Submission to:

Serious Incident Response Scheme for Commonwealth funded residential aged care - Finer details of operation

11 October 2019

Aged **C**are **C**risis (**ACC**) welcomes the opportunity to make a submission to this very important Bill.

ACC are an independent group of Australian citizens. Members of our group are engaged with the aged-care sector in a variety of ways – as advocates, health professionals, legal experts, users of services and as volunteers.

The tenor of much of our feedback indicates a high level of community concern relating to the neglect or mistreatment of aged care residents, appalling staff levels in aged care homes and the complete lack of information around direct care staffing.

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1 Introduction

Over the last 20 years Aged Care Crisis and its members have examined the aged care system in the USA, the UK and Australia. There are serious structural problems in the system in all three countries and these create strong perverse incentives. These are based on patterns of thinking (paradigms) that became influential in Australia in the 1990s and were then fully expressed in the 1997 aged care legislation.   They were inappropriate for the sector.

Recurrent failures since that time have been addressed by attempts to regulate this system while ignoring the structural issues, the perverse incentives created and the flaws in the patterns of thought on which this was based. They have been singularly unsuccessful and the situation has progressively become worse.

We have addressed these issues in multiple previous submissions to government.

1.1 Regulation and the nature of care

In aged care we are dealing with intimate and personal care. It depends on close personal relationships. These are built on trust and the capacity to enter into the life of others. Caring involves physical intimacy and an acknowledgement of our vulnerability. The relationships must accommodate to this and to the emotional content of the lives of those cared for. The free market system and the sort of relationships it creates intrudes into and disrupt these relationships.

The centralised tightly structured and process driven management and regulatory system we have in Australia has not responded to the complexity and the emotional context of aged care. It is not possible for such a system to do so. This is why both the MyAgedCare processes and the centralised regulatory systems have failed. The new Aged Care Quality and Safety Commission does not address these issues. The Aged Care Roadmap, which expresses the philosophy underpinning this system, is poorly suited to the sector and should be scrapped.

Whose responsibility?: Aged Care Crisis argues that the care of vulnerable members of our society who are in need is the responsibility of every one of us and of every community. It is through the relationships formed in doing this that citizens develop empathy, a sense of social responsibility, and altruistic values. In doing so we build social capital.

While we cannot provide the care what is needed in our society as individuals, anyone or any organisation who provides care is doing it on our behalf. They are doing it as our agents. They are accountable to each of us and to each of the communities they are privileged to serve. It is our responsibility to hold our agents to account and see that they do what we require.

The current aged care system and the belief in free markets has taken that away from us. The structures of society that support our humanitarian values and generate social capital have been damaged. Government is too far removed and the structured processes it uses are incapable of addressing the problems that arise.

1.2 How this happened

Patterns of thinking and the legislation based on them, starting in the early 1990s and applied rigorously since 1997 are largely responsible for the steady deterioration of staffing and care. As has happened in multiple situations where social processes are based on belief rather than evidence and logic, challenges to the structure of aged care and the paradigms on which it is based have been discounted, often by attacking the messenger. Data that might challenge the belief is suppressed.

There are a number of problems in the efforts that have been made to address the steadily deteriorating situation over the last 20 years.

- The system has tried to address the problems by regulating, instead of addressing the problems in the structure of the system. Any system that depends on regulation to make it work is not fit for purpose.

- Because of its nature, aged care cannot be effectively regulated by a centralised bureaucracy. Governments were warned by Gregory in 1993 and Senator Gibb in 1997 that there was no effective way to regulate the system being introduced or to maintain adequate staffing.

- The particular sort of regulation that has been adopted, which has been called 'regulatory capitalism' or the 'audit society' is particularly unsuited to a sector where there are strong perverse incentives. It seeks to steer the provider in the right direction (eg accreditation) and then relies on a variety of self-regulatory and governance structures within industry. Such a system only works when the objectives of society and industry are closely aligned and this is not the case. What has happened in aged care and the banks has exposed its inadequacy in the face of perverse incentives.

- There has been a revolving door and the regulators have been captured by industry's thinking and rationalisations.

1.3 Finding a way out of the system within which aged care is trapped

For over ten years, Aged Care Crisis has argued that the management and oversight of aged care should be returned to communities and structures set in place that would enable citizens to work with their agents in providing care in their communities and in doing so monitor their activities, oversee the collection of objective data, protect and help the recipients of care. This would enable citizens to hold their agents to account.

The most powerful regulator in this context is the social control that citizens exert on one another in day to day interaction. It confronts inappropriate ideas before they become harmful and addresses any problems promptly and at source.

Control is exerted by word of mouth and by the advice given to prospective residents and families. The most effective sanction would be the right of the community to terminate a recalcitrant provider in their community. This would be facilitated in a system where ownership of facilities and their operation were separated by using Real Estate Investment Trusts (REIT). The provider could be more readily changed without disrupting residents or staff.

It is government's role to support and mentor society and not assume its functions. It is the role of central regulators to give form and structure to the community's values and to be ready to act when they are unable to constrain unacceptable conduct. In doing so central regulators objectify our expectations and the limits of acceptable behaviour.

We are strongly supporting those in Queensland and Victoria who are now pressing for fully empowered visitors and advocates to be more often on site and more closely involved in detecting problems and monitoring care.

We argue that these visitors/advocates should be drawn from local communities, be supported by the local expertise that is available locally and so often lacking in board rooms, policy makers and regulators. They should form the nucleus of community structures to which they report and which oversee and manage aged care locally. Government would mentor and support. Information on performance would be supplied to communities and government.

1.4 The proposed Serious Incident Response Scheme (SIRS)

The changes made in 1997 were based on a belief that ignored evidence. It was made in the face of strong criticism, political opposition and an unhappy and critical electorate. The belief and the future of believers was threatened by evidence and the exposure of failures. As a consequence evidence was not collected and the system has operated to contain and manage adverse information rather than addressing the reasons for it.

The industry and government have been locked in a tight embrace since 1997. Industry has advised and been consulted at every step. Nothing was done without their approval. Every beneficial change has been reluctantly acceded to under pressure from the community and the press. Many proposals have been watered down by the industry's influence.

The information that the SIRS is intended to collect and evaluate is long overdue and it is information that needs to be transparently collected and evaluated. It is not the intent but the mechanism that is problematic.

1.4.1   The problem with the SIRS scheme

We do not have any basic data on which to base recommendations and decisions in regard to serious incidents. These matters have never been properly investigated or reported. It is inappropriate for a centralised body and business consultants who have little personal experience to simply impose something like this.

Those who are primarily concerned are the community whose vulnerable parents will depend on it. They are vitally interested. It is particularly worrying when those stakeholders and those who will oversee this have been shown to be incapable of providing a safe system properly for the last 20 years then present us with the sort of system that they want and without involving citizens in the creation of a system that they might want.

Déjà vu: This proposal is reminiscent of the changes made to the *'Quality of Care Amendment (Minimising the Use of Restraints) Principles 2019'*. This was developed by the department and its stakeholders. A suggestion that the community and those who would implement it be consulted was rejected. The latter were faced by a fete accompli.

Those who had to implement it were horrified and wrote to politicians strongly opposing it. The 'Parliamentary Joint Committee on Human Rights' was persuaded to review the matter. Those expected to implement the changes asked the parliament to intervene and discard the changes to the principles that had been made.

In the case of SIRS, starting a belated consultation when all the important decisions have already been made is not much of an improvement.

Using KPMG: The program was developed by KPMG. This is an organisation where an internet search for information from the USA, Hong Kong, Spain, Canada, South Africa, The United Kingdom, Malaysia and even Australia reveals a worrying association with business and political misdemeanours on a global scale. There has been strong criticism of standards of audit and conduct. It has been fined and some staff even jailed. KPMG seems to be very supportive of everything that its clients would want.

KPMG is an accounting business and an economic adviser. Its qualifications for helping the government to make policy on clinical and social issues seem to be lacking. We conclude that the economic impact for industry are given priority over clinical and social issues. They seem a particularly inappropriate choice for addressing clinical issues like Quality Indicators or social issues like abuse and neglect.

The SIRs program was further developed through the usual stakeholders. These are industry and aligned community supporters of the patterns of belief that have been expressed in the Aged Care Roadmap.

This consultation: As a consequence the community is presented with a carefully structured plan that avoids any risk of confronting the patterns of thinking and their consequences. It is presented with the arguments for and against a few options that allow some comment on the final portion, but not on the structure. This is a strategy that has been used in previous consultations.

1.5 In regard to the proposal itself

1. Some attempt to define the nature and the type of matters to be addressed is useful legally if and when these matters come to court where precedents and limits are set. They remain too crude for everyday use but can be used as guiding principles. They refer to matters that too often depend on the context, particularly on whether the trust within any particular trusting relationship has been breached. They do not help to resolve real life issues as they arise. These need to be assessed by someone independent who is regularly on site and familiar with the context and the people involved.

2. Predictably KPMG anticipated what stakeholders would want, indicating that these problems "*should be dealt with as part of an approved provider's internal governance arrangements*". It is clear from the way that the sector has behaved over the last 20 years that these self-regulatory structures have not worked. While many will oblige others will exploit the opportunities this provides to protect their brand and exploit commercial opportunities. Effective oversight is essential.

The Commission does not have the capacity to administer and oversee this sort of problem effectively. The belief in minimal regulation remains and with that comes regulatory reluctance. Phrases like *"the context of a risk-based, end-to-end quality and safety regulatory framework"* have lost their glitter. Experience shows that there will be some improvement but as soon as some find ways around it, others will follow.

3. Assurance to the Australian community comes from having someone from that community whom they have appointed, know and trust, closely monitoring. It does not come from a *"a defined national scheme"*. The public has lost confidence in government and in such government controlled schemes. Experience is that they are rarely transparent.

1.6 A better approach

The sector and the problem of serious incidents are well suited to an approach that adopts the principles of co-production, co-design of research, co-evaluation and ultimately co-regulation[1]. It should be treated as a work in progress built step by step working together with visitors and community in our nursing homes.

KPMG considered an Ombudsman, modelled on those In NSW. Stakeholders generally supported this option ahead of others. This may be because it has only an advisory and educative role and does not have enforcement powers. In itself this might be useful but local oversight backed by a regulator with the capacity to enforce is still essential and might make it superfluous. In a co-regulation model this advisory and joint educational role would be filled by an involved community and its empowered visitors. A regulator with enforcement powers is required for recalcitrant operators.

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[1] **The many shades of co-produced evidence** Pippa Coutts Carnegie Trust UK 2019 http://bit.ly/2kuzbs9

2 Responding to the questions and other issues in the consultation.

Our comments in the sections below describe how the SIRS might operate in a co-designed, co-developed and co-evaluated project working with empowered visitors and empowered communities. Ongoing research could be done by working with social scientists who research these issues.

1. I consent to the Department collecting the information requested in Citizen Space about me, including any sensitive information, for the purposes indicated above.

YES

2. We would like your permission to publish your online survey responses to this consultation, please indicate your publishing preference below:

Publish response, without my name private but including my organisation's name.

5. What is your organisation's name?

Aged Care Crisis Inc.

6. What stakeholder category do you most identify with?

Consumer advocacy organisation

7. Where does your organisation operate (if applicable)? Otherwise, where do you live?

All states and territories in Australia

In a metropolitan area or major city

8. Do you want to upload your submission as a document, or complete the online survey version?

Yes - I want to upload my submission

Section: Definition of a 'serious incident'

10. Are there any other components/definitions that should be in scope for a SIRS?

YES

If yes, please explain

This will emerge on the ground as it develops.

11. Should acts by family and/or visitors be covered by a SIRS?

YES

12. Should a SIRS include an unexplained death, noting the role of Coroners?

YES

Please explain further

You cannot develop policies and manage issues if neither the communities that are ultimately responsible nor government know about it. These need to develop as the area is explored to determine what works.

Alleged, suspected or actual serious incidents by a staff member against a consumer

13. Are there any additions or refinements required to the definitions of incidents by staff against consumers?

If so, which definitions, and what additions/refinements should be made?

14. Are there any definitions that require specific thresholds?

YES

If so, which ones and what should the threshold be? (For example, financial abuse would only be considere a serious incident when it was in relation to a certain dollar value or above)

Requirements and definitions if needed could be developed as experience grew. The knowledge is not yet available.

15. Is the definition of seriously inappropriate, improper, inhumane or cruel treatment appropriate?

Please explain further

YES

These can be guiding starting points as a guide but must be re-assessed as data becomes available and experience grows. Rigid definitions are hard to undo.

Inappropriate physical and chemical restraint

Providers in the USA have found ways of circumventing multiple efforts to contain this through regulation and Quality Indicators. Regularly on site empowered visitors and advocates working with an empowered community would be much more effective not only in monitoring, but in controlling.

Neglect

On site visitors, advocates and community would be the most effective means of preventing this and addressing it early.

Alleged, suspected or actual serious incidents between aged care consumers

16. Are there any additions or refinements required to the definitions of incidents between aged care consumers?

This will become clear as data is collected.

17. Are there any definitions that require specific thresholds?

If so, which ones and what should the threshold be? (For example, physical abuse causing serious injury between aged care consumers would only be considered a serious incident if the injury required immediate medical attention).

Alleged, suspected or actual serious incidents between aged care consumers

Requirements and definitions if needed could be developed as experience grew.

The definitions of serious incidents including financial, physical, sexual and emotional abuse

Guidelines are clearly required that specify what is unacceptable. They will need to be examined and developed by community and those assessing them as experience and knowledge develops. The nuances created by context and relationships can only be assessed locally. The level of incidents that give rise to concern and need to be reported will sometimes depend more on context and the offence given than what was done. To some extent this will depend on relationships and the way in which trust is breached.

The data collected will be a measure of the culture within an organisation and the nature of the relationships between staff and residents.

Unexplained death or serious injury

18. Should unexplained death or serious injury be included in the definition of a serious incident?

YES

The circumstances should be recorded and reviewed.

19. What is an appropriate threshold for 'serious injury' that would ensure reporting is appropriately targeted?

Please provide detail.

That would evolve as experience is gained but guidelines should be negotiated.

Class and kind exemptions

20. Should the ability to exempt certain classes or kinds of incidents be a power of the Aged Care Quality and Safety Commission or the Minister?

Please explain further

It would be much better if it came from within a process in which the providers are engaged with the community they serve and it evolved from this. It would be more appropriate to have someone more independent like the Public Guardian or an Ombudsman.

What won't be considered a serious incident?

21. Are the examples provided appropriate and clear on what would not be considered a serious incident?

Please explain further

The examples provide some guidelines from which to begin the process, but it is the community as it gains knowledge rather than the providers that should guide the process. The providers should be talking to the community, empowered visitors and advocates - reaching a position with them.

Who must/will be able to report

We argue that except in urgent situations the provider will be responsible for briefing and consulting the empowered visitor/advocate as soon as there is a problem and after investigation with the visitor an agreed report will be provided. If they are unable to agree dissenting reports will be given. In urgent situations the provider should report immediately and the visitor should investigate and either ratify or follow with an independent report.

Staff and family should engage with the visitor and be able to provide a dissenting report if they feel it is needed. Police and other authorities should be notified when appropriate. These as well as minor and non-urgent matters that are satisfactorily resolved for all parties could be reported into a central computer data base and summarized regularly for the community.

Rationale and evidence

22. Is there a need to define 'key personnel' that can report an incident on the approve provider's behalf?

No

If so, who should be considered 'key personnel'?

It should be the provider's responsibility to ensure that matters have been reported at least to the empowered visitor but anyone should be able to do so and to escalate that by reporting centrally if they feel that the response has been inadequate.

Timeframes for reporting

23. Are the proposed reporting timeframes appropriate?

If not, what changes should be made?

They are a guide for serious incidents. In investigating and addressing incidents from a regulatory perspective the Commission should work with the visitor who would monitor remedial activity and see that resident, family and the community group were kept fully informed of progress.

Information to be provided at each proposed reporting stage

24. Is the proposed level of information to be provided at each stage appropriate?

If no, what changes should be made and why?

25. Does the proposed level of information/details required adequately cover incidents between consumers?

26. If the incident is between consumers, what additional information should be reported at each stage (e.g. details of any cognitive impairment that had been assessed by an appropriate health professional)?

27. Would providers know the relevant information needed within these timeframes to allow reporting to be met (i.e. is the level of information appropriate to the specified timeframe)?

What changes should be made and why?

These are suitable guidelines for orientation but ultimately these too should be developed by the communities that are piloting and developing the system and they should be helped by social scientists.

This information should include the name of the empowered visitor involved and working with the provider. This is the person who will be monitoring and verifying that everything is and has been done to address the issue and prevent recurrences.

Proportionate reporting

28. Should proportionate reporting have time limits? (For example, all proportionate reporting agreements are to be reviewed every 12 months).

29. Are there any incident types that should be excluded from a proportionate reporting agreement (for example, sexual abuse by an aged care worker)?

Proportionate reporting is not appropriate as it will compromise the data. It will not be possible to draw any useful decisions when the data is skewed by omitting some. It is the community and the visitors who will decide on how intense the oversight should be and the provider who will need to earn their trust. In this way the intensity and depth of oversight and analysis may be safely reduced without a loss of data. The real incidence and nature of significant events should always be documented.

Rationale and evidence

The disincentive to reporting complained of would be removed if someone were regularly on site talking to staff, residents and family. A failure to report and discuss with the visitor would compromise the cooperative working relationship on which success would depend.

The incidence in each facility would be evaluated and reported locally and then centrally for each provider and type of provider when they were collated. This would allow policy to be based on outcomes and performance.

The regulatory powers seem reasonable but their exercise should be in consultation with the local community who may prefer to replace the provider with someone more suitable. Public reporting would be through the community system so addressing The major problem of government control and transparency.

Record keeping requirements

30. Are the proposed record keeping requirements sufficient?

These will become apparent as the system is trialled. Record keeping is essential.

Powers of the Commission in relation to reportable incidents

31. Are the proposed powers for the Commission adequate, for example in relation to investigation and the ability to respond to reports?

32. What compliance and enforcement responses should the Commission have for example civil penalties, sanctions, enforceable undertakings?

33. Should these penalties be able to be applied to individuals or approved providers or both?

If individuals, who?

With community and visitors having power and a major role in oversight there will be total transparency. Risk profiling might be much less important and greater reliance can be placed on supporting local services and maintain good relationships and communication with them. SIRS will be administered locally and this will be supported centrally. Education will be supported centrally and resources and educational support will be provided. The sort of system that we are proposing will stimulate inquiry and independent learning.

The lower parts of the academic criminologist's regulatory triangles (eg Braithwaite) would be addressed locally in the community. Serious incidents and recalcitrant behaviour should be rapidly escalated to the central regulator who should have all the resources at the top of the pyramid for penalising individuals, facilities or a provider including fines, suspension of admissions or banishment.

These are clumsy methods but are essential when responding to recalcitrance. The most effective regulator will remain the community who may decide to terminate the provider's right to serve their community and bring in another provider to manage the facility. It is not suggested that the visitors and community work without supervision. They should be in regular contact with a supporting mentor. They would work with the regulator and all issues would be recorded.

Public reporting by the Aged Care Quality and Safety Commission on SIRS

34. Is there additional information the Commission should publish?

If so, what?

35. Should individual providers be required to publicly report SIRS data?

If so, what and how often?

36. What might be the consequences of requiring public reporting by approved providers?

It is anticipated that the collection of data and its evaluation first be done locally within the context of each facility and its relevance there. Its content would be reported to provider and community locally and then sent up to a central representative community body working with an academic institution. It would be collated, evaluated further and reported publicly and used to guide policy. Those who need the information will be responsible for evaluating the data so ensuring total transparency.

This would address one of the most serious problems in the current system – the control of data by those who have an interest in concealing it.

37. Are there any additional matters of significance to consider in relation to reporting?

If so, please explain further?

All parties are likely to have items of information that are useful to them collected. This would be debated and added as it progresses. A flexible framework would allow variation to examine local issues while still collecting core data.

Any other matters

38. Are there any other matters of significance that need to be defined for the design or operation of a SIRS? If so, please explain further.

This should be developed as part of an integrated local community service working with its agents to ensure that they are providing the best care possible with available resources.

3 Suggestions and Recommendations

Instead of prescribing and developing a detailed and prescriptive system of reporting by providers whose record is poor, the difficulties of effective oversight and regulation under the current system should be acknowledged. The present plan should be abandoned or modified to make it a platform for developing and empowering community.

Help should be honestly sought from the community explaining the difficulties. They should be informed about the potential of empowered local visitors and advocates. Assistance and suggestions for implementing such a system using local resources should be sought. Volunteer communities should be sought to pilot such a scheme and develop it then evaluate its performance to see if it would work. They may seek support from experienced people in their communities or from nearby universities.

The community have been hollowed out and pushed aside so have lost capacity and confidence. This will need to be rebuilt and developed so it will not be a quick fix. But we have had too many of those and they have not worked.

3.1 Additional issues raised by KPMG

Additional cost and burden: Addressing SIRS within the context of a whole of system structural change to one in which the approach to aged care changes from a managerial and neoliberal one to a cooperate market working with community in a restructured system based on the principles of co-design and co-evaluation would address the problems identified by KPMG.

It would be a part of such a system. This would avoid the need for significant additional resourcing and investment, an increase in the regulatory burden or additional legislation other than that needed to empower visitors. It would be the sort of thing that such a system would automatically watch over. It is past time that there was a general aged care database that was transparent to anyone needing to evaluate data or plan research.

3.1.1 Other issues

KPMG saw advantage in Introducing a SIRS for home and flexible care and that too would fit readily into a co-designed system for integrating and overseeing the care and support of elderly in the community.

The matters listed under "2.2.2.3 *Reporting, responses and oversight of reportable conduct"* would be better and more responsively addressed through the regularly on site scheme supported by suitable mentors that we have suggested.

The matters raised under "Part 3: Policy Objectives" would be addressed by a co-designed and co-evaluated system.