's Card or Health Care Card were not always enough to help participants to maintain a minimum standard of living. Of most concern, people with chronic illnesses are often ineligible for such subsidies, an issue that was also identified in the Harmer Pension Review (10).

The reforms to the aged care system are occurring at a time when the health and welfare systems are also under-going reform. As part of this Inquiry, the Commissioners should identify the linkages between policies that are required to minimise the negative economic impact that is associated with aging with chronic illness.

Recommendation 5: Improve the policy links between the government sectors involved in social welfare to get their acts together in supporting older and chronically ill Australians, especially those living in their own homes.

We greatly appreciate the opportunity to make a submission to this inquiry and value the commissioners' time and consideration of the issues we have raised here.

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The Menzies Centre for Health Policy is a collaborative Centre between The Australian National University and the University of Sydney. It aims to provide the Australian people with a better understanding of their health system and what it provides for them. The Centre encourages informed debate about how Australians can influence health policy to ensure that it is consistent with their values and priorities and is able to deliver safe, high quality health care that is sustainable in the long term.

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