Royal Commission
into Aged Care Quality and Safety

Amended Statement of John Michael Rungie

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Occupation: Ageing-well specialist

Date: 11/6/19

1. This statement made by me accurately sets out the evidence that I am prepared to give to the Royal Commission into Aged Care Quality and Safety. This statement is true and correct to the best of my knowledge and belief.

2. Where direct speech is referred to in this statement, it is provided in words or words to the effect of those, which to the best of my recollection, were used at the time.

3. The views I express in this statement are my own based on my education, training and experience. They are not intended to represent any views of any entities (formal and informal) of which I am a Director or a member. My views are not expressed on behalf of, or intended to represent, the views of my former employer, ACH Group.

Professional background

4. I am currently a Director of the Global Centre for Modern Ageing, member of the Aged Care Financing Authority, member of the Every-age Counts Coalition Steering Group, member of the GAP Standing Committee on Productive Ageing, member of the Dunstan Foundation Partners Group, member of COTA SA Policy Council, member of the SAHMRI Resilience and Wellbeing Strategic Advisory Board, Lead of Longevity 4.0. I have been in most of these roles for 2-3 years since leaving my full-time position at ACH Group.

   I have a PhD in Biological Sciences, worked in disability and aged care for 40 years, taken numerous international study tours of aged care, 20 year member of The Executive Connection (monthly training for CEOs), visiting scholar at University of Syracuse in Human Service Change Agentry, 2013 Churchill Fellow in "Roles for Older People" and a recent graduate of the Modern Elder Academy.

5. Each of my standing positions has a defined responsibility to that Entity. I combine this activity with a wide variety of informal conversation, writing, mentoring, public speaking and consulting activity. The aim of all this activity is to build mastery in, and enable the progression of: older peoples' own transitions, growing commercial and enterprise

activity in ageing well, broad conversation that enriches community perceptions of and engagement of older people and develops policy, Aged Care reform based on care delivering good lives.

ACH Group

6. Prior to my current Ageing-well specialist role, I worked for ACH Group, a not-for-profit Aged Care Provider in SA and Victoria, commencing in 1980 as operations manager and CEO from 1996 to 2016.

7. ACH Group is a large incorporated NFP established in 1952. It's a typical NFP Aged Care Provider, offering Housing (both ILU and Resident Funded), Home Care and Residential Aged Care Facilities ('**RACF**'). In the 1980s it started reviewing its programs for impact on clients using the published and internationally recognised tool PASSING developed initially for disabled people (Wolfensberger and Thomas,2007, Training Institute for Human Service Planning, Leadership and Change Agentry, Syracuse University). This led to a range of innovations being progressively developed by ACH Group over the next 3 decades: an early and ongoing commitment to individualised home care, a non-communal RACF, a short-term, re-enablement RACF, small site housing and programs that focused on re-enablement, wellbeing, personal growth and life quality

8. Examples of programs supporting life quality at ACH Group in my time there include:

- A RACF where each resident gets a house, rather than a room, with visitors coming in the street frontage front door and services coming in the back door. This significantly increased individualisation possibilities and reduced loss e.g. residents brought their spouses, pets, furniture and ability to entertain.
- Clients were encouraged to join local community choirs staffed by trained choir musicians, not activity staff, resulting in people with dementia learning new singing skills and people with Parkinson's Disease learning breathing techniques, all in a normative, reputation enhancing club.
- Clients enquiring for respite were referred to a program that helped them to plan and take holidays to destinations of their choosing. The program usually matched the client to a volunteer travel companion and resulted in the many benefits of holidays that we all enjoy.
- Encore Network was a pilot program for 16 "retired people" looking for new purpose who agreed to meet for a day /month for a year in a facilitated arrangement to learn from another and use one another to invent and develop new purposeful activity.

CIMPACT

9. CIMPACT was developed by ACH Group in 2004 based on PASSING... due to an ongoing concern that clients were not thriving. ACH Group knew that the tool would have to both measure impact on clients and also raise negative impacts into the consciousness of staff and others as a way of getting them to be champions for doing better. The use of CIMPACT requires reviewers to be trained to identify needs with

clients and advocates regardless of the constraints of the service model and in a framework of life quality that has not been modified from that expected for typical citizens. The development of CIMPACT was guided by 4 approaches; Social Role Valorisation framework (Wolfensberger, 2013, Plantagenet,ON;Valor Press), appreciative enquiry, peer review, continuous improvement. It delivers actions plans for improved impact and trains reviewers and staff of the reviewed programs. It is able to be applied across all types of aged care services and repeatedly over time yielding comparison and improvement data.

10. CIMPACT measures in 5 life domains:

- roles that support contribution and community engagement
- support of independence, wellness and growth
- right relationships with a wide range of people
- respect of uniqueness, working with strengths and addressing needs
- presence of relevant, intentional and typical safeguards.

11. Since 2004, CIMPACT reviews have been conducted 5-11 times per year and was in use at the time I left my employment with ACH Group. Broadly the findings indicate:

- poor services rate poorly in all 5 domains;
- good services rate well in the domains of independence, relationships and needs, but not in the domains of roles and safeguards;
- excellent services deliver on all 5 domains and particularly are able to enable roles. The roles domain is a key to life quality, and the safeguards domain is a key to preventing low expectations (as well as the more basic need to prevent abuse and neglect).
- life quality can be achieved in any service model, but is most likely to be achieved in highly individualised, non-communal service models, and it is rarely and only with extraordinary effort achieved in communal service models;
- accredited and award-winning service approaches often don't achieve the "preferred" standard in CIMPACT set by the Board of ACH Group.

Challenges in Aged Care

12. The following sections of my statement specifically addresses 6 Aspects of Aged Care with the intention of developing some understanding of the reasons for quality failure, which can then create a basis for quality improvement strategies.

13. I do this from a background of long-term observation and measurement of quality of life in Aged Care, innovation in Aged Care and more recently an enterprise focus on understanding and what it takes to live well as an older person.

Aged care not achieving quality of life

14. Whilst quality of care can be achieved in RACFs, this seldom translates into quality of life.

15. How do we know?

a. Observation over a day shows most people living in RACFs are engaged in activity for only very small amounts of time. I have observed this over a number of years in a number of RACFs. This has also been the findings of ACH Group's CIMPACT reviews (see 15 (c)).

b. A limited amount of research indicating high rates of depression, suicide, low numbers of visitors (see published work of Prof. Joe Ibrahim. Dept Forensic Medicine, Monash University).

c. Aged Care Provider, ACH Group, has measured life quality in its services since 2004, indicating that life quality is difficult to achieve with frail people, but even more so in the current RACF service model.

d. Over the years we have observed 20 losses (attached) on moving into RACF (such as loss of a house, possessions, mailbox, reputation, partner, pets, neighbours, roles, familiarities), many of which are avoidable, but with little effort made to avoid or mitigate them. Loss and large amounts of change are known to affect people negatively, especially if they can't resolve the loss and are able to replace them with new things/people. Sadly, loss is already a factor of growing old, and entry to RACF significantly adds to this. For vulnerable people there is little likelihood of being able to deal with this, and it likely to result in significant negative effects e.g. confusion, lack of motivation, sickness, isolation, poverty.

   We have been surprised at the low awareness of Providers to these 20 losses, which is probably why care continues to be offered by a service model that causes it. It's my opinion that some losses could be mitigated within the current service model. However, mitigation of the majority of losses are likely to require a change of service model to achieve. All of this is yet to be tested and awaits greater awareness by Providers and greater choice and control by clients.

e. Strong preference to not move is expressed by many older people, and now being demonstrated by growing waiting lists for Home Care and dropping of occupancy rates in RACFs.

Unnecessary institutionalisation

16. There is a concern that little is known about the numbers of people in RACFs who don't need to be there. This unnecessary institutionalisation is an attack on human rights and has been substantially addressed for most other cohorts e.g. disability, mental health, at risk children.

a. There is no goal to keep people out of RACFs. In fact, is often described as a housing alternative to living in the community.

b. There are long waiting lists for Home Care while there are vacancies in RACFs, there are stories of people moving into RACFs because there were no Home Care packages available.

c. There is a lack of the organised special effort seen in other cohorts to test what it would take to keep people out.

d. It's very difficult to leave RACFs if you improve. Many people enter RACFs from hospital and after a time of convalescence and re-enablement some could go home. A number of practices make this almost impossible e.g. attitudes by professionals and families that clients never improve, no inclusion in care plans of re-enablement goals, selling the house to pay the RAD, attitudes of the one way trip result in quick disposal of house and possessions needed for a return, the preferences of the older person are not considered.

e. The majority of people who take respite in RACFs move in permanently without ever going home. Many are using respite as an immediate solution when RACF is needed, but it's not known how many don't fit into this category and end up staying when they could have gone home.

f. There is no data collected on the numbers of RACF residents who would prefer to or could live at home.

Institutions are inherently disappointing

17. The current RACF service model will always struggle to deliver quality. Institutions have always disappointed and there is a long literature and community experience to the extreme failing of institutions to serve and protect those they are set up to champion for.

It is surprising that at the time of very public exposure of appalling abuse in institutions for children (both residential and in the community) that the Aged Care sector has not looked to see what caused this and whether Aged Care institutions have the same attributes (particularly the development of internal cultures that are hidden from public, external review and even the hierarchy of the organisation) that could also put their clients at risk. Even good institutions that have higher levels of safeguarding and engagement of public and hierarchy can struggle to sustain this over the long term as leadership and public come and go. Typically Institutions:

a. strip people of a lifetime of accumulation,

b. lack individuality,

c. isolate people from family and community,

d. are unfamiliar and confusing. Communal living is not something most residents, families or staff know much about or even like, so it is difficult to know how to behave

e. have a very high turnover of residents and staff, this is not a place to make friends,

f. are not joyful, hopeful or growth orientated.

18. Providers have a narrative about life in RACFs which is very different to the above, indicating a lack of awareness of the problem and therefore their ability to address it. There are likely to be a number of causes of this lack of awareness that we can suggest, but have not been validated. These could include ageism, not collecting real client impact data, no co-invention with the client in the absence of being able to imagine a different and better future, no strong client objection to the current service offering, the strong desire of Aged Care workers to be compassionate but not developmental, families failing to be able to advocate against a very stable service offering, Providers seeing themselves as powerless Government sub-contractors.

Low re-enablement and growth efforts

19. There is a lack of rehabilitation, re-enablement and personal growth effort. Personal growth is an important component of life quality for us all and doesn't diminish as we age.

It can be hard to imagine how a frail older person might grow, or even want to grow. And there will be cases where it simply is not possible to find a way. But for many growth has been abandoned long before it is no longer possible. Even as a frail older person, if you are not moving forward you are probably moving backwards.

a. There is an assumption that residents cannot improve

b. There is an assumption that residents are in RACFs for 'care and comfort' only.

c. There is no incentive for providers to improve residents' independence, in fact significant disincentives. Disincentives certainly come in the form of reduced payments, but they also come in the form of increased cost of staff, facilities and programs.

d. There are many practices which actually make residents independence worse

e. Moving out is very difficult.

Home care is an unknown

20. Home Care is preferred by many older people, but much of what this type of care is actually doing for clients is unknown

a. We don't know how buying patterns are changing since the introduction of Consumer Directed Care, if at all. We do know that clients are spending less, but we don't know why.

b. The focus is on care and sustaining independence, but not on rehabilitation, re-enablement, growth and learning.

c. There is little effort to see being frail as a life stage, to understand what a good life when frail looks like. There's little effort to work with clients to think about how they grow into a frail life stage and make the most of it.

d. We don't know much about how safe Home Care is for some clients, and how skilled Providers are in assessing unreasonable risk and mitigating it.

e. It is not clear how much Home Care is actively being used to avoid RACF, particularly when the waiting lists are disincentives. Providers may be conflicted here in using their knowledge of Home Care clients to fill their vacancies in RACFs.

f. Work with the State Health Departments to manage multiple chronic conditions is complex and often not achieved.

g. It is very difficult to flex up and down in Home Care as an individual's condition changes for better or worse, and even more difficult to connect this flexing up and down to RACF.

Lack of Innovation in Aged Care

21. There is a lack of innovation and learning from innovation in Aged Care.

a. There are few incentives to innovate. The RACF sector is regulated and capped, reducing market pressure to improve. Allocations for new places are not done on the basis of innovation. The current service model serves Providers well.

b. There is not a clear vision of what a good frail life looks like, making it hard to strive for or know when Providers are successful or unsuccessful. There is an assumption that Aged Care is increasingly becoming a market – at least in Home Care, and that it is becoming more competitive in Residential care, which will drive innovation. However, most clients are quite vulnerable and in confusing life situations and cannot present their changing needs by refusing to buy which ultimately pressures Providers to change.

c. Providers are not connecting with and learning from the ageing well start-ups, who are developing highly innovative products and services.

d. Providers are not joint venturing to offer a "best of breed" range of services offered in managed concierge arrangements.

e. There is little use of Living Labs to drive co-invention of new services and products

f. Little understanding that transformational change is needed, and that continuous re-jigging of the current RACF service model and approaches won't make enough improvement

Other comments

22. Both Person-centred Care and Choice and Control are critical to the success of quality and safety. However, on their own my view is they will prove disappointing

23. Person-centred care, to my knowledge, is used two ways in Aged Care. One refers to a specific program of careful observation and a resulting individualised action plan, the other more generally to caring for people as individuals. Both are important and should be expected. Neither seem to have the breadth of scope or power to address changing the service model or changing substantially what is on offer to address a person's care needs. There would seem to be an inherent limitation to person-centred care in the

current system in that it can only adjust the amounts of what is on offer within the current service model.

24. Choice and Control are at the very foundation of the way an older person might be able to live a good frail life. The introduction of Choice and Control into Aged Care policy is one of the most exciting reforms in Aged Care. However, as already covered in "Home Care is an unknown", we don't know much about how clients in Home Care are exercising this Choice and Control to make a difference to their lives. There is an assumption that the policy has created a market in which clients will use their buying power to drive the development of new products and services that meet their needs better. Anecdotally there does not seem to be much change to what's on offer. The only changes I've really observed to date have been that clients are buying less and Providers have dropped their prices, are advertising more, and helping some clients through the complicated access process.

25. These clients are vulnerable people and are likely to need substantial empowerment to be effective consumers e.g. working through purpose and maintaining independence as a frail person, explanation of new products and support to try them, learning from and with others, support to use technology.

26. Choice and Control is much more limited in RACFs where the offering is uniform, inflexible and invested in a communal outcome.

27. **ATTACHMENT**

THE 20 LOSSES INCURRED WHEN YOU MOVE INTO RESIDENTIAL CARE

Garden/Pets/Hobbies

Partner

Daily chores, Planning, Housekeeping, Shopping

Planning /Sense of future

Hosting

Privacy

Reputation

Using and Maintaining Life Skills

Neighbours

Getting Out

Possessions

Rhythms and Routines

Address

Familiarities

Community Safeguards

Independence

Individuality

Recovery and Rehabilitation

Personal Growth

Acquiring

Signed: [signature]

Date: 11/6/19

Witness: Janet V. Keightley

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