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The new voice of Alzheimer's Australia

Serious Incident Response Scheme for Commonwealth funded Residential Aged Care

A response from Dementia Australia

3 October 2019

About Dementia Australia

Dementia Australia (formerly known as Alzheimer's Australia) is the peak, non-profit organisation for people with dementia and their families and carers. We represent the more than 447,115 Australians living with dementia and the estimated 1.5 million Australians involved in their care.

Dementia Australia works with people impacted by dementia, all governments, and other key stakeholders to ensure that people with all forms of dementia, their families and carers are appropriately supported – at work, at home (including residential aged care) or in their local community.

Our close engagement with individuals and communities means that we are an important advocate for those impacted by dementia and we are also well placed to provide input on policy matters, identify service gaps and draw on our expertise to collaborate with a wide range of stakeholders, including researchers, technology experts and providers.

In addition to advocating for the needs of people living with all types of dementia, and for their families and carers, Dementia Australia provides support services, education and information aimed at addressing the gaps in mainstream services.

Dementia Australia is a member of Alzheimer's Disease International, the umbrella organisation of dementia associations around the world.

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Response to the consultation on the Serious Incident Response Scheme

Please see below, Dementia Australia's response to the online survey

1. Are there any other components/definitions that should be in scope for a SIRS? If yes, please explain.

In terms of staff to consumer, a serious incident should be defined as:

a) Demeaning behaviour – e.g. inappropriate removal of clothes
b) Sexual misconduct, inappropriate behaviour or harassment, including any sexual activity, one off or a pattern of behaviour, innuendo, verbalisation, leering, taunts
c) Verbal abuse
d) Injury – one-off, absence of care, psychological torture (eg putting a dark mat at the door of the room because the person living with dementia thinks it is a hole)
e) Death – circumstances giving rise to death
f) Financial – poor management of financials, fraudulent activity
g) Restraint – physical and chemical
h) Intentional or reckless behaviour by staff
i) Inadequate person care

In addition, the paper defines neglect as 'intentional or reckless failure in duty of care', the interpretation of which is underpinned by an agreed definition for 'duty of care'. Examples cited relate to pressure sores, which implies the 'care' reference is in the context of medical/nursing care only. A more holistic definition may be required, relating to 'absence of…' in all aspects of health (medical) and wellbeing.

In terms of consumer to consumer, the following needs to be included:

a) Physical or verbal behaviour – noting there needs to be the development of a matrix on seriousness, offensiveness to consumer, consent of consumer, and calibrated by another context – for example a known perpetrator or if it occurs in particular living conditions
b) Verbal – swearing, taunts, abusiveness, sexual jokes, unsolicited asking for sex, intrusive questions
c) Physical - no touch – stripping, touching, spitting etc.
d) Physical - touch – hitting/punching, raping

It may also require an additional caveat or strategies that complement reporting processes for incidents involving people living with dementia, as there could be misunderstanding, confusion and a lack of recollection that they have done anything wrong. This is particularly the case in the later stages of disease progression. As such, it is important that both staff and residents have an understanding of the definition of a serious incident (as well as de-escalation strategies before an incident occurs) and receive dementia education through training and other capacity building activities. In the case of residents living with dementia, the involvement of family, carers and advocates can help reduce risk, enhance understanding and support cooperation with SIRS.

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

If a serious incident is carried out by a family member or visitor, or they are the victim of a serious incident in the residential care setting, then it should be covered by a SIRS. Providers have a duty of care to staff, residents and visitors alike and need to be held responsible for this.

Consumers can also complain via the Aged Care Quality and Safety Commission and that gives a point of cross reference for follow-up interventions/responses.

The challenge will lie in shifting to a culture in which providers are empowered rather than fearful of reporting. If the process is complex or there are severe repercussions resulting from a report, this may act as a deterrent to reporting. Ensuring a proactive participation in a SIRS needs to be factored into the decision making framework.

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

A SIRS should include an unexplained death if the serious incident led to the death. It should follow that of the disability sector definition, which includes death as reportable through a SIRS.

4. Is this definition of seriously inappropriate, improper, inhumane or cruel treatment appropriate?

Yes. Dementia Australia supports this definition, particularly the inclusion of emotional abuse within the definition of seriously inappropriate, improper, inhumane or cruel treatment.

It is worth noting, however, that definitions of what ‘appropriate’ and ‘inappropriate’ behaviours and care mean will need to be explicitly stated, particularly where cultural differences may impact how these terms are understood and enacted. Education/capacity building activities are recommended to ensure definitions are universally understood.

5. 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?

No. However, there will be a challenge in determining the dividing line between poor care and a serious incident. The Commission will need to ensure that these are explicitly defined and understood across the aged care sector.

They will also need to fit a SIRS and associated activities into the broader context of aged care reform, including the reforms being driven in the elder abuse space by the Attorney General and others. It is important that all of these safeguards complement each other and are underpinned by consistency in definitions and language.

6. Are there any definitions that require specific thresholds? If so, which ones and what should the threshold be? (For example, financial abuse would only be considered a serious incident when it was in relation to a certain dollar value or above).

Definitions for specific thresholds are complex and further consultation with the sector is required to ensure that the right balance is struck, especially in relation to dementia.

7. Are there any additions or refinements required to the definitions of incidents between aged care consumers? If so, what?

It is important to reference dementia explicitly in the context of resident on resident incidents, particularly surrounding consent and capacity. People living with dementia may not have the control over their choices or the ability to make decisions on their own. In these cases, the involvement of families, carers and advocates needs to be taken into consideration to ensure the person with dementia and fellow consumers are safe and that quality care is maintained.

8. 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).

Further consultation is required and definitions (including thresholds) are contingent on a number of related strategies to ensure the functional, clinical and cognitive impacts of dementia are appropriately defined and understood.

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

Yes – It should be aligned with the definition in the disability sector's serious incident reporting.

10. What is an appropriate threshold for 'serious injury' that would ensure reporting is appropriately targeted? Please provide detail.

Based on wording in the Commonwealth Government's Guide to the assessment of the degree of permanent impairment, a definition might be: "medically determined injury or impairment preventing the person from performing usual daily activities, including physical and psychological effects, for example, loss of body function".

It is important to include the severity of the incident in relation to a risk matrix that would need to be developed as part of the SIRs. The threshold would also need to factor in the response/perception of the consumer and the impact it had on their life.

11. 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?

The Aged Care Quality and Safety Commission should have the capacity, skills and knowledge to appropriately hold decision making power.

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

The examples provided are appropriate; however, there should be an inclusion of a dementia-specific example as staff and other resident interactions with people living with dementia may differ depending on the stage of the disease. Behaviours may need further investigation and parameters may need to be put in place to protect both the resident with dementia other consumers and staff. Strategies need to be included for managing the associated challenges someone with dementia might face (including an unwillingness to report; an inability to remember an incident; or an incident relating to changed behaviours.

13. Is there a need to define 'key personnel' that can report an incident on the approve provider's behalf? If so, who should be considered 'key personnel'?

Dementia Australia believes that there needs to be a definition of key personnel to eliminate any potential confusion. Staff, residents, advocates, families and carers need to be clear on who key personnel are within a service and who to report serious incidents to, as well as having the relevant details and to feel supported and safe to report serious incidents.

Key personnel could include those identified in the Aged Care Act 1997 as defined in section 8-3A:

- people responsible for the executive decisions of the applicant (this includes directors and board members)
- people having authority or responsibility for (or significant influence over) planning, directing or controlling the activities of the applicant
- any person responsible for nursing services provided, or to be provided, by the applicant, whether or not the person is employed by the applicant and
- any person who is, or likely to be, responsible for the day-to-day operation of an aged care service conducted, or proposed to be conducted, by the applicant, whether or not the person is employed by the applicant.
- Key personnel cannot be a disqualified individual.

www.agedcare.health.gov.au/funding/becoming-an-approved-provider#2.1

14. Are the proposed reporting timeframes appropriate? If not, what changes should be made?

The proposed reporting timeframes are aligned with the NDIS reportable incidents scheme. That being said, key personnel and approved providers should report the serious incident to the Commission upon knowledge of the incident taking place.

15. Is the proposed level of information to be provided at each stage appropriate? If no, what changes should be made and why?

Yes.

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

Yes.

17. 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)?

Information regarding the cognitive impairment of a person should be reported at each stage. Additionally, a list of the person's conditions that could have contributed to the serious incident, particularly regarding cognitive impairment, delirium and mental illness, should be captured. This inclusion may lead to the provision of additional information on the incident and contribute to modifying behaviours or other strategies that minimize risk of any future incidents or harm. Additionally, any medications the person is taking/is prescribed should also be reported to identify any potential interactions that may have contributed to the circumstances of the serious incident.

18. 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?

There is a very real risk that the SIRS will not be successfully or consistently implemented unless there is a very clear program and operational guidelines. Currently, understanding how and when to implement a SIRS within the context of aged care, disability and elder abuse reforms, would be challenging.

The roles and responsibilities of providers, consumers, advocates and families/carers need to be clearly articulated, as do SIRS criteria, escalation frameworks, reporting requirements and follow-up actions, monitoring and evaluation.

This will require capacity building exercises and education to ensure that this is effectively carried out. There would be a need to implement a reporting framework and ensure that processes and systems were in place within organisations to facilitate the process and assist providers to report the correct information using the necessary protocols. The focus needs to remain on safety and harm minimisation.

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

Proportionate reporting should have time limits to ensure that quality does not decline and safeguards are continually maintained and kept in place. Without time limits, monitoring and evaluation, there is a risk that the quality of care provided could slip. Through the imposition of time limits, there is also the potential to shift with changing environmental and political contexts that further protect residents and staff within the residential aged care setting.

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

No. However there needs to be clear delineation of what should be criminal prosecution of an individual and what provider responsibility is.

21. Are the proposed record keeping requirements sufficient? If no, what changes should be made?

The record keeping requirements need to be aligned with existing incident response schemes, such as those in the disability sector.

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

The proposed powers of the Commission in relation to investigation and the ability to respond to reports should refer to existing incident response schemes, such as those in the disability sector.

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

The compliance and enforcement responses of the Commission should refer to existing incident response schemes, such as those in the disability sector.

24. Should these penalties be able to be applied to individuals or approved providers or both? If individuals, who?

The penalties should apply to individuals and approved providers. Those responsible for carrying out the serious incident should be held to account for their actions and face the reasonable consequences for their actions. It is important though that there are no significant barriers to providers reporting and the main focus needs to be about safety and reducing serious incidents from occurring. A learning approach needs to be integrated into the SIRS structural framework to facilitate positive change and enable reporting. It is about identifying perpetrators, mitigating their behaviour through criminal and/or performance proceeding to ensure they can mitigate future risk, manage the current incident effectively and support the victim/s. The main focus is on improving care and keeping residents safe. It needs to be looked at it terms of systemic errors and poor clinical governance, to see the whole picture. Perhaps the penalties, and definitions to whom these should be applied, should be based on a risk matrix that defines the type and severity of the incident.

25. Is there additional information the Commission should publish? If so, what?

No. In consideration of information being published, there needs to be acknowledgement of the complexity of system and performance transparency versus privacy and confidentiality.

26. Should individual providers be required to publicly report SIRS data? If so, what and how often?

Transparency is important to facilitate consumer choice and informed decision making, but public data on a SIRS would need to be mindful of privacy, confidentiality and the dignity of those experiencing a serious incident.

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

The main concern from Dementia Australia is that, through public reporting by approved providers, there may be scope for discrimination against people living with dementia, their families and carers. A high prevalence of incident data that involves people with dementia, for example, could mean that facilities may not accept people with high care needs, as detailed in Brodaty's triangle (e.g. severe and extreme behavioural and psychological symptoms of dementia) as they may be deemed to be a 'high risk' for being involved in a serious incident. This needs to be taken into consideration and safeguards put in place to ensure people living with dementia do not face discrimination when entering residential aged care.

However, people (i.e. the public) have a right to know this information to make informed choices about their services. It will be a responsibility of the Commission to ensure safeguards are in place to protect residents and staff, as well as structures in place to ensure reporting is carried out.

28. Are there any additional matters of significance to consider in relation to reporting? If so, please explain further.

SIRS needs to align with existing frameworks such as Human Rights, the NDIS and Australian Aged Care Quality Standards. There also needs to be clearly defined roles of the Aged Care Quality & Safety Commission and regulatory roles.