

Committee Secretary
Senate Standing Committees on Community Affairs
PO Box 6100
Parliament House
Canberra ACT 2600

Reference: Aged Care Amendment (Implementing Care Reform) Bill 2022

Thanks for the opportunity to make a submission to your inquiry.

I am writing to ask that Consumers, Families and Substitute Decision Makers [C,F&SDM] are thoughtfully considered while implementing these amendments.

We know from the Aged Care Royal Commission that C,F&SDM have rarely been central in the design of services and systems for Aged Care.

The lack of consideration given to C,F&SDM reflects many things, including the power of the Aged Care Providers Lobby and the failure of Governments to resource and empower Regulators.

However, it seems that the biggest failure has been the failure to adequately recognise that C,F&SDM are genuine stakeholders in Aged Care.

The C,F&SDM and Taxpayers have equally been kept in the dark, denied transparency and fundamentally ignored in the design and management of Aged Care.

Despite soothing statements like “client centred care” and “consumer consultation” [sometimes meaning Government will keep talking to you until you are sick of the process or Government will give you 28 days or less to respond to a plan they have been working on for a year or more] C,F&SDM have basically been ignored.

I acknowledge that there are long standing consumer representation bodies that operate at both a system wide advocacy level or provide advocacy for individual issues.

My observation is that such representation generally gets to consider the options presented by decision makers.

When it comes to legislative change, I want C,F&SDM to be thoughtfully considered in basic design and capacity of all aged care data systems; thereby influencing what options are presented to decision makers.

Critical issues such data ownership, access and confidentiality should be at the heart of system design. This is especially true now that we have the Royal Commission evidence showing a number of ways in which the current systems do not function well.

We also have the recent experience of natural disasters, the Pandemic, and commercial failures that have caused rapid changes of staff, movement of residents. and significant transfers to Hospital from residential care and home care.

Three examples follow;

The commercial disaster of Earle Haven Residential Aged Care Facility [see Qld Govt report], where Client Data was held “hostage” in a dispute between the Approved Provider and sub-contractor. Food and medications were withheld, staff were sacked on the spot and order had to be restored by courageous and committed aged care workers [at that point unpaid and not covered by insurances], Police and the Ambulance Service.

The multiple floodings of the new Yeronga Regis Aged Care Facility in Brisbane which was built in a well known floodplain, accepted by Aged Care Regulators, yet loses electricity to operate lifts for evacuation or access to client records.

The failures of the “surge” workforce at some Victorian Residential Aged Care Facilities during COVID. That very difficult work would have been made more achievable if centralised offsite and accurate Client Data was available to Departmental and workforce planners.

Although we hope for the best, Earle Haven has once again proven that we must plan for the worst behaviour of Approved Providers and their senior management.

Although the legislation relating to Star Ratings, information sharing, increased financial and prudential oversight, and strengthened arrangements for the use of restrictive practices has been enacted it is not too late to ensure that the data systems supporting that legislation, the Bill before your committee, and all future changes are designed to meet the expectations of C,F&SDM

Unless we deal with data ownership, access and confidentiality ,up front, system design may actually limit the extent to which we can meet the reasonable expectations of C,F&SDM.

Policy changes that will eventually be required to meet the needs of C,F&SDM can be worked out in due course,provided the initial design is flexible enough.

For example; ownership of client records in the medical system is generally accepted as; the record belongs to the Practitioner, but a copy will be provided to the client upon request, within a reasonable period of time.

I hope that will eventually become “.....the client [patient] owns the medical record but the Practitioner may retain a copy to meet their own ethical and legal obligations.....”.

Aged Care needs to adopt a standard something like “the Client and the Australian Government own the Client record and the Provider can use it while a client is in the Providers care. A copy of the client record may be retained by the Provider for a specified period to meet their ethical and legal obligations. At no time does the Provider acquire ownership of the client record or the right to consolidate that data for other purposes.....”.

Because Age Care Providers are subject to written agreements with the Australian Government and specified obligations to clients, we can deal with data ownership, access and confidentiality within Aged Care without waiting for other sectors.

Co-ordinate with other sectors where possible, particularly with the NDIS, however, Aged Care needs to move forward without delay.

Greater processing speed, generally cheap storage, generally good data transfer rates and good commercial encryption have transformed what is achievable.

Software vendors and Providers will have their own views and can be expected to defend their own interests by promoting what is most useful to themselves.

I do not doubt many of them have a helpful sector wide view and a valuable contribution to make, however it would be unreasonable to expect them to ignore their own commercial interests.

Not for Profits of course have the same commercial self-interest, they just spell it out differently.

Organisations do not want change that will cost money to implement and improve the transparency of their operations and empower their customers.

I am asking that C,F&SDM and Taxpayers are now given priority in the design and management of the new Aged Care data systems required to support legislative change.

I believe C,F&SDM expect, and Governments will eventually approve changes to the effect that:

The Australian Government and the Client have sole ownership of all Aged Care client data and that data is protected so that it is not available for any other purpose, even without personal identification.

Complete real time transparency of all client and Service Provider interactions, such that what happened,when, with and by whom, is recorded and accessible to C,F&SDM and Regulators.

Confidentiality provisions that protect client confidentiality, tracking of all access to the confidential client data and reforms the concept of Client Confidentiality so that the claim of Client Confidentiality ceases to be the curtain which protects Approved Providers and others from scrutiny by C,F&SDM.

My employed role has been as an advocate for Carers and now semi retired I am involved with some of the local Primary Health Network Committees as a Consumer Representative. That includes Aged and Palliative Care.

I understand the Aged Care system fairly well, and I know that we need to embed the expectations of C,F&SDM in the systems design work that continues everyday so that real change is achieved.

If I can be helpful in expanding on these comments please let me know.

Sincerely,

Max Vardanega

12 August 2022