Response to Draft Report of the Productivity Commission- Released Jan 2011

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I commend the Productivity Commission on their Draft Report. It's attention to and inclusion of content from the submissions, provided by both professional aged care organizations and personnel and concerned family members and citizens was enlightening for me and offers many positive suggestions for consideration. I support the suggestions of co-payment when people can afford it- even if part of the value of the very valuable family home is borrowed against. I support the suggestions of trying to provide assistance for people to remain in their homes. I support the need for Councils to provide a local environment suitable for aged people in their homes to be able to mobilize and access local transport facilities especially in rural areas and small towns. I support the need to improve the number, training and wages of direct care staff.

It is exciting to think many of the problems occurring in residential care will be addressed and corrected!

In Australia, the Commission's statistics indicate we have between 115,000 (p23)-150,000 (p11) people in residential high care (09/10). The difference probably relates to people in respite. This small number was a surprise to me, and it adds to my inability to understand why most frail, older high care people have to be 'institutionalised' (quickly made immobile and incontinent and all the ramifications evolving from these two states) by the system.

Many submissions do make horrendous reading, with respect to care aspects. Obviously there are many, many people who object to and are disappointed in the institutionalization of aspects of residential high care. Many, myself included, cannot believe how aged care providers manage to say one thing, but do another. I was certainly aghast to read, on p127 of the Commission's Draft Report that

'there is little incentive for providers to engage in activities that promote the restoration of health and functional independence in care recipients as restoration generally results in a reduced care subsidy, particularly in residential aged care.'
How can a situation like this occur and not be corrected?

I also found it interesting that, in 2007 (why not 2009/10?) 133,000 people were direct care employees (p358), the equivalent of 80,000 full time. When this figure is related to the total number of people (high and low care) in residential care (215,000 people) (p11) there is a (rough) ratio of 1 direct care worker to 2.5 residential care people. My math may be questionable, but it seems to follow, on average, that if there are 15 high care people in a facility then, statistically, there should be 6 direct care workers working with those people. But these 6 direct care workers are spread over 24 hours or 3x8 hour shifts which allows only 2 direct care workers per shift. And a 40 hour working week, does not allow for the 48 weekend hours! Throw in the 6 weekend shifts and meal breaks for direct care workers and the number of direct carers to residents is watered down even more! But, as I observed, as well as 'caring' duties the 2 carers had to set the table for each meal (breakfast, morning tea, lunch, afternoon tea, dinner), ensure all residents attended, give out the right meal to the right resident, feed some residents, help others cut up parts of the meal, sweets, tea/coffee/specialized drinks, scrape plates and return them to meal trolley. ! I accept part time staff can be shuffled around but this ratio does appear to explain why institutionalisation occurs, which appears to suit providers as they then receive increased subsidies.

As I outlined in my first submission, my interest is in the care aspects of the report and how best to achieve the best care and quality of life possible for high care, frail people. My comments are from my one family personal experience and reading the submissions from the web site and the draft report.

Many submissions stressed that as a society we can, and must do better for people who are cognitively alert but physically frail. The Commission also recognized the deficiencies in this area. People who are growing older do become frailer -but much knowledge, wisdom, appreciation of family and friends and interest in community, country and world events is still a big part of their life, even if many physical activities are no longer possible. When a 21 year old becomes wheelchair bound because of an accident it doesn't follow that they are useless and not functioning cognitively! Frailty does not, in many cases, equate either with uselessness or cognitive impairment.

In the Draft Report many submissions commented on;

1. The lack of availability of occupational and diversional therapists. Many submissions also reported factual evidence stressing the benefits to be gained from provision of occupational and diversional therapy for prevention of both anxiety and depression in people in high Care.
2 Difficulty in obtaining doctors and geriatricians to attend facilities (remuneration and consultation issues.)
3 Difficulty for families to find out what services could be provided beyond those listed by the facility; and genuine reluctance of a facility to enable families to organize and access these extra services for their parent.
4 How staff shortages and inexperienced staff may cause a build up of anxiety in high care people as they are forced to wait for basic requests to be met- the frustrations of people sometimes leading to behaviors (rudeness, subservience, hopelessness) not normally attributed to them.
5 How staff shortages may cause people to lose functional independence – mobilizing ((vascular problems) toileting (UTIs) feeding (starvation) and hence regress into a state of depression.
6 How physical restraint, strapping into a chair and other forms of 'disguised physical restraint'- jamming the bedside table against a chair they are sitting in; putting feet up in a mechanically, reclining chair and then pulling the plug; not answering the push button and chemical restraint (respiridone) may cause people to lose functional independence and possibly develop a state of delirium.
7 How the wage rates of well trained carers and RNs do not reflect the responsibilities their work entails. How the trend to make the work basically 'part time' does not provide security of job tenure nor a career path for people who want to work in aged care.
8 The lack of transparency in facilities. Families, with their aged parent's best interest at heart must be able to view care plans and offer comment on them. Care plans should evolve with input from all parties. The use of the word 'privacy' is often used as an excuse for a lack of transparency.

We need to get care considerations worked out, especially, and I repeat, when the person 'who has more wrong with them is more valuable to the institution in which they are being cared.' (p108) This is an appalling situation.

Despite claims by Aged Care Facilities, respect, independence and choice for our frail aged people will only be achieved:

1 With an increase in the ratio of better trained, well paid staff, with career prospects. Perhaps a system, similar to the promotion of teachers could work- start as a trained carer, gain experience and more education and be able to progress to deputy carer, head carer and even director- in charge of the facility.
2 When facilities are prepared to provide allied health professionals for occupational and diversional therapy, rather than respiridone.
3 When families are provided with more information about High Care and the changes it may cause to a parent's position when they have DVA status.
4 When living space is not just bricks and mortar but encompasses more of what makes us all free, thinking, social people i.e. more open, outdoor space showing signs of life e.g. fish ponds, chook pens, dogs, cats, vegetable gardens, play area for grand children, barbeque areas for families, a covered area for cards, scrabble or just sitting chatting, knitting, sewing or thinking, and accessible to the aged by self propelled wheel chairs, by manual walkers or by assisted propelled wheel chairs!
5 When a level of risk is accepted as normal. Unfortunately if people are medicated with antipsychotics self mobilizing on walkers would not be 'normal risk', whereas without antipsychotics it would be.

I realize, from reading the Draft Report and pre and post report submissions, that despite my very limited experience with the High Aged Care system, my observations and suggestions do not represent a lone voice. I intend to continue adding my voice to the demands of the community and the Productivity Commission for a better deal for frail people who are unable to shout quite as loudly as I can.

My concerns are not with costs or who will pay what and how much. I know these things will get worked out provided

1. Personal and community opinion is carefully considered, (which appears to be happening at this stage)
2. Vested interests do not influence decision making through political donations or 'jobs for the boys.' We are a large country with the need to service regional areas. Frail aged people should not be regarded as a source of large profits for private enterprise- the government (taxpayers) must shoulder the responsibility. And people who can afford to pay must do so.
3. Politicians do not shelve the results crying poor.
4. People supporting euthanasia do not keep pushing their mantra 'no quality of life, time to take your life.' It is often the operation of the aged care facility which causes the deterioration of cognitively aware, but frail, people.

What needs to be done to care for ageing people

1. Assessment and Care Plans. Family members should have access to assessment and care plans. I think the concept of 'privacy' can be used as an excuse for non transparency. Families should be told they must get their parent to sign to allow family to view the care plan. Families need to be able to gauge how their loved one is coping with the residential care situation.
2. Choice of care services. Older fragile people are not particularly worried about weighing up the pros and cons of this service or that service- the emphasis on choice is really irrelevant to them. They just want to be cared for properly- they want their emotional, physical and mental needs to be met- and close family advice and communication re. carers opinions and care plans, doctors and allied services must be available for discussion, so that the right decisions are made. Our frail parents are using all their physical and mental resources on staying alive and being as useful and as independent as they can for as long as they possibly can. They rely on family members to help them make the right choices so it is the family who should have access to all the information, so they can discuss with their frail parent, if cognitively alert, or make the best decision if not. It is certainly very important to respect the aged person, and giving them time is one way of showing respect. This rarely happens in the system now. The respect is only token. Carers, working in the system groan desperately, because of time constraints. Family should be allowed to provide information re. the life of their loved one so carers can engage with them. (p247 – many submissions expressed frustration at not being able to influence care decisions under current arrangements.)

3. The use of antipsychotic drugs (e.g respiridone) for anxiety; sleeping tablets, stronger and stronger pain

alleviation drugs coupled with whatever else e.g. antibiotics, fluid tablets. Drugs for pain are needed, but surely family are entitled to be informed when new drugs are introduced, or the amount is increased- the effects of combinations of drugs. Drugs should not be used for, what amounts to, chemical restraint because there are not enough carers to spend some time with the aged person alleviating their fears. When frail aged people are beside themselves with anxiety, family MUST be informed. Carers are very blasé about 'sundowning'- I honestly believe it is a creation of the system because there are not enough workers to provide the reassurance needed, and because evening meals, dressing and toileting are all done by 5.30pm- in summer a long night follows, especially if your bed is on the floor- 'to prevent you from falling out', which is aged care speak for 'to stop you from getting out.'

4. The use of physical restraint: I would never have dreamed I would be asked to sign a form asking for permission to physically restrain my mother- after all she was not a violent person. This form was just an ordinary printed piece of A4paper with a couple of simple sentences- 'I allow physical restraint' 'I allow chemical restraint'- and a couple of boxes to tick and a place for a family signature, doctor's signature and RN's signature. Easy enough to agree to one form of restraint, and sign the paper, and someone could quite easily put a cross in the box for the other form of restraint. One signature for both forms of restraint. button bell, or putting the push button bell out of reach. Placing the bed on the floor. No wonder people go into their own world- they are trying to escape this one their loving family has condemned them to-unknowingly.

5. No occupational therapy using fingers, simple coordination, thinking and creativity (eg crocheting/knitting/large needlework items, making pompoms finger painting, collage, brush painting, colouring in, pencil drawing –the list is endless), clay modeling, stuffing simple toys, threading with leather and large beads, cards, scrabble, arranging flowers, peeling peas, folding serviettes.) I am not a trained occupational therapist- but I know most of those activities could have been accomplished by my mother when she first entered High Care. The activities offered centred around sitting in a chair and watching other people dancing or singing, indoor bowls (watch your ball roll down the common room); watch movie, Bingo plus some 'pretend' activities Skype (programmed, but always something cropped up, so it wasn't on) and 'bookclub' (read off a sheet around a table.) Occupational therapist should be with every facility.

6. No mention of Diversional Therapy-should be happening in every facility!

7. Taking away mobility- not allowing independent use of walker- insisting the need for one of the only 2 carers (for 14 High Care people) no attempt to suggest the use of self mobilizing, light wheel chairs, so a person has the freedom to slowly move around, and get out doors in the fresh air and sun. I discovered these wheel chairs by visiting another nursing home because my mother asked me to 'find another place for me- this is not a happy place.' Yet despite the fact my mother tried to keep mobilizing on her walker (I told the home we wanted her to keep mobilizing, as long as she could do it- if she fell so be it)- and loved to be outside no one suggested such a wheel chair could have suited my mother! I went to Mobility Matters and found out about them myself- but finding your way around aged care shouldn't be a treasure hunt! Anyone can fall over, but we don't stop them from walking. Accidents still exist, and commonsense!

1. Things for productivity commission
2. Lack of 'relevant' information re. possible effects of this change in our mother. (rose coloured glasses; sick sister; anxiety (so called sundowning)no real link to the retirement village activities adjacent to the facility; no mention that because 3 sisters were over 8 hours driving away-need for daily visits to help adapt; no mention that we should get mum to sign a form to see her care plan- power of attorney not enough; no mention that physical restraints might be asked to be used/ also chemical;

We were not informed of the situation with respect to Drs.- visit on a set day- do not call out, even if asked by family to do so. We were no advised of the existence of people called 'geriatricians' who can help to co-ordinate drug combinations.

Use of physical restraint, without permission; the fact that one can actually sign a form for physical or chemical restrain without any real explanation of when it will be used

3. Use of chemical restraint in the guise of controlling anxiety. Anxiety magically becoming some sort of a mental

or physical complaint requiring the ‘magic’ of the antipsychotic respiridone

4. .
5. Reluctance to summon Dr. (when requested by absent family) at times other than his weekly visit. No mention of a need for a geriatrician as her combination of drugs became a ‘cocktail’-and her brain e4scaped into delirium after acute renal failure and the pain of dry gangrene toes.
6. Suggesting long time physiotherapist would have to have a police check to come to Facility.
7. Despite frequent requests to view Care Plan, our requests were just ignored, even though 2 daughters had power of attorney.

8. No information given on the effects of going into High Care on Mum’s gold card DVA status. No suggestion more care provided in own unit.
9. Emails offering information, requesting information were never specifically answered- just some sort of a general, weasel word comment.
10. The 2 carer staff (15 High Care people) expected to dish up breakfast, morning tea, lunch, afternoon tea, dinner, set table, clear away, pour warm and cold drinks, feed the 3 or 4 people who had to be fed, all the time making sure they were giving the right meals to the right people, and trying to be cheery at the same time- having to ignore any distressful; situations the people may have been experiencing.- then bedding everyone down! Impossible- no wonder there is a need to send people off with the pixies!
11. Not given sufficient time to work things out properly- ‘social acceptable form of blackmail’- ‘Room will not come up for another 6 months- must decide now.)
12. Not able to view her care plan, despite family member having power of attorney. Suggestions really treated in an offhand manner- when we were trying to get answers.
13. After a stay in hospital for acute renal failure, renal Dr. said ‘I have taken her off that cocktail of drugs she was on- it’s not quantity of life, but quality that coumts’.
14. Two dry gangrene toes just left to drop off. If we had realized the pain, and need to control it- more medicines.
15. I would like to know, considering the gradual decline of my mother just how the following things affected the money received by the home she was in. Bad leg-need for assistance to mobilize, renal failure, two dry gangrene toes.
16. Doctors’s visits were not in private. When family members there, the RN would still be in the room with the doctor. If we, as family members wanted to say something about our parent’s care we didn’t like to, in case it bounced back on our parent. ‘Don’t bite the hand that feeds you’
17. As a war widow we were not advised of what changes would occur with Mum being able to access things.