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Sent: Wednesday, 6 March 2024 3:37 PM
To: Aged Care Legislative Reform
Subject: Feedback on the Exposure draft Bill for a new Aged Care Act
Attachments: 2024 Summary of a Mental Health Survey of Home Care Package Recipients and Carers.pdf; RE: Feedback on the Exposure draft Bill for a new Aged Care Act [SEC=OFFICIAL]; Re: Feedback on the Exposure draft Bill for a new Aged Care Act [SEC=OFFICIAL]

Categories: ACTION REQUIRED

Attached is a summary of a survey on the Mental Health of Home Care Package Recipients and Carers during the Legislative Reform process.

The results are alarming and require immediate attention. The rushed process of releasing the draft Bill just prior to when politicians, bureaucrats, lawyers and others went on Christmas holidays, leaving older Australians to try and understand a complex legislative document with little to no advice, was distressing for many who receive Aged Care funding.

Together with the updated guidelines and exclusions for services under Home Care Packages and the over-zealous and singular regulatory approach of the Quality and Safety Commission, this rushed legislative timetable has brought very high levels of psychological distress to many older people.

- Specific feedback on the draft Bill includes:
- the removal in the draft Bill of any reference to consumer-directed-care (CDC), from the current Act. CDC is an international evidence-based model on which Australian self-management of HCPs is based (Laragy & Vasiliadis, 2020; 2022). It promotes self-determination and autonomy in aged care and is understood globally. There has been no rationale or reason for removing it from the draft Bill, and is contrary to research evidence. A significant part of the psychological distress reported in the attached survey has been associated with perceived loss of self-determination and autonomy over funding of HCPs, and the consequences of a new Act without CDC or self-management of HCPs.
- In the draft Bill, service providers are empowered and made responsible for "protecting" older adults with no choice for individuals to opt out of the mandatory surveillance that the Regulations impose. This aspect contravenes accepted Human Rights conventions and infantilises older adults receiving HCPs, particularly those who choose to self-manage their funding under the CDC model.
- There is no reference in the draft Bill to a dignity of risk for older people, particularly those self-managing their aged care funding and living at home. Empowering service providers with funded responsibility for protection of all Home Care recipients against abuse (regardless of their individual choice), serves to continue the marketisation of the aged care sector where the profit-motive is driving providers to succeed, and older adults are seen as commodities to improve balance sheets.
- There is no separation in the draft Bill of the needs of residential aged care residents from the needs of those receiving funding and living at home. Residential homes are not mini-nursing homes and should not be treated as such.
- Section 21 of the draft Bill removes the right of appeal to courts or tribunals. This is contrary to other parts of the Bill that espouse human rights. As Professor Stephen Duckett writes: 'Nothing in this (aged care rights division of the new Act) creates rights or duties that are enforceable by proceedings in a court or tribunal'. This is described as "rights washing".

- The reliance on computer-generated assessments through the IAT and potentially AI, rather than skilled allied health and medical professionals, de-humanises and trivialises older adults.
- There is no reference in the draft Bill to those of us with chronic diseases and disability who are excluded from the NDIS because of age.
- Section 159 can be described as a "throwaway line" for the use of consultants, with no description that defines their role in terms of delegation of authority and decision-making.

Thank you

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a HCP recipient.

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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.

March 2024.

*Have a number of older Australians in need of assistance given up
on the Aged Care Home Care/Support at Home Programs?
or have they given up on life, itself?*

This is a brief summary of the results of an online survey of the psychological health of Home Care Package (HCP) recipients and their carers. A full report is in preparation.

The aim of the HCP program is to provide funding for older people with complex needs to enable them to remain at home rather than enter a residential aged care facility. A number of policy and legislative changes in aged care occurred during 2023 and 2024 that impacted on older people and led to an increase in reports of significant levels of distress for those living at home, including suicidal ideation. These changes included:

- Publishing the “Home Care Packages Program Operational Manual: A Guide for Home Care Providers” (known as the “updated guidelines”) in January 2023, with a subsequent publication and webinar on HCP “Program Inclusions and Exclusions- FAQs for Providers – version 1” in April 2023.
- A stricter and singular approach by the Australian Quality and Safety Commission (the Commission) to regulating providers who supervise HCP funds, regardless of the individual circumstances of HCP recipients and carers who access those funds.
- Release of the Exposure draft Bill for a new Aged Care Act, published in December 2023, including the removal of all references to consumer-directed-care (CDC) from the current Aged Care Act. CDC is an internationally evidenced model of aged care and part of Australian aged care since 2015. CDC is the theoretical foundation upon which the model of self-management of HCPs in Australia, rests.

The updated guidelines resulted in more providers declining requests from recipients and carers for services and items from their HCP funding, more often. Anecdotally, this created significant hardship for many HCP recipients and their carers, and reports of this distress increased on social media and aged care forums.

The stricter approach to auditing providers by the Commissioner resulted in at least one provider, who offered clients self-management of their HCP, being sanctioned for not providing more monitoring and oversight of workers engaged by HCP recipients e.g. gardeners, cleaners etc. The assumption underlying the Commission’s approach for mandatory surveillance by providers of all HCP recipients, is that all older people cannot be relied upon to manage their workers without being subjected to elder abuse. There is no dignity of risk or choice for older people to opt out of this mandatory surveillance, and it seemingly constitutes an ageist and thus discriminatory practice. Not surprisingly this has been very distressing for HCP recipients and carers who value their human rights.

Finally, the Exposure draft Aged Care Bill released to the public just before Christmas 2023, when politicians, bureaucrats, legal advisors and others went on leave, resulted in older Australians trying to understand a complex legislative document with little assistance from policymakers or others. Over this period older people reported feeling anxious, uncertain and fearful of the consequences of the new Act. As if to reinforce this anxiety, a number of experienced social commentators and researchers have since questioned aspects of Bill as not being in the best interests of older Australians.

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Examples of reports on social media and forums of the impact of these changes included:

I am a full-time carer for my elderly mother who has dementia and is paralysed from a stroke. She requires daily laxatives, suppositories and enemas, which I administer. The provider has told me that, under the new guidelines, these bowel-movement inducers are not covered from her HCP. This is on top of a sequence of other exclusions over the past year. Why, Minister Wells, has your government adopted such a paternalistic attitude to aged care? What if it was your mother?

After 20 years of taking magnesium supplements for my cardiac health, I stopped because I can't afford to buy them. I ended up in hospital with a pulse of 40 and so tired! The minute I got to hospital, staff inserted an IV line with a dose of magnesium. It took 25 minutes for me to say that I was ready to go home! It was like a miracle. My cardiologist agrees that for me and my strange heart issues, magnesium is critical. But even with his support I won't be able to get around this exclusion. For me this is a life-threatening situation and I'm really upset and worried about it.

I am a 64 y/o fulltime carer of my 96 y/o mother. I have been lucky to have found some great support staff through my mother's Self-Managed HCP which have helped me clean the house, maintain the lawn, prepare some meals for my mother and do some minor plumbing. But I have lost them all over the last couple of months because of the excessive compliance demands and regulation by the government. I fear that I will now be forced to go for a Full-Managed HCP, but I have been there before and all it means is zero control or say, unreliable staff, extremely excessive fees and ongoing stress. Why can't I choose the staff I need without all this government interference? I am a very committed and capable carer. I need to be supported, not treated like I am incompetent.

I am a carer for my father-in-law. He has multiple amputations on his feet. He melted the skin off his foot from being next to a heater trying to keep warm (he couldn't feel the burning). He spent months in and out of hospital recovering, then months in a wheelchair. We were funded for an air conditioner, but the exclusions cruelled that. I can't guarantee that it won't happen for him again.

An online survey was undertaken in January 2024 to gain a snapshot of the psychological state of a sample of HCP recipients and their carers (n=142), following these changes in aged care policy. In the survey HCP recipients and carers completed the Kessler Psychological Distress Scale (K10), the brief Older Persons Quality Of Life Questionnaire (OPQOL-brief), demographic questions and questions pertaining to the impact of the "updated guidelines" and the stricter regulatory approach towards HCPs.

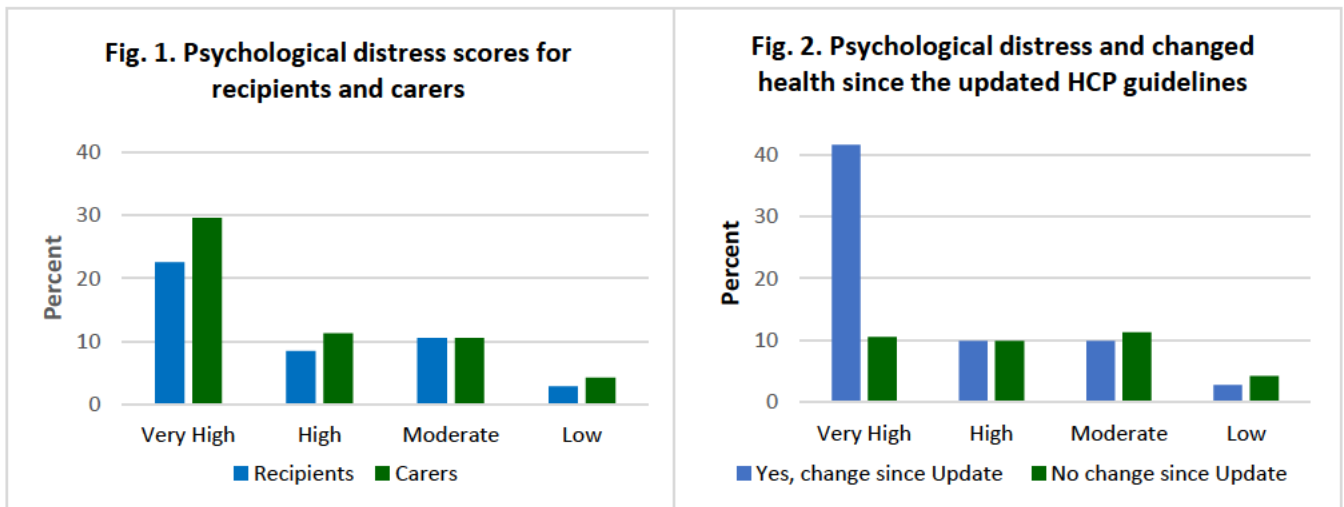
Of the 142 participants in the survey, 44% were HCP recipients and 56% carers, 89% were female and 11% male, 77% of recipients self-identified as having a disability and 33% identified without a disability, 65% self-managed their HCP and 35% were fully managed by a provider. The age range of most recipients was 65 years to 84 years (37%) whereas most carers were under 65 years of age (39%).

Psychological distress:

Overall, **72% of recipients and carers reported on the K10 "Very High" (53%) to "High" (19%) levels of psychological distress, 21% reported Moderate levels and 7% reported low levels of distress.**

Figure 1 shows that separately, **41% of carers and 31% of recipients reported "Very High" to "High" levels of psychological distress on the K10.**

Using evidence-based clinical cut-off scores (Vasiliadis, 2015), 70% of carers reported the presence of features of major depression, and over 80% reported the presence of features of minor depression according to DSM-V criteria. For recipients, over 65% reported the presence of features of major depression, and over 80% reported the presence of features of minor depression according to DSM-V criteria.



In response to a question whether there had been a noticeable change in recipient's mental and physical health since the January 2023 "updated HCP guidelines", 65% of HCP recipients and carers reported that there had been a noticeable change in recipient's health since then (Figure 2). Of those who reported a change in health, 80% rated "Moderate" to "Very High" levels of psychological distress on the K10.

Analysis of total K10 scores indicated that those who reported a change in health since the guidelines ($M=32.08$, $sd=9.78$) registered significantly more psychological distress than those who reported no change in health following the updated guidelines ($M=24.61$, $sd=8.42$, $r=-0.367$), $z=-4.38$, $p<0.001$. As shown in Figure 2, most of this difference in psychological distress was attributable to "Very High" K10 scores.

Quality of Life:

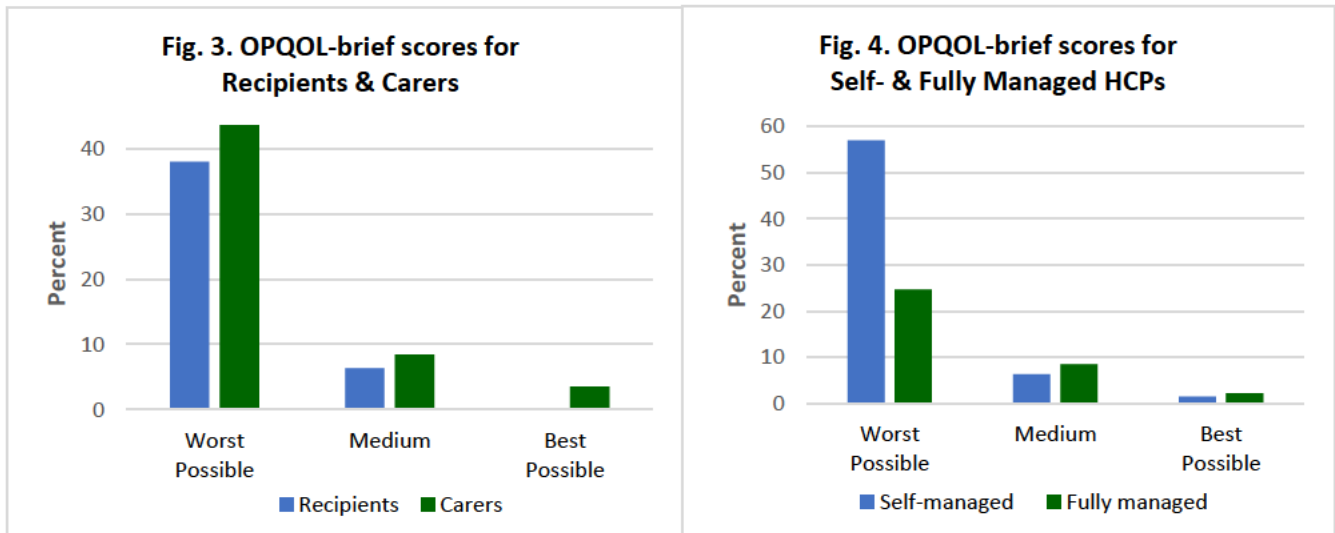
On the OPQOL-brief, a measure of quality of life, in response to a question about quality of life "as a whole", 45% of carers and recipients rated their quality of life on the whole as "Bad" or "Very Bad", 35% rated it as "Alright" and 20% rated it as "Good" or "Very Good".

On the summed total scores for the OPQOL-brief, 82% of recipients and carers rated their quality of life as "the worst possible outcome". No recipients and 4% of carers rated their quality of life as "the best possible outcome". (Figure 3)

Figure 4 indicates that 60% of self-managed recipients and carers and 25% of those fully managed and their carers rated their quality of life as "the worst possible outcome", whereas 3% of both rated their QoL as "the best possible outcome". Compared to published normative data for the OPQOL-brief for older adults, both self- and fully managed groups experienced a worse quality of life than older people of a similar age (Kwaamba et al., 2015).

Analysis of Qualitative Data:

Recipients and carers were given an opportunity in the survey to provide more details on the impact of the updated guidelines, and oversight and regulation of their HCPs on their lives. More complete details of the content analyses will be provided in the full report. The key points are presented below.



- ***The “updated guidelines” for providers***

In response to a question about the guidelines, 79% of recipients and carers reported that the updated guidelines had impacted their lives.

A content analysis of the responses of those affected by the updated guidelines, clearly shows increased levels of distress associated with the confused and inconsistent application of the guidelines by providers, exclusion of medically necessary medications and supplements, restrictions on home maintenance and basic repairs, the negative impact on quality of life, and a lack of understanding by government of individual needs. Of concern to many who responded was that the enforcement of the exclusion of non-PBS medication from HCP funding was the reason that people are going without essential medication and their physical and mental health is suffering accordingly.

In response to a question on what they would like to see changed in the guidelines for providers, recipients and carers want greater autonomy over the allocation of funds, a more flexible approach, including the setting of precedents in exceptional circumstances, the inclusion of essential items for living, reduced bureaucratic hurdles, restoring and maintaining the dignity of participants and a better quality of life.

- ***Surveillance – “oversight and monitoring” at home***

In response to a question about how much monitoring/oversight by providers of participants’ health and safety was required in their homes, 87% of recipients and carers reported they wanted “provider surveillance” to occur on “no occasions or rarely/sometimes”. In response to a question about whether they wanted more or less regulation of support workers by a Provider in their home, 88% of recipients and carers wanted either “less regulation or no change” in regulations.

Clearly, mandatory surveillance by providers of all recipients in their homes, and more regulation of support workers is not what participants in the survey wanted.

A content analysis of participants’ responses to items about oversight and regulatory behaviour illustrates a clear level of distress that older people are reporting as a consequence of a perceived loss of autonomy and freedom of choice, excessive regulation and bureaucratic hurdles, mandatory reporting by support workers of recipients without recipients or carers’ knowledge or consent, impact on mental wellbeing, opposition to additional regulation and challenges of finding support workers in rural areas, with more regulation.

Conclusions:

The impetus for this online survey was threefold and came from increased reports of significant levels of distress on social media and aged care forums, following:

- the “updated guidelines” and “inclusions and exclusions FAQs” for providers in 2023.
- the stricter and one-size-fits-all approach by the Quality and Safety Commissioner late in 2023, and
- the rushed publication of the Exposure draft Bill for a new Aged Care Act in late December 2023.

A majority of HCP recipients and carers surveyed (n=142) were significantly affected by these policy changes. This level of distress persists today. What is now clear from this survey, is the alarming and severe levels of distress which should be treated as warning signs for government, medical and health professionals to act and address the emotional toll of these changes on older Australians.

Of concern is that **53% of recipients and carers reported “Very High” levels of psychological distress on the K10**. Rainbow et al (2023), in a study of Australians seeking on-line help, reported that very high levels of distress on the K10 could be used to flag the need for further assessment, examining the presence of suicidal ideation. Factors such as burdensomeness, financial wellbeing, and belonging, compound this very high risk.

Apart from the emotional cost to HCP recipients, with **over 80% of recipients in this survey reporting the presence of features of clinical depression on the K10, carers also registered a significant personal and emotional cost** and are often overlooked as being essential to the wellbeing and functioning of recipients. In the survey, **80% of carers reported features of clinical depression**. More urgent attention is required by government to focus on the needs of carers as an integral part of our aged care system.

Together with significant levels of distress, **82% of recipients and carers rated their quality of life as “the worst possible outcome”, with no recipients and 4% of carers rating their quality of life as “the best possible outcome”**. This presents an alarming picture of distress and lack of wellbeing for older Australians living at home and receiving HCP funding, and their carers.

Results indicating that the quality of life for those who self-manage a HCP was significantly worse than those who are fully managed by a provider, at first glance, seems surprising, given that self-management of HCPs is meant to provide more autonomy, choice and control over HCP funding and thus a better quality of life. However, it is understandable that those with the most to lose from restrictive guidelines, over-regulation and an anxiety-provoking legislative process, will be most affected emotionally. This is seen as a policy-induced negative effect. When self-managing HCP recipients and carers perceive a loss of autonomy and self-determination in their lives, their “Very High” levels of psychological distress and poor quality of life is a consequence of that loss.

It would be alarming and reckless for government to see this result as an opportunity to impose more scrutiny “to protect” those who self-manage their HCPs, when its policy changes underly this distress. To erode self-management further or to continue with the removal of CDC from aged care legislation, will serve to exacerbate this distress. We recommend that if the government values the dignity and wellbeing of its older citizens, that it be proactive and take steps to ensure that CDC is included in the new Act and that genuine self-management, following principles of self-determination and autonomy, is included in the Act to promote resilience rather than distress among HCP recipients and carers (Angevaare et al., 2020).

The ageist-ill health pathway is well established in research (Behzadnia, 2019; Levy et al., 2020) and structural or systemic ageism increases health costs (Chang et al, 2020; Levy et al, 2020). We urge the government and Commissioner to take an individualised approach to policy and regulation and at least provide the choice to opt out of mandatory surveillance (a dignity of risk approach) for those who have the cognitive capacity to protect themselves against elder abuse and choose to do so.

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Given that the HCP program, and its proposed Support at Home program, postponed for commencement until 2025, aims to keep older people at home longer, rather than enter a residential aged care facility, the results of this survey shows that in terms of psychological distress and quality of life, the government is undermining its stated aim. There is little information in writing about the regulatory framework of the proposed Support at Home program, which concerns many. Already, a number of reports have appeared on social media forums that older people are “giving up, because it’s just too hard” to stay at home. What is unclear in these reports is whether they are giving up on an unfair and restrictive HCP program, or on life itself.

As participants in the HCP program, we believe that most recipients and carers are aware of the need for financial compliance, accountability and fiscal responsibility when receiving taxpayer-generated funds. The majority of older people receiving taxpayer-funded HCPs want to stay at home and they behave with restraint and good sense in regard to the spending of those funds. However, a marketized aged care sector, that relies on the profit-motive to drive providers to succeed, has been handed a policy regime that denies that any changes to provider guidelines occurred, applies a strict, ageist and mandatory one-size-fits-all approach to regulation, and makes it more difficult each day for people not to enter residential aged care.

We recommend that the government consider encouraging more not-for-profit organisations to become involved in the aged care sector. These 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. Local government has relinquished its role in aged care, yet maintains its organisational structures to service regional, rural and remote areas and should be considered as an option for those residents.

If the government has a duty-of care towards all of its citizens, and has assumed that duty for older Australians, we believe that it needs to act now to remedy this distressing set of circumstances that has created this alarming level of distress. We recommend that the government urgently:

- Provide a counselling helpline, independently funded and run by an independent organisation that has the capacity and training in counselling to understand and act on the stories of older people in distress, e.g. Lifeline, Beyond Blue, etc. We believe that neither COTA nor OPAN have the skill set for this or are appropriate organisations to offer this service.
- Adopt a more flexible and individualised approach to the spending of HCP funds for those living at home, such as allowing precedents to be set for the purchase of medically supported services from funds in exceptional circumstances. These precedents are to be published on a publicly accessible website, with explanatory information and searchable metadata for universal reference.
- Also, as occurs in the commercial world, a discretionary allowance would address many of the challenges for governance. A set non-accumulative discretionary monthly allowance would empower individuals to use this support on services that would address their individual and unique needs.
- Offer the choice to opt out of mandatory surveillance (a dignity of risk approach) for those recipients and carers who have the cognitive capacity to protect themselves against elder abuse and choose to do so.
- Include specific references to consumer-directed-care as the model underpinning self-management of Support at Home funding (Laragy & Vasiliadis, 2020; 2022).
- Encourage more involvement of not-for-profit values-based service providers, such as cooperative organisations, to play a role in aged care, particularly for those who live in regional and remote areas.
- Encourage more involvement of local government, with its potential links to Primary Health Care Networks, to better serve the physical and mental health of older Australians receiving HCPs.

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As the saying goes, *the true measure of a society is how it treats its most vulnerable*. The important question for government is: will it measure up to this challenge while ensuring self-determination and autonomy for older Australians receiving a HCP and their carers? Regardless of the answer, the “very high” levels of reported distress and poor quality of life in this survey, indicates that the clock is ticking, and a proactive approach is needed urgently.

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Robert Savellis.

March 2024.