Submission on Caring for Older Australians

I welcome the opportunity to provide a submission to the Productivity Commission's Inquiry into Caring for Older Australians.

This submission comments mainly on the aged care facility system and the support services for carers.

My experience stems from being a young person (age 42) with severe disabilities* who is a regular respite resident and has had respite in several aged care facilities within a certain region of NSW; and from information given me from many of my paid part-time carers (past and present) and casual agency carers (past and present) all of whom have worked or still work as nurses in aged care facilities (all different aged care facilities in different locations around Sydney, NSW). As well as from having an informal carer (my husband, who is my primary carer).

* My disabilities include:

- quadriplegia (following two brainstem haemorrhages [type of stroke] one at age 21 and the other at age 36)
- partially blind in one eye
- completely deaf in one ear, hearing impaired in the other
- Severe Dry Eye Syndrome (both eyes)
- double vision
- bilateral shoulder replacements
- bilateral hip replacements
- (secondary) Addison's disease

Myself and many other young adults with severe disabilities are forced to go into aged care facilities for respite as there are hardly any other more suitable options available

Considering that three of the four aged care facilities (for residents with high level needs) in this region will not accept me as they deem that my needs are too high, and respite residential care for young adults with disabilities is almost non-existent, the current system certainly needs improving.

In fact, on the federal government's Department of Health website it actually states that an aged care facility is not an appropriate place for a young adult with disabilities

http://www.sport.gov.au/internet/main/publishing.nsf/Content/health-investinginagedcare-report-index.htm~health-investinginagedcare-report-13.htm~health-investinginagedcare-report-13-2.htm

Aged care facilities are definitely not an appropriate place for a young person with severe disabilities. The staff are used to caring for aged persons, not younger adults with severe disabilities. Furthermore, the nurses are too rushed (due to a shortage of Assistants in Nursing and Registered Nurses).

Additionally, "the demand on providers' resources required to care for young disabled residents may disadvantage frail aged residents."

http://www.sport.gov.au/internet/main/publishing.nsf/Content/health-investinginagedcare-report-index.htm~health-investinginagedcare-report-13.htm~health-investinginagedcare-report-13-2.htm

The current system is stretched financially already. There are too few nurses per resident. I cannot see the current health reform package addressing this. Although the package seeks to increase numbers of Registered Nursesand Enrolled Nurses, the reality is that the majority of the caring work (feeding, washing, dressing, toileting etc) is done by Assistants in Nursing. (And Assistants in Nursing who have a Certificate 4 in Aged Care are now allowed to take on many of the Registered Nursesduties e.g. giving out tablets, administering eyedrops, so they are being employed in preference of Registered Nursesas they cost less to employ.)

I have only seen two Enrolled Nurses in my last three years of regular respite breaks at an aged care facility. One of my carers (who was previously an Assistant in Nursing at an aged care facility) said that she never saw a single enrolled nurse in the entire time that she worked at the aged care facility.

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If this inquiry is to "Systematically examine the future workforce requirements of the aged care sector, ... and develop options to ensure that the sector has access to a sufficient and appropriately trained workforce."

It has to realise that the <u>current level of staffing (in terms of Assistants in Nursing and Registered Nurses) in aged care facilities is **EXTREMELY INADEQUATE**.</u>

If this issue is not addressed very quickly the current nurses will get burnt out from over-work and there will not be any new nurses to replace them. Additionally, do you really want to make a nurse become burnt out? The nurse would suffer psychological and financial distress which would impact on her family and this would follow on to the community.

Following are just a few examples of the experiences I have had as a direct result of there not being enough nurses compared to the number of residents in aged care facilities:

- it is not unusual to have to wait 30 minutes from when you first call a nurse (using your call bell) to when somebody attends you.
- getting dried thoroughly after a shower is a rarity. This leads to fungal infections.
- Clothing is just pulled onto the resident in order to cover them so that they are decent - rarely adjusted to suit the residents comfort and aesthetic needs.
- Meals often go cold before a nurse is available to feed you because they are busy having to feed other residents.

When I return home from a stay in an aged care facility, invariably I come home with more problems then I go in with e.g.

- urinary tract infection (due to nurses changing my catheter bag incorrectly),
- pressure areas (due to nurses not seating me correctly in my wheelchair or being unaware of how to position my leg [when in bed] to avoid pressure on my heel [this is despite giving

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- written instructions to the registered nurses and having instructions taped on the wall in my room],
- bruises and abrasions (due to nurses having to hurry and therefore they handle me less carefully) etc

Carers have also told me of the extreme over work they experienced when working in nursing homes.

I am truly grateful to be able to come home after a short period of respite. I get adequate care again and hot meals!

I am concerned for myself now (as a young person with severe disabilities who has to go into aged care facilities for respite), current permanent residents of the aged care facilities and for myself in the future (as an old person with severe disabilities) who will have to go into an aged care facility permanently, as the government seems to think the level of staffing and quality of care in current aged care facilities is of a high standard and is adequate.

Right now it would of course be much more preferable to be allowed to have my Attendant Care Program carers (a state government program run by the Dept of Ageing, Disability & Home Care) work alongside aged care facility nurses and provide most of my care (whilst showing the nurses how to look after me so that they will be able to do so when my carers are not there) when I am in an aged care facility (currently, my carers are only allowed to come in to provide social/recreational assistance - NO PERSONAL CARE!)

Not only would this ensure that I receive high-quality and appropriate care (it is lunacy to expect that aged care facility nurses can attend my needs with as much experience and expertise as my carers when the aged care facility nurses only see me for three weeks, three times a year!) It would free up the aged care facility nurses more often and they would be more readily able to attend the permanent residents (and as there is such a shortage of nurses in aged care facilities, this would be a very good thing).

An important part of high-quality care from the perspective of residents in aged care facilities is having somebody to talk to. With the way things are these days where there are not enough nurses for

the number of residents*, forcing nurses to rush from one task to another and one resident to another, there is precious little time for nurses to actually talk to the residents ** (having someone to talk to them and listen to them is often something that an old person in a nursing home does not get and it would make such a positive difference to their lives!)

* In one aged care facility I have been in recently there are 2 Registered Nursesfor 60 residents (this is on weekdays and some weekend shifts), and only 1 Registered Nurse for 60 residents (on the night shift and some weekend shifts). There are only two Assistants In Nursing for 24 residents (on the afternoon shift). This disgusting ratio of nurses to residents is not an unusual occurrence throughout aged care facilities!

** One Registered Nurse recently told me that she had worked out that after all her duties she only had enough time left over to spend five minutes with each resident

One possible way for the government to address this appalling shortage of nurses (Assistants In Nursing and Registered Nurses) is to provide sufficient funding to aged care facilities to allow them to employ more nurses and perhaps offer increased salaries to existing and future nurses.

As the labour market will shrink substantially in the future it might be prudent for aged care facilities (and other aged care services) to provide more substantial education and training to volunteers and informal carers so that they can take a greater role in caring for the aged.

Re: how aged care facilities get funding from the government for each resident

An assessment form (designed by the government) is filled in by the aged care facility for each resident. This form is used by the government to calculate the amount of funding it gives to the aged care facility.

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Approximately 5 years ago (I'm not sure if there has been another change since then) the government changed the form that the aged care facility fills in explaining what each resident's relevant issues and care needs are.

The changed form was, and possibly still is, structured in such a way that the aged care facility cannot report <u>all</u> of the resident's relevant issues and care needs.

As the residents needs/issues are not reported, sufficient funding is not forthcoming. (Is this a way that the government is cost-cutting surreptitiously???) This can result in one or more of the following:

- the resident getting substandard care
- informal carers of the resident having to provide care that the aged care facilities should be providing (and this puts stress on the carer)
- the aged care facility provides the resident with all of the care that the resident needs by reducing the amount of care that other residents receive

Also, it would be preferable to have two types of forms - one for aged residents and another for young respite residents, in order to ensure that no residents are disadvantaged!

With regard to Regulatory procedures

The regulatory body for aged care facilities is the Aged Care Standards and Accreditation Agency.

All residential aged care homes must be accredited in order to receive funding from the Australian Government through residential care subsidies

Some (possibly more or all) aged care facilities put on extra staff when an accreditation assessment is being done in order to appear that they always have a suitably sized workforce and so that they can meet accreditation standards. Juliette Maxwell Page 7 of 10

This is giving an entirely false impression that the current system is adequate.

If the aged care facilities do not put on extra staff they do not meet accreditation standards and this results in penalties.

I believe that all of the objectives listed in chapter 3 of the issues paper "objectives of the aged care system" should be given equal weighting.

It is impossible to achieve what the National Healthcare Agreement states should be the case "that Older Australians [should] receive high quality, affordable health and aged care services that are appropriate to their needs and enable choice and seamless, timely transitions within and across sectors. (COAG 2009)", without giving equal importance to each of the objectives

In considering the question " *Are reforms required to more appropriately support informal carers and volunteers?*"

The answer is yes!

In particular, a much greater amount of support needs to be given to sole informal carers (informal carers who have no family or friends who can provide the care needed by the aged person and thus give the original informal carer some respite).

In the situation of the sole informal carer, as time goes on they become more and more run down as they have to continue caring for the aged person without getting enough support for themselves. This leads to the sole informal carer becoming burnt out* and no longer able to provide care to the aged person.

*Sometimes suffering serious mental health issues e.g. depression

This can result in the aged person having to go into an aged care facility and this leads to the informal carer feeling guilty that they have been unable to care adequately for their loved one, a greater burden on formal care, not to mention the stresses that are placed on the

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aged person who has to be torn out of their familiar and cosy home and away from the person they love.

Training/Educating The Aged Care Facilities Workforce

I recommend that the following article/poem (that was e-mailed to me by a friend) be incorporated in all levels of nurse training (Registered Nurses, Enrolled Nurses and Assistants In Nursing)

THE CRABBY OLD MAN

When an old man died in the geriatric ward of a nursing home in North Platte, Nebraska, it was believed that he had nothing left of any value.

Later, when the nurses were going through his meager possessions, they found this poem. Its quality and content so impressed the staff that copies were made and distributed to every nurse in the hospital. One nurse took her copy to Missouri.

The old man's sole bequest to posterity has since appeared in the Christmas edition of the News Magazine of the St. Louis Association for Mental Health. A slide presentation has also been made based on his simple, but eloquent, poem.

And this little old man, with nothing left to give to the world, is now the author of this 'anonymous' poem winging across the Internet.

Crabby Old Man

What do you see nurses? What do you see?
What are you thinking when you're looking at me?

A crabby old man not very wise,
Uncertain of habit with faraway eyes?

Who dribbles his food and makes no reply.
When you say in a loud voice 'I do wish you'd try!'

Who seems not to notice the things that you do.
And forever is losing A sock or shoe?

Who, resisting or not lets you do as you will, With bathing and feeding The long day to fill?

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Is that what you're thinking? Is that what you see? Then open your eyes, nurse you're not looking at me. I'll tell you who I am. As I sit here so still, As I do at your bidding, as I eat at your will. I'm a small child of Ten with a father and mother, Brothers and sisters who love one another. A young boy of Sixteen . . . with wings on his feet. Dreaming that soon now a lover he'll meet. A groom soon at Twenty my heart gives a leap. Remembering, the vows that I promised to keep. At Twenty-Five, now I have young of my own. Who need me to guide And a secure happy home. A man of Thirty My young now grown fast, Bound to each other With ties that should last. At Forty, my young sons have grown and are gone, But my woman's beside me to see I don't mourn. At Fifty, once more, babies play 'round my knee, Again, we know children My loved one and me. Dark days are upon me my wife is now dead. I look at the future shudder with dread. For my young are all rearing young of their own. And I think of the years and the love that I've known. I'm now an old man and nature is cruel. Tis jest to make old age look like a fool. The body, it crumbles grace and vigor, depart. There is now a stone where I once had a heart. But inside this old carcass a young guy still dwells, And now and again my battered heart swells. I remember the joys I remember the pain. And I'm loving and living life over again. I think of the years, all too few gone too fast.

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And accept the stark fact . . . . that nothing can last.
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So open your eyes, people . . . . . open and see. Not a crabby old man .. . . Look closer .. . . see ME!!
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There is one issue that this inquiry seems to have overlooked. With the incredible advances in medical technology there will be an increase in the number of young people with severe disabilities living longer = increased population of aged with severe disabilities

We definitely are very lucky to live in a society in which the government subsidises aged care services. It is very generous of the government to do so. However, there is much about the current system that needs a great deal of improvement.

I also think the title "aged care facility" should be changed. When one says they will discuss "aged care facilities" it sounds like they are going to talk about council toilet blocks for senior citizens!

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