

Aged Care Act: Background and information for politicians (Part 2)

May 2024

1 Part 2 - Information about available submissions by others

Aged Care Crisis submission on the draft act is described in Part 1. Many others are writing submissions and contributing to the discussion.

1.1 Submissions by others

ACC has strongly criticised the Department of Health and the consultants they contract over the years for stifling discussion and criticism by not publishing submissions. When others started criticising this recently, the department belatedly indicated they will publish the submissions to the draft act but only later when they have completed their analysis. That is not much of an improvement.

We have however, been sent copies of submissions by many perhaps more critical groups and individuals. We try to indicate what they focus on below using short extracts. We can supply copies to those who want them if there is no link available.

Background: COTA and OPAN have both played a major role in developing policy and advising government over the years. OPAN is funded by government and COTA has often been funded to undertake projects for government. While we appreciated their dedication, we have been critical of the major role they were given in influencing policy over the years.

COTA and OPAN hosted a series of face-to-face workshops around Australia for the department. The department's website indicates that they "*informed the consultations on the foundations of the new Aged Care Act undertaken during August and September 2023*". The department also did surveys and accepted submissions¹. How many were contracted to consultants is not clear. They reported that these showed a "*mostly positive sentiment towards the proposed foundations of the new Act*".

COTA and OPAN also conducted multiple virtual roundtables with advocacy groups around Australia as well as a number of webinars. We do not know how all this was funded. While they were well run and amicable and there were many good suggestions for changes, there was not much appetite for strong criticisms of what was being done. They pressed strongly to get the act passed quickly² calling for a "*robust Aged Care Act without delay Rights of older people have been ignored for too long*" with "*an urgent priority for 2024*".

Several advocacy groups including Aged Care Crisis still had major issues that were not being addressed and refused to add their name to the proposed submission. They formed a separate group, which worked together with the Aged Care Justice group to make a more critical combined submission. Some including Aged Care Crisis (above) made their own submissions as well. Other groups and individuals who were not involved in these sessions have corresponded with us. We will deal with these first.

¹ A New Aged Care Act: the foundations - Consultation Summary Report Dec 2023
https://www.health.gov.au/sites/default/files/2023-12/a-new-aged-care-act-the-foundations-consultation-summary-report_0.pdf

² Media Release – Federal Government must deliver robust Aged Care Act without delay! COTA and OPAN 12 March 2024
<https://cota.org.au/media-release-federal-government-must-deliver-robust-aged-care-act-without-delay>

Joint Submission in Response to the Exposure Draft Aged Care Bill 2023 -- 8 March 2024
(12 pages) (<https://agedcarereformnow.com.au/submissions/>)

(Aged Care Justice, Allied Aged Care, Aged Care Crisis, Aged Care Reform Now, Carers' Circle, Older Women's Network NSW and Quality Aged Care Action Group Inc.)

This submission was prepared by the legal group Aged Care Justice (ACJ), on behalf of the other groups after several roundtable meetings. One of ACJ's patrons is retired high court judge Tony Pagone who was one of the Commissioners on the Royal Commission-

While ACJ were focused on human rights and the way the act was worded they realised that the way the system was structured and managed was important if the objectives of the act were to be met. Their submission indicates that there are *"many gaps in the legislation creating concerns about rights enforcement, clinical care requirements, workforce standards and effective and transparent governance of Providers"*. The issues addressed include a move from *"large institutions to small-scale congregate living that facilitates a small household model of care"*. --- concern that *"care funded privately is not funded by the act"* --concern that *"ensuring reforms are responsive to the needs and wants of people with complex health conditions"*

It deals with: 1) issues around workforce, 2) clinical care, 3) Supporters and Representatives 4) Reporting and Transparency, 5) The Aged Care Quality and Safety Commission (ACQSC) criticising its lack of independence and urging a network of regional offices, 6) Complaint Handling which should be more independent, 7) Compensation, 8) Service Agreement and Individual Enforceable Rights, 9) Restrictive practices, 10) Other issues including issues about skills, co-design, financial transparency.

The submission supports our advocacy for greater local involvement and in Appendix 1 it proposes and supports a funded '**Aged Care Community Legal Centre**' to resolve problems. We have supported lawyers wanting this for several years and believe it should be regional and work closely with the regionalised oversight services we advocate.

Quality Aged Care Action Group (QACAG) submission, Feb 2024 (16 pages) -
(<https://qacag.org.au/submission.html>)

(Includes representatives from: Older Women's Network; Combined Pensioners & Superannuants Association of NSW Inc.; Kings Cross Community Centre; Senior Rights Service; Multicultural Communities Council of the Illawarra; Public Services Association; Carers Circle; Aged Care Reform Now; NSW Nurses and Midwives' Association and the Retired Teachers' Association.)

QAQAG contributed to the ACJ submission above. Its own submission indicates that it explored the issues with its members and got feedback. They urged that *"this work is not rushed to ensure we get it right, by allowing sufficient time for feedback to be considered"* as the act *"will set the scene for years to come"*. They considered that it *"should be re-drafted incorporating changes"* then reviewed again. They consider that *"the Act lacks clarity and appears to have been written in haste"*.

There are *"glaring omissions which still make this a funding-based, rather than human rights-based Act"*. They draw attention to the absence of the 'United Nations Principles for Older Persons' from the objects and note that its requirements are not met. They then make multiple criticisms of the act and make suggestions for change.

The Australian Federation of Disability Organisations (AFDO) 8 March 2024 (47 pages)
(<https://www.afdo.org.au/our-work/submissions/>)

The AFDO represents 36 community and advocacy groups advocating and supporting those with many types of disability. They are particularly concerned by the plight of those who are getting disability care under the NDIS and then have to use the aged care system as well as those who become disabled after they turn 65. The aged care system does not cater to their needs in the same way and they fall between the cracks. The new act does not address that problem. The AFDO do not seem to be aware of the structural problems in this market and are generally supportive of COTA and OPANs position and they have worked with them.

A consortium of 17 peak groups and three individuals representing people suffering from chronic conditions and disabilities 8 March 2024 (4 pages)

Their main concern is *“the means by which a person’s needs are assessed to take into account their individual life circumstances”* but particularly *“the powers of the System Governor that allow for the use of a computer program”*. They propose changes that include independent experts. They refer to the problem of *“progressive neurological condition”* and make seven recommendations about assessments. Their focus is probably more on home care than residential care.

Two individuals (Peter Wilcocks and Robin Vote) also made separate submissions, summarised below:

Peter Willcocks. (14 pages)

Peter writes from personal experience of disability and having to use the aged care system when over sixty-five. His in-depth analysis is excellent and well written. He writes about the limits of the KPMG meetings to hear views but not engage or answer questions. He attended one and did not consider it a “realistic consultancy”. He is very critical of the way the consultation process has been outsourced. He has a list of criticisms of the act then focuses on the use of computers and AI. He has researched this and quotes from experts. He indicates what should be in the act about assessments of care needs.

He is very critical of the privatisation of the assessment process. He explores ‘rights washing’ and the lack of input and control the user has when contrasted with the promises being made. He indicates this *“does not mean nor reflect choice or consumer directed care”* and then quotes Stephen Duckett saying that this is just another example of *“high sounding rhetoric is simply there to placate consumers and advocates”*. He stresses the huge difference in power and in access to the courts between the system governor and the residents asking *“Where is the Rights based approach?”* He is worried about rights in the complaints system and by the use of consultants by the commissioner as well as several items missing from the act.

Robin Vote 24 Feb 2024 (4 pages)

Robin is a citizen contemplating future aged care. She has a long experience in government and in community services, and more recently been a supporter of an empowered community visitors scheme for aged care. She too was worried by the way consultations were rushed over Christmas describing it as a *“Crafty move”*.

The draft was complex and difficult to read so that *“Parliamentarians will not have the time or inclination to explore and understand”*.

She was positive about much in the act but other parts were *“problematic and even potentially harmful”*. It was *“a half baked offering”*. The promised principles and rights *“may prove very difficult to attain”*. She is critical of the material where the term ‘Key personnel’ in the old act has been replaced by ‘Responsible person’. This is particularly so when subcontractors are involved. She describes it as *“a lawyers’ clambake and an insurance company’s dream”*. It might lead to *“cost increases and probably the withdrawal of some providers, especially smaller companies, from the sector”*.

She notes that The Royal Commission did not write about the *“use of computer programs in assessing or classifying individuals”* and that most are frightened by the prospect of AI. She writes critically about the ‘named visitor’ and ‘palliative care’.

Dementia Alliance International (DAI) 8 March 2024 (35 pages)

(<https://dementiaallianceinternational.org/human-rights/submissions>)

DAI is a global organisation representing and advocating for people with Dementia. It claims to be *“the only independent and autonomous voice of people of any age, diagnosed with any type of dementia in Australia, and globally”*. They have an interest in the way language is used particularly by government because they so often *“tacitly support outdated concepts”* and *“the very naming convention of the Act further perpetuates ageist attitudes and beliefs”*.

They refer to *“the power imbalance that older persons currently live with”* and the terms which create a passive rather than an active image. They worry that as a consequence people providing care *“become emotionally drained, demoralised and overwhelmed”*. They are critical of the Behaviour Resource Utilisation Assessment (BRUA) and the *“current paradigm of ‘Behaviour Suppression Plans”*.

They are critical of the aspirational nature of the act writing *“Statements of Rights and Principles that are not directly enforceable simply provide older persons with a false sense of security”*, when *“there is nothing behind the screenshot”*. They want a clear and accessible complaint pathway to *“support the older person in making a complaint”*. They are critical of reliance on the ACQSC which the Royal Commission was very critical of. They want far more transparency with *“equal access to all documentation”*.

They are critical of current advocacy and its absence from the legislation and of the way so much of the act is not available for comment. The risk based regulatory framework is of little value to the individual and more is needed at the individual level. In providing services they are worried about loss of *“person-based flexibility”*.

They raise many issues that others have raised as well including restrictive practices, supporters and representatives, the way the providers are being classified, the assessment process, computers and the use of algorithms, consumer advisory bodies, statutory duties, compensation and other problems. They worry about the *“human impact of an inflexible classification matrix”* and urge the department to *“look at additional human centred controls and alternative options”*.

They are concerned by the power imbalance and worry that *“systems that allow harm to occur remain unchanged”*. Like us they are very concerned at the absence of lived experience advising the Commissioner and they advocate for *“living experience consultants, as well as a living experience advisory body to ensure that the commission hears the views of a diverse range of older persons”*. They also believe that the ACQSAC has the same problem. They want an independent Complaints Commissioner. They make multiple recommendations.

While these strong criticisms come from a different experience to ours they fit with ACC assessment. The decentralised reach down and supported community empowered model with its central representation that we advocate would meet many of their concerns and enable them to be dealt with expeditiously.

Motor Neurone Disease (MND) Australia 16 Feb 2024 (8 pages)

(<https://www.mndaaustralia.org.au/advocacy/government-submissions-hearings>)

MND note the omission of some of the Royal Commission recommendations and then write *“nor is disability explicitly stated in the new Act”*. Many MND patients are more than 65 years old and the funding and support falls far short of that under the NDIS. With most dying in about 2 years, the waiting times are unacceptable. They are critical of assessment processes and the use of computers and AI for this. They are concerned by the *“considerable out of pocket expenses”* and the injustice of this. It concludes that *“there are almost no enforceable human rights within the new legislation”*.

Parkinson’s Australia February 2024 (12 pages)

(<https://www.parkinsons.org.au/wp-content/uploads/2024/01/ACA-Submission.pdf>)

This group advocates for *“one of the most vulnerable groups”*. Their concerns relate to the complexity of the process, the inadequacy of the Support at Home program, the omission of Consumer Directed Care (CDC) in the act, the one size fits all assessment process, the funding and other inequities associated with the 65 year old divide between NDIS and aged care, the inadequacy of aged care packages for this group, the inadequacy of support for the carers on whom they depend and the absence of community-based cognitive rehabilitation.

Margaret Duckett (2 pages)

Margaret Duckett was a Board Director of Seniors Rights Service (SRS) for ten years and Board Chair for six of them. She has also been Director of Ageing for the NSW Department of Ageing, Disability, and Home Care. She has practical experience as a carer of her mother and is now a recipient of home care herself. She knows what she is talking about.

She is *“aware of widespread discontent with the exposure draft”*, and was *“appalled with what I read”*. It was cobbled together and has enormous loopholes. While the focus is on human rights the material is *“drafted at odds with those principles”*. *“I am extremely disappointed to believe that relatively few of past and existing problems in aged care support will be rectified by this proposed legislation”*.

Dr Carmel Laragy, Senior Research Fellow, School of Social and Political Sciences, Faculty of Arts, The University of Melbourne (3 pages)

Dr Laragy is a university academic who has had *“years of experience as a social work clinician and a research academic studying self-managed aged home care and disability services”*. Her recent publications about the draft act were attached to her submission (not available to us)

She compares documents and concludes that the principles in the draft are not supported and that *“Choice, control, and responsibility are removed from older people and their families”*. She comments on her recent *“research study of self-managed home support services”*. Older people aspired to those principles but this is not delivered.

The draft *“fails to emphasise the importance of strengthening the personal and community networks around older people”* and focuses on *“administrative and legalistic procedures”* that outsource this to providers. This *“disempowers older people, removes their dignity of risk, and effectively stifles self- management”*. *“The admirable principles are violated through legalistic and intrusive mechanisms”*. The draft describes a *“service system designed to remove choice and control from older people - - - - Better strategies can be developed with the input of all affected parties”*.

Brian Corless and Robert Savellis. A Summary of Results of a Survey on the Mental Health of Home Care Package Recipients and Carers following changes in Aged Care in 2023/24.

This is a summary of research conducted by a retired Clinical Psychologist and a Legal/Healthcare Business Analyst. Both are experiencing this system and seeing the consequences of the changes being made. They found *“more providers declining requests from recipients and carers for services”*. *“There is no dignity of risk or choice for older people to opt out of this mandatory surveillance”* and this *“has been very distressing for HCP recipients and carers who value their human rights”*.

The rushed process over Christmas resulted in *“older Australians trying to understand a complex legislative document with little assistance”* and during this period *“reported feeling anxious, uncertain and fearful of the consequences of the new Act”*. They did an online survey of 142 recipients and carers in January 2024 and found that 72% reported high or very high levels of stress and *“70% of carers reported the presence of features of major depression”*. - - - - 65% of HCP recipients and carers reported *“a noticeable change in recipient’s health since”* January 2023. These had experienced more psychological distress. In addition *“82% of recipients and carers rated their quality of life as ‘the worst possible outcome’”*.

The authors discuss these issues and are worried by the profit motive. They press for more not-for-profit organisations *“such as cooperatives as service providers, generally have a values-based, humanitarian approach to aged care rather than seeing older people as commodities to improve the balance sheet”*. They also support local government but many of these are now vacating the sector. They make some recommendations.

Joint Submission–Aged Care Act Exp Draft--COTA & OPAN 12 Mar 2024 (297 pages)
(<https://cota.org.au/information/resources/submission/joint-submission-aged-care-act-exposure-draft/>)

Joint Submission with multiple national organisations working with older people and carers, including Association of Independent Retirees (AIR), Carers Australia, Dementia Australia, Elder Abuse Action Australia (EAAA), Federation of Ethnic Communities’ Councils of Australia (FECCA), National association of people with HIV Australia (napwha), LGBTIQ+, National Seniors Australia, Unified body of Partners in Culturally Appropriate Care (PICAC Alliance), The Returned and Services League of Australia (RSL).

The combined submission: This is the longest, most detailed and most credible looking of the submissions. It recognises that this is a badly written draft and it focuses on what is in the draft in detail addressing many of the issues that others have identified at length. The first 118 pages address the issues and the remaining 179 are a table setting out the wording they want changed in the draft and explaining why.

This strongly supports the focus on human rights. It stresses the role of independent advocates and they certainly want to be relieved of some of the past constraints. They want the Complaints Commissioner to be more independent of the regulator. The words of support for all the objectives of the act are there.

They clearly think that the act could be improved writing “*significant improvements can be made. There are still many gaps and many areas that need to be written*”. They want that to be enforceable but seem to depend on increased regulation to do that. As indicated earlier they want the act to go through as quickly as possible and did not want major alterations.

Criticism: Aged Care Crisis do not have major issues with most of the suggestions. Our problem is that this detailed and credible looking submission diverts attention away from the major problems in the existing free-market system that have not been addressed. It relies on ever more complex processes and regulations that will cause even more problems in the sector. This is the “*renovation model*” that industry and Commissioner Briggs advised but which Commissioner Pagone criticised and said would not work. We think it would be much more sensible to fix the system so that it works and does not depend on more and more regulation.

Understanding where this is coming from: It is important to understand where COTA and OPAN come from because they have been largely responsible for developing the system that failed. It is theirs. Some of the others have been part of the system as well.

COTA has been close to industry and government at least since 2000. In a 2002 submission³ to parliament, it indicated “*The Commonwealth Government provides financial support to assist COTA (Australia) in fulfilling its policy, consultation, representation and information dissemination roles*” and “*COTA (Australia)'s membership includes key national organisations which represent consumers and service providers*”.

It has played a central role in pursuing Neoliberal market policies over the years, working with industry on the National Aged Care Alliance (NACA) and on the government’s Aged Care Sector Committee. Its chairperson since 2017, Jane Halton, was head of the health department during the Howard years. She was replaced in 2024 by Christopher Pyne who was minister for aged care when Abbott was Minister for Health in the later years of the Howard government.

COTA played a central role with NACA in the development⁴ of the Living Longer Living Better (LLLB) aged care reforms introduced by Labor’s Mark Butler in 2012. Its CEO, Ian Yates urged politicians to vote for it and then promoted it at the National Press Club. COTA was funded to carry out community consultations. In 2011 COTA’s current CEO, Pat Sparrow moved from not-for profit aged care provider group ACSA to COTA where she became responsible for reform. ACC was very critical of these LLLB (Living Longer Living Better) changes at the time as they did not address the problems in the system.

In 2014 Sparrow became aged care advisor to Minister Scott Morrison during the Abbott government. COTA’s Ian Yates was a member of the new Aged Care Sector Committee advising government in 2014. This was when market pressures were markedly increased compounding the problems in the sector and making the situation worse. The system that failed was the system COTA helped design and then supported strongly.

³ Long Term Strategies to Address the Ageing of the Australian Population over the Next Forty Years COTA submission to House of Representatives Standing Committee on Ageing
https://www.aph.gov.au/parliamentary_business/committees/house_of_representatives_committees?url=ageing/strategies/subs/sub91.pdf

⁴ Why the appointment of Mark Butler as Shadow Minister for Health and Ageing is significant Aged Care Crisis Feb 2021
<https://www.agedcarecrisis.com/opinion/articles/453-why-appt-of-mark-butler-is-significant>

After Abbott was replaced by Turnbull, Sparrow returned to ACSA as CEO. ACSA responded to failures like that at the Oakden facility (South Australia) in 2017 by defending the system⁵ claiming “*Aged care is a highly regulated industry and subject to rigorous accreditation standards by the Australian Aged Care Quality Agency (AACQA)*”.

When industry was threatened by the ABC Four Corners programs in 2018, ACSA launched a story-telling platform ‘*Humans of Aged Care*’ which Sparrow indicated⁶. was “*to present all the positive aspects of aged care*”. It continued during the Royal Commission and is still there now operated by the ACCPA⁷.

As CEO of ACSA Sparrow played a key role in the industry during the Royal Commission. Sparrow was actively involved in putting industry’s position to the Royal Commission, and in holding the industry together. Members of the ‘Aged Care Guild’ were among the largest providers and the adverse publicity that resulted forced it to dissolve.

Under Sparrow, ACSA first amalgamated with for profit group LASA and then with the remnants of the Guild to form the ACCPA (Aged & Community Care Providers Association). The providers now speak with a single voice and are more powerful than before. They have set about restoring their reputation and enlisting community support for their position. The “*renovation model*’ that Commissioner Briggs advised was the one that the Morrison government and this industry wanted. This draft act reflects that and it’s what the industry want.

Sparrow replaced Ian Yates as CEO of COTA in 2022 and Yates moved into government posts (Acting Inspector General of aged care and Chair of the new Council of Elders).

OPAN is the central body created in 2017 to represent the nine groups contracted and funded to provide advocacy in aged care. It is funded by government.

Feedback Sessions: As indicated, COTA and OPAN have been running local community discussions and webinars across the country, as well as round-table discussions with other advocacy groups. We assume the funding of this came from government.

We have attended several of these and found Sparrow (COTA) and Craig Gear (OPAN) dedicated and approachable but committed to the renovation model recommended by Commissioner Briggs. This is understandable as this is the model they created. They were not receptive to Commissioner Pagone’s recommendations and other alternative approaches and it was difficult to press these issues with them.

⁵ Statement regarding Oakden Older Persons Mental Health Service ACSA 21 Apr 2017 <http://bit.ly/2rxJuNA>

⁶ ACSA launches aged care storytelling platform Australian Ageing Agenda 4 Sept 2018 <http://bit.ly/2FZXnwg>

⁷ Humans for Aged Care ACCPA <https://www.humansofagedcare.com.au>

1.1.1 Concluding comment

The Howard government's changes in 1997 were 'reforms' made by dedicated believers who have never doubted. Those who built on this to create the 2012 LLLB reforms were also dedicated believers continuing the reform process. They have never had any doubts. The findings of the Royal Commission's interim report were simply not credible for them and we think many in government and industry have been unable to accept that.

This is illustrated⁸ by Graeme Prior, an aged care industry leader praised as a 'thought leader'. In May 2020 only a few weeks after the Royal Commission's damning Interim report he was still reported as describing the aged care system as *'World Class'*.

Australia is well represented on the International Federation of Ageing and Graeme Prior is its current CEO. In October 2021 he gave an international presentation on the Royal Commission findings. In this, he played down the findings and praised much of the previous system which he considered had *"built a great base to work off"*. The secretary of the IFA, also Australian, added *"I'm very proud and very proud of the aged care system in Australia"* so rejecting the Royal Commission's conclusion that it was one to be ashamed of.

We suspect that this reflects a much wider belief that the Royal Commission was only a hiccup in the reform process started in 1997 and refined in 2012 and the new Aged Care Act is needed to continue those reforms. They cannot accept their reform program was, and still is, deeply flawed. Believers are still in positions of power and have taken charge of the new act.

The new act centralises and puts power and control of the system in the hands of a few people appointed by the minister ensuring that it is still captured and even more protected from exposure than in the past. This is a continuation of their reforms.

This must be prevented. The draft act needs amendments that will prevent capture and make it fully transparent and accountable to the communities it serves and open it to 21st century ideas and changes. We will be surprised if the final bill brought to parliament will give communities a role in managing the care their members receive. It will need a few amendments to enable that.

We are social beings. Good societies and responsible citizens are collegial and guided by ethical principles, values and a responsibility to the 'common good'. We form empathic relationships and many embrace 'love thy neighbour' religious beliefs. As citizens and as communities, we have a responsibility for our fellows that markets have never had. Yet we have been pushed aside. The care of our most vulnerable fellows has been handed to the market. This ideology and this act continue to keep us at arm's length. It stops us from fulfilling our responsibilities and holding the market to account.

⁸ For more and links See page 34 of our 2021 (revised 2023) analysis 'Why our society and human services are in trouble' <https://www.agedcarecrisis.com/images/whysocietyandhumanservicesareintrouble.pdf>

This is an in-depth analysis which examines the social science behind ideologies as an introduction to what has happened in human services and aged care. It looks at what social scientists are saying is needed now and then at what has happened instead.