Melbourne, 10 March 2011

Caring for Older Australians
Productivity Commission
GPO Box 1428
Canberra City ACT 2601

Re: Caring for Older Australians: Productivity Commission Submission

To whom it may concern:

In its draft report entitled Caring for Older Australians, the Productivity Commission (PC) endorses Consumer-Directed Care (CDC) as a corner stone to more flexible and responsive community aged care affording consumers greater control and autonomy. The draft report discusses three design options focusing on 'an aged care entitlement system with choice among approved service providers', a 'voucher' system, and 'cashing out' (pp 252). The PC's preferences are stated as a limited 'cashing out' of entitlements in combination with a choice of brokerage and approved service providers (pp. 253). In our view, the PC's draft report would benefit from a more in depth discussion of CDC, if CDC is to be relevant to older Australians. In what follows, I am presenting the preliminary research findings providing an overview of the preferences of old Australians with complex care needs regarding CDC. The findings are based on research evidence based on the People at Centre Stage Project (PACS), a CDC demonstration project that commenced in January 2009. The PACS model was developed over 12 months in collaboration with CACPs and EACH clients as well as carers, representatives of service providers, and other industry stakeholders. The model was piloted during the first half of 2010. The trial phase of the project (a cohort study with 106 people in the intervention and 101 people in the control group) currently under way is to be completed in March 2012.

The PACS model is based on a 'positive (or 'enabling') risk management process that negotiates in collaboration with clients how risks can be taken safely. In other words, clients are directly involved in the development of a CDC approach that fits their circumstances. 'Positive risk management' is increasingly seen as key to individualized support services in the UK and in central Europe. PACS is made up of three levels of self direction that follow on from a pre-self direction stage. The pre-self direction stage includes a capacity building phase that emphasizes healthy living (nutrition, hydration, mental health, exercise, etc.), technical skills (use of computers, budgeting, book keeping), and the provision of industry-specific information. In addition, the pre-self direction stage employs a 'restorative approach' involving clients in the setting of goals and activities directed towards maintaining and/or restoring aspects of their health. **Level 1** self direction focuses on care planning and aims at mentoring the client to complete their own care plan. **Level 2** focuses on care coordination including limited administrative responsibilities and **Level 3** includes substantial financial and administrative responsibilities. Case management is scaled back at Levels 2 and 3 and additional resources are made available to participants. Yet, participants cannot 'cash out' all case management. Case managers are always involved in monitoring and reviewing participants' care arrangements. PACS is an 'apprenticeship' model building clients up to a level of self direction they are capable and confident to take on. A brief overview of the PACS model is provided in Attachment 2.

The PACS model includes a purchase limited debit card (a debit card that can only be used for the purchase of certain goods or services but not others such as alcohol, gambling etc.) that holds a minor amount of cash that is topped up each month. The debit card can be used for incidentals such as taxi fares to and from medical appointments or other expenses that meet DoHA guidelines. To date the participating agencies (Uniting Care Community Options, the Brotherhood of St Laurence, and Uniting Aged Care Strathdon) have not been able to implement this facility due to technical difficulties.

Preliminary results from the PACS project reflect closely the findings of a systematic literature review conducted in 2009 (see Attachment 1). Most importantly, we found that very few people are interested in taking on budgeting and bookkeeping responsibilities. Out of a total of around 800 clients on CACPs, EACH, and EACH-D packages that form the pool of potential participants for PACS, only 13 people (106 people agreed to participate in the intervention group. Enrolments in the intervention group were capped to manage the financial risk face by the implementing organizations) are currently interested in Level 3 (financial and administrative responsibilities) self direction. Of these, only 3 (carers of people with substantial care needs) are currently able to self-direct their care at that level. The other 10 people interested in Level 3 are in the process of building the required capacity. The remaining participants are equally distributed between Level 1 (care planning) and Level 2 (care coordination). Over the course of the trial phase, we expect a significant shift from Level 1 to Level 2 as many people are interested in taking on care coordination. However, movement from Level 2 to Level 3 is likely to be minimal. In other words, the vast majority of older Australians with complex care needs involved in PACS is interested in taking on care coordination tasks but is less interested and motivated to take on budgeting and bookkeeping. Yet, around a third of the people enrolled in the intervention group appreciate the increased financial transparency and the monthly expenditure statements.

For those interested in Level 2, the key motivator to take on care coordination tasks is the increased flexibility in terms of service provision. It makes sense to contact service providers directly to change shifts, to arrange for repairs, or to reschedule an allied health appointment. It is easier to do this directly rather than to go through a case manager. For those interested in Level 3 self direction, the key motivators are to take on a challenge, a desire to learn, greater autonomy and independence, and increased financial benefits. However, it is important to emphasize that financial incentives play a minor role for the vast majority of PACS participants. Indeed, most participants who are not carers, are interested in a more person-centered, flexible, and responsive service delivery. Yet this kind of service provision hinges on a positive risk management approach that begins at the Department of Health and Ageing and filters through all the tiers of the community aged care industry. It requires a careful revision of guidelines, rules and regulations, as well as the Aged Care Act, eliminating features derived from a defensive response to risk and replacing them with positive risk management processes that assist people in leading a more fulfilled life.

The partial cashing out of benefits may be of importance to some participants. For the vast majority of PACS participants, this is not an issue, however. The vast majority regards their case managers as an essential ingredient of the services they receive. Indeed, many participants want to take on care coordination tasks in order to free up case managers to engage in more valued activities such as discussions preparing them for the future. Similarly, the choice of brokerage or service provider agencies may be important to some. However, most people will be unable to make an informed choice unless they receive substantial support from an independent third party. Moreover, for most people the point in time when they are approved for a Commonwealth package may not be the best to make a decision regarding service providers. PACS as well as the available research evidence suggest that CDC is not suitable for people experiencing a crisis episode. While we agree that older people should be able to choose their service providers, the

decision when and how people can choose service providers should be taken with great care and requires further research.

PACS suggests that people's preference for and capacity to self-direct their own care is varied. Whereas some will want to take on significant financial and administrative responsibilities in order to gain extra flexibility and resources, most will not. For the vast majority of PACS participants, their decision to embrace CDC is rooted in a desire to render their care flexible and to make small changes to their care arrangements that are very important to them. PACS also indicates that people are very conscious of their perceived limits and will not take on responsibilities they cannot handle. Bearing this in mind and notwithstanding equity considerations that have to be addressed, it is not unreasonable to suggest that older Australians should have the right to determine the level of self-direction they feel comfortable with and/or are willing to build the required level of capability for. Community aged care in Australia should be safe, flexible, and responsive. To institutionalize a very restrictive version of CDC that does not take into account the preferences and capacity of older Australians, will not achieve this objective.

Best Regards,

Goetz Ottmann (PhD)