

PRODUCTIVITY COMMISSION ENQUIRY

- CARING FOR OLDER AUSTRALIANS - 2011

Submission by R. Browne, C. Allen & D. Medley

FOREWORD

Despite our individual and mutual interest in the aged care issue, we only became aware of the Enquiry earlier this year, through 'The Senior' magazine. Since then only one of us has had any chance to read the Draft Report, and only parts of, relaying this between us as possible.

From what we now know we have to say that the concepts, ideas and recommendations that have come forth do provide a real sense of confidence that something far more than the superficial will result at long last, for Australia's ageing population, especially for those who are fully dependent.

The tone of the Report is encouraging; it seems that wisdom and a spirit of generosity has helped weave the ideas together. We can only hope that the Commission's words will be translated into action by the government/s in power, with no watering-down of the changes proposed to bring long-awaited improvements,

Given the various obstacles of co-writing and editing, and now well into 'time-on' our comments are in summary form. They generally follow the flow of the Report and focus on Chapters 8-12.

We note that although the Enquiry submissions number over 500, it seems that only a small percentage are from those who are or have been recipients of community care, which is disappointing but understandable. It would be heartening to have seen more general input from here.

It is a pity that as current or past carers we are usually too engrossed in keeping daily life together to participate, much as we want to.

END OF FOREWORD

BACKGROUND

We write as a group of current and past carers, and acknowledge there are many perspectives on elders and ageing for the Commissioners to consider. During the recent public hearings in Melbourne following the release of the Commission's Draft Report, we gave just a summary of our views, which come from our particular experiences of aged care. Because these experiences are intensive and prolonged, our views are therefore not 'off the cuff'.

Each of us is or has been a full-time carer at home for a parent. Apart from individual efforts, we have jointly taken part in advocacy meetings, other forums and support groups; we have/had EPOAs and/or Guardianship responsibilities; in one case, also the dogged pursuit of complaints through CIS and the OACC.

We have developed far more than superficial knowledge of how the system currently operates for society's elders and for us, the carers.

ISSUE: Re terminology: 'Informal carers' Ref. pp.xxviii/82/91/347-8 et al;

" WE ARE NOT Informal CARERS "

The phrase, 'informal carers' is jarring, is unsettling and feels demeaning to those of us who have been intensively involved in caring for someone. It appears early in the Report and lingers on, and we would like to see it replaced. We regard the term as unacceptable because:

1. It carries overtones of the casual, part-time, unskilled, untrained, even second-rate. It certainly does not reflect the twenty-four hours-a-day, competent, skilled and devoted carers that most of us are. Even if our loved person is in a residential facility, we are still 'on duty' mentally and emotionally on a full-time basis, visiting often (to ensure proper care happens) and physically helping as well. Not to mention the worrying, planning, hoping that's involved. Does any of this really imply 'informal'?

- also -

2. When the Final Report soon becomes the talk of the nation, we will be referred to as 'informal carers'. Millions of Australians have no knowledge of the carer role (as yet), so what impression will they form of the 'informal' carers? Probably not one that is realistic.

- also -

3. Staff who work in either a facility or community care are now generally termed Personal Care Attendants, the PCAs. This term, however, does not seem to be in general use in the Report. To most of us, including many in the 'paid' sector, it has become an acceptable point of distinction, that the family carers are termed the 'carers', paid staff are PCAs - see point 5.

- also -

4. Another reason for our uneasiness is that too many PCAs -not all, of course - do not actually behave 'caringly'. We, the family or friends, are the ones who do the actual 'caring' and often feel insulted by the comparison. There are many exceptions admittedly, where PCAs show more care than family, but that is not the norm, we hope.

- also -

5. Without reading all submissions it is impossible to know whether this matter has been picked up for comment by any carer support groups but it certainly should have been.

The distinction as noted has been well documented in Chapter 2 of the Report on the 2008/9 House of Representatives Enquiry into 'Better Support for Carers'. Why has this not been given effect here?

- and -

Last word: If you accept nothing else out of the words in these pages, we ask that you please replace the 'informal' with something more fitting to our role, eg. 'family or', 'at-home carers'.

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ISSUE: CARE & SUPPORT: CHAPTER 8, P.225 ...

Draft Report Key Points

In general we feel these proposals are commendable, esp. choice of providers, flexibility, timeliness of and needs-based assessments. Also the expansion of advocacy and ageing at home.

Our comments centre on Funding/Approved Providers; needs-based assessments/entitlements (ACATs & APs roles); advocacy; rehabilitation.

a/ FUNDING /PACKAGES: Given the likely removal of packages, Will the new model now preclude the opportunity for APs to 'skim/top slice' funding dollars? Our comments here intersect with Regulation and are reiterated towards the

end. Currently the delivery of packages is cause for much consumer anxiety and complaint. Skimming' or 'top slicing' package dollares is rife (many consumer reports, no less our own).

The new model must ensure the delivery of care (minus packages?) will have fail-safe mechanisms to prevent this 'skimming', that there will be immediate & strong penalties if it happens.

Will this be dealt with under the new model ?

b/ ASSESSMENTS & ENTITLEMENTS

i) **Aged Care Assessment Teams** - Under the new model the client/carer should have to verify & co-sign the FINAL version, ie. BEFORE forms sent to DoHA. Many clients would be stunned to know their papers are likely to contain significant errors. Clients are not privy to the final version as notes are previewed in-home then finalised in-office.

Errors emerge out of the blue ! Hence. inaccurate & inappropriate services &/or equipment can result.

(RB: For three annual assessments - I had to seek significant amendments -but first had to insist on seeing the papers. Each year's episode got worse.)
And so ...

- consumers must firstly be informed of the need for this but also -
- be required to read and co-sign the final version.

ACATs are important, but not infallible.

Unless there is a fail-safe stage here to prevent this happening, wastage in time, effort and money will continue.

ii) **Approved Providers** -

Will the new model allow flexibility in choice of provider for various needs? Also - allow for negotiation by client for alternate services ?

ie. we need flexibility here, not care managers who work for providers who still try to behave badly. So -

If we experience this - what then? We need immediate recourse to solutions not the current long-winded CIS/ACC routine that gets nowhere.

Within our circle we have experiences of unsuitable pressure rugs, food thickeners, inappropriate chairs, hoists, etc.etc. Drops in the ocean of unsatisfactory providership.

What will be the failsafe mechanisms applied under the new model?

d/ **REHABILITATION:** Will the new model with needs-based entitlements include rehab. for people with dementia ? If not, then why not?

Currently an on-going worry for many people who have the ability for re-mobility. (RB: This was our situation - system denied rehab. due to dementia! Disbelief & many phone calls ensued, exasperation, then our own personal programme, with carer help. Some months later - my father was mobile again. Joy of joys! Quality of life for the next 2 years. NO thanks to the system.

Prof. Henry Brodati who has submitted to the Enquiry, confirmed this situation when on Radio National in 2008 (Australia Talks)...and other listeners' calls regarding various limb/joint operations. Dementia means bottom of list, or, not on it for rehabilitation (our wording.)

So - how many of our elders are languishing in facilities because ..?...the system decrees they 'will not be able ...because...?.. it's easier and cheaper! Goodbye to quality of life that everyone so glibly speaks of.

Other comments:**# Box 8.8 P.265 Clinical in-reach pilots**

This programme offer a valuable option in the care process. Having endured numerous transfers between home/hospitals and the complications with transport (booking errors, chain-reaction delays, anxiety for all involved, and the physical difficulties) it would surely be a move in the right direction.

Could this not be applied to the RACF situation?

Facility staff, in Victoria at least) tear their hair out nowadays due to the changed in non-urgent ambulance booking procedures - a problem extending across the state. How do other states fare?

Once it was simple, now fraught, with missed appointments, wasted time, etc. on a wholesale basis. The in-reach option may save the sanity of many.

Draft Report P.266

-ref. Pam Webster's submission: Her remarks can be surely endorsed by many of us, from personal & friends' experience.

It seems ludicrous that entitlement &/or management you receive is date-dependent - eg. stroke at 64/5, one day disability, the next - aged!

Ch. 8.4 The issue of quality P.267

We concur that provider and management attitudes are keys to success. However, 'ownership' is crucial and comes before the other two.

In at least one submission (Melbourne 23.3.11 - Mary Archibald PSM), the suitability of ownership and Boards of Management was raised as a prime factor that ought to be focused on far more than is.

Most of us know how difficult it can be to perform at high standard when part of a culture that aspires only to mediocrity - or worse.

Why should we have to wait for 'competition' to be the arbiter of provider suitability for our families ?

Will the promises on paper of quality be translated into reality for US ?
Whose priorities will win out?

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ISSUE: DELIVERING CARE...WORKFORCE ISSUES: CHAPTER 11, P.345 ...

Draft Report Key Points

The only disagreement here is -again - that 'informal' is an inappropriate term. We certainly hope the Final Report will reflect our role with a more suitable adjective, as explained at the outset. Comments here range around Primary carer role/ carer support services/ respite services/ other support services

a/ Primary carers - This is a vital role that carers and families carry but encounter problems with in hospitals, facilities, and with providers.

Primary carers are the ones whose experience and opinions are supposedly given priority. Too often paid staff either disregard - may be ignorant of - this important role and the need to consult accordingly, and sometimes accede to. Much greater awareness raising of and respect for this role needs to occur.

(RB. & CA.- personal experiences where hospitals &/or care managers ignored our primary carer's wishes/ instructions. Usually the p.c. has the understanding of how certain care aspects need to be enacted for the caree. Too

often it seems that authority for the sake of it comes into play. One hospital clearly knew & respected the legislation, another did not, nor did one care manager, hence problems.

b/ Ch.11.2 Encouraging & supporting carers - Ref. Pp 348-9

i) WE add to this dot point list that of mentoring & partnerships. Many ways exist in which family/friend carers with some time and energy can and would make themselves available to support their peers. This has not been included enough in considerations. On a financial basis alone, it should be realized that good will often saves many dollars - and carers have one of the largest reservoirs of good will possible.

1) Support services - P. 349

Surely 'legal' services should be included?

Carers & families usually find access to legal advice/support very difficult, if not impossible, due to financial limitations - or poverty! This applies equally to past-carers. We NEED this to be included.

c/ Respite services - P. 350

i) Comment: It's either 'not enough, not available, not suitable'. We agree! AND - if on a Package, clients need to be told that emergency respite is not necessarily available - in theory yes, but not in reality. Usually, it is a 'no carers available' response to the call.

NB: If packages remain for another couple of years, new clients should be alerted to this problem (unless the rules changes): that this respite may now be very difficult to access.

This lack of advice has been prevalent for many of us in recent years.

ii) Extra comment - Quality of respite

If respite is to become more readily available for carers, a pre-requisite must be that the standards improve beforehand- both in-home & in facilities.

We support Carers NSW comments where they stress the importance of services designed to meet our needs, not the other way round. This is crucial.

It is no exaggeration to state that for in-facility respite, many carers visit often if not daily. We know that the caree is likely to return home either with a UTI, emotionally less stable, undernourished, immobile (all quite likely) - so why would we risk respite when we have to work harder than before to pick up the pieces?

(Personal reports: DM: One personal, positive story: when care is competent & appropriate, and if the person is mobile, respite can & has worked well. The person's mobility seems a crucial factor as they can move around, be engaged socially & are generally more independent, even with dementia.

iii) Respite information for carers (in conjunction with Chapter 5)

The current system as many have said before us, is a semi-functional mish-mash of dis- and misinformation.

For RB, three calls to Carelink with no response, ever. And, late 2007 with urgent need, being ushered OUT of the local Carer Respite before questions could be asked (the receptionist said her supervisor could not talk to me then, no reasons given. Stunned expression on her face. I left.)

For CA, the typical round of obstacles and lack of answers, and no carers available when urgent needs arose.

For DM - moving from interstate, with no information, no ready access to it, and no continuity of carer support between states. Another tedious process of personal researching followed - for over a year.)
WE agree with the submission excerpts on pp.102-4, especially the Alzheimer's Australia statement re dementia respite.

iv) Other aspects

1) Carers' skills

WE reiterate our previous comment, that carers, both current and past, are an untapped resource as mentors and support persons. A wealth of experience and training resides in the carer peer group.

Many options exist for both voluntary and paid, formal and casual. What better way for a carer who can & who wishes. to earn some dollars through in-home support (or in RACFs) by assisting their peers. This sounds simplistic but this type of program often works well: community bonds, income-earning, emotional as well as physical support, etc.

Another avenue could be cottage-style businesses to be set up around the needs that exist both within the home and RACFs.

Sophisticated planning, design and organisation is necessary, but it seems we are well into the time when the less complicated ought to be considered in tandem with this.

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ISSUE: REGULATION: CHAPTER 12 P.381 ...

Draft Report Key Points

Our knowledge of and experience with the system are from the consumer perspective. Also from many discussions with agency & facility staff both past and present, providers, & friends' experiences too.

Staff training issues and the resulting quality (lack of) have impacted our lives intensely so we are well aware of the urgent need for changes there. WE hope that in the loosening of the regulatory framework, standards not only can improve to an acceptable standard (dot point 1), but a 'commendable'. Our aim should be for the best so at least we attain 'better'.

ISSUES FOR COMMENT ARE: Benchmarking/ AAT appeals/ complaint handling

a/ Benchmarking: Within community care at present, it has been clearly stated by CIS (case notes - RB) that there is no benchmarking package funds expenditure. Providers, says DoHA, are free to spend these dollars as they wish - no constraints other than 'the client's interest'. THIS OFTEN FAILS TO HAPPEN.

How will this change under the new model? For effective, efficient community care, WE need to hold the reins, whichever model of CDC is chosen. As it stands, this is a real problem of inequity - within providers across regions, and between providers. Will this be resolved ?

One option Providers create is by 'winding down' the package. IT HAS happened to one of us & others we know: services sliced out overnight, false reasons, no warning. Given the ineffectual complaint system, etc. penalties are unlikely to apply. But clients lose.

WE ask - will the new cost-determinations by government be obligatory on providers & to what extent? ie. order to preclude the bad behaviour referred to earlier ? This is imperative for community care.

b/ AAT Appeals

One of us has laboured through the current CIS/OACC system for some time, regarding EACH provision, with tomes of paperwork and some satisfaction. The points in Box 12.2. (P.397) are well-worthy of a large tick. Thank you to Professor Walton.

We need urgent improvement in these bodies; we need the best aspects of the former Resolution Scheme coupled with greater effectiveness of the current Investigation scheme.

- We need
- i) face-to-face options -yes
- ii) conciliation - yes
- iii) mediation - yes
- iv) responsive - yes
- v) less risk-averse -yes
- vi) less paperwork - yes
- vii) more CIS accuracy -yes
- viii) more flexible timeframes
- ix) aged care arm of the AAT

c/ AAT Cost-waiver ?

IF an individual appeals to the AAT, will there be a cost-waiver, or significant reduction?

Providers can stand their own cost with no problem, but this will be prohibitive for individuals, an in-built discriminator. And, most likely for sole carers or care recipients without family support.

d/ Complaint handling

This whole process needs to be restructured. It does not work for consumers' best interests. Hopefully, Prof.Walton's recommendations will come to pass and we will see a better horizon, urgently !

Citing two submission excerpts:

- P.400 the Commonwealth Ombudsman notes the adversarial nature of the process - there can be no doubt about this (RB)

This entire reference should be learned by heart for those charged with the restructuring task. An excellent statement.

- P.401 - Blake Dawson's comments: All of this comment too, is spot-on, as to the nature of the 'skewed system'.

All of Page 401 is worthy of pasting up in large, bold letters for all to see. The words encapsulate the problems and offer practical remedies. What wastage there has been in this system since 2007 !

e/ Other comments:

1) Quality of Community Care - Ref. Pp. 410-411

The issue of quality is paramount to those of us who use community care. A culture of quality needs to engendered and strengthened in this area whether it be for Packages, or HACC support. or something so basic as an allied service or GP visiting the home - IF we can find such a GP !

REFERENCES

Archibald, Mary PSM, Submission to P.C. Public Hearing, Caring for Older Australians, Melbourne, 23 March, 2011

Brodari, Professor Henry, ABC Radio National Broadcast 'Australia Talks' 2008

HRSCFCHY (House of Representatives Standing Committee on Family, Community, Housing and Youth) 2009, Who Cares..? Report on the inquiry into better support for carers, Canberra

PC (Productivity Commission) 2011, Caring for Older Australians, Inquiry Draft Report, AusInfo, Canberra.