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Caring for Older Australians
Productivity Commission
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# Caring for Older Australians

*Submission to Productivity Commission*

Thank you for the opportunity to provide a submission to your inquiry. My family's major recommendations to the Commission related to the provision of community care and are described on the following pages under the relevant questions in your issues paper.

## *Background:*

Before providing our recommendations, I should explain my twofold interest:

- I have worked in or for the community care sector since the mid eighties, as a State Government regional coordinator and as a national, state and local consultant.
- My sister and I are non-resident carers of our elderly parents. Mum and Dad want to continue to live in their own home. Their characteristics and needs, which impact on their community care, include:
    - Dad is 91, very frail and a Veteran (holding a white card);
    - Mum is 88, reasonably fit for her age, but living with dementia;
    - Both are on the aged pension, with Dad receiving a small Veterans' disability supplement;
    - Our family navigates the complex interfaces between the HACC, Veterans', Health, Centrelink and Commonwealth community aged care support systems. While I would be considered a well informed consumer, this navigational act is at times overwhelming. Attachment A (CONFIDENTIAL) lists the range of services received and assessments made of my parents' situation since March of 2010;
    - The good news is that despite significant functional difficulties, my parents are continuing to live at home with family support and the support of both government subsidised and privately purchased providers;
    - Dad is very well supported by the Veterans' system for which we are very grateful. We are aware that without his Veterans' status, he is likely to have received far less support from the general community care system;
    - The listing at Attachment A shows that my mother, who becomes anxious under questioning, has been assessed directly and indirectly by some 16 workers/agencies since about March of this year. Meanwhile, despite these assessments and her obvious needs, we still continue to privately purchase her major home support needs (housekeeping and personal care), because no government subsidised options are currently available to her. She is on a waiting list for a care package.

## *Your discussion questions:*

***Page 13** of your issues paper: The availability, accessibility and continuity of community aged care and its interface with health and social services.*
***Pages 15 and 20**: Choice and seamless, timely transitions within and across sectors*
*And **page 23**: Dual gatekeeping mechanisms and common system entry points*

- Our parents' eligibility and need for community care support is not in doubt.
- However, our family has had to negotiate increasingly complex access systems, including centralised Health Intake and Community Care Access points. We have found these to be time intensive, duplicatory and not consumer or carer friendly.
- All but one of my five or six communications with the Parramatta based, Hunter Community Care Access Point, were not positive or efficient. The system seems to have moved beyond it original objectives of determining eligibility and streamlining consumer and carer access to support. The requirement for all Hunter referrals to new HACC service types to be made through the access point puts barriers in the way of streamlined and natural service provision pathways; creates a bottleneck; requires consumers, carers and indeed providers, who already know what they want and from whom, to make additional phonecalls to outline needs to people who may care or know less than those already involved; and works against effective cross agency planning, problem solving and collaboration.
- Our family is currently trying to coordinate support provided by 14 organisations, involving some 24 different services, each with their own policies and access systems. As noted above, Mum has been assessed at least 16 times since March of this year, yet continues to receive only one ongoing government subsidised community care service – meals three times a week. (She is also currently in receipt of episodic case management, which has considerably relieved us of some of the organisational and referral responsibilities.)
- At various times, we have turned down possible support options as, at the time, we were already negotiating with enough agencies, had told our story too many times to too many people, or we have not wanted to introduce yet more agencies and services into our parents' home and lives. Despite the number of assessments already undertaken, we continue to encounter new program specific assessments, which would be required if we took up all of the support options recommended. These additional assessments present barriers and don't build on what is already known by so many. For example, we explored an extended primary health care plan for Dad to complement the physiotherapy support we had begun to purchase. The system was time consuming and we and one of Dad's support workers had to push to convince the GP of the need to invest in this effort. (The physiotherapy intervention did however have a positive and ongoing effect on Dad's mobility and confidence.) Further, some assessments, such as annual ACAT re-approval of not yet utilised care packages or low level residential care, seem unnecessary for people with the functional dependencies and ages of my parents.
- We have met a lot of assessors/coordinators, but have seen very little, or possibly no, cross agency/service coordination prior to Mum's recent receipt of episodic case management.
- We have encountered barriers to effective and responsive support. For example, weekly respite has recently been provided by Veterans' to my father. Because of his frailty, my father does not wish to go out but rather to use the four hours for a sleep and a break from his concern for Mum. But the service rules prohibit the respite worker taking Mum anywhere beyond walking distance, as travel anywhere by car or taxi is not allowed.

So our conclusions are:

- Despite my extensive knowledge of the community care system, the system remains difficult to access and negotiate, with increasing barriers being placed in the way of seamless and responsive support.

- I, and others, regularly fail in our efforts to provide sensible answers to my father's reasonable questions about the reasons for the plethora of rules, individuals and agencies with whom we have to deal.
- Our experience, and international literature (eg Henwood, Geron) show that older people value their relationships with workers far more than current community care systems reflect. They also are given little control or choice (eg Kendrick) and don't understand service rules and rigidities which prevent them from choosing their most desired support.
- The accessibility and availability of support for my father as a veteran stands in stark contrast to the support available to my mother.
- At times we have accepted services of lesser importance to the family because program rules have not allowed the provision of services considered of greater need, such as provision of personal care for Mum. (My parents are therefore privately purchasing most of Mum's ongoing support.)
- Cohesive, seamless, responsive and coordinated community care wide support is much discussed but rarely delivered.
- If we could combine and use the community care support and resources to which our parents are entitled, from the current range of Veterans', community care and Centrelink programs, we believe we could create far more coherent, responsive and efficient support. We would not necessarily want to directly employ staff, but rather use agencies and workers of our choice to deliver our parents' most needed and preferred services within a coherent and coordinated plan. We believe that a well designed Consumer Directed Care option could help us achieve this.

We recommend that:

- Any **community aged care system must embrace all community support and respite programs and options**, breaking down the current Government, program or Departmental specific silos which make responsive and efficient support so difficult to organise. Preferably the system would be based on a **Consumer Directed Care** approach to give consumers and carers control and choice of delivery strategies and support options. The design of such a system would also need to be built on breaking down the barriers and rules which prevent consumers receiving the support they most want to continue living in their own homes.
- **Access and assessment systems** should similarly be community care wide, rather than program, GP or Departmentally specific. Once eligibility is determined, access systems should only be used to complement natural service provision pathways to assist consumer and carer access, rather than being used as a referral bottleneck or a tool for other resource distribution objectives. Community wide assessment or sharing of assessment results should be promoted, so that constant re-assessment and re-telling of stories and issues is not so prevalent.

We support the move of aged care to the Commonwealth as one means of breaking down the lack of integration in the current community aged care system. However, moving the HACC system to the Commonwealth will not be sufficient. **Integration of existing Commonwealth programs (both within and across Commonwealth Departments)** will also be essential.

## *Page 13 of your issues paper: Maintaining people's independence.*

The current community care system needs to greatly enhance its capacity to work with older people to identify what will build independence and ability to live at home and to provide targeted, possibly one-off support, to help each person to continue at home with maybe no, reduced or delayed ongoing community care support. **Professor Gil Lewin's submission 114 is supported.**

## *Page 13: Is the current system equipped to meet future challenges?*
## *Page 22: Regulation and enforcement*

For a community care system to be viable into the future for the increasing number of aged people in Australia who will want to live at home for as long as possible, the system must be built on a different risk construct than has been applied to residential aged care.

It must be recognised that aged people who choose to continue to live at home are generally actively choosing to do so. For the vast majority of older people, remaining at home is achieved via their own resources and effort, complemented by support available from their family, friends, neighbours, community networks (such as community organisations, churches, landlords, shopkeepers and pharmacists) and from the community care and health systems. The ABS Surveys of Disability, Ageing and Carers continue to show that informal care significantly outweighs formal care in the support of older people.

A community care risk analysis needs to also recognise that older people, in choosing community over residential care, are usually making a decision, which implicitly and sometimes explicitly places a greater value on the quality of community life and its inherent risks, than on the comparative safety of residential aged care.

Given community care is only one of usually many contributors to older people's lives in their homes and that older people living in their homes are effectively choosing quality of life and risk over the comparative safety of residential aged care, we **recommend** that:

- community care be not subject to the accountability and responsibility documentation levels and systems applied to residential aged care.

Further, while investment in community care should be greatly increased, it is likely that on average it will always receive lower government subsidies per aged person than residential aged care. It therefore needs greater capacity to more responsively, creatively, efficiently and effectively support the rapidly expanding number of older people choosing to continue to live at home. In line with this and within its different community care risk construct, it is **recommended** that:

- community care's quality and regulatory systems move from being so focussed on process documentation to being more focussed on community care's contribution to assisting older people and their carers to achieve the results and outcomes they desire.

Otherwise the community care system will not be sufficiently resourced to meet future challenges, nor sufficiently focussed on these challenges.

## *References:*


Geron SM 2000? *The Quality of Consumer-Directed Long Term Care.* http://www.asaging.org/generations/gen-24-3/qualitycons.html

Henwood M 1999. *"I'll Tell You What I Want, What I Really, Really Want" Quality in Home Care – Subjective and Objective Dimensions – Rethinking Home Care Options for the 21st Century.* Conference Presentation, Victoria http://www.health.vic.gov.au/agedcare/publications/conferencejuly99/mhenwoodqihc.pdf

Kendrick M J, Petty R E, Bezanson L & Jones D L 2006. *Promoting Self-Direction and Consumer Control in Home- and Community-Based Service Systems.* Independent Living Research Utilization. kendrickconsult@attglobal.net