

Annex

Glossary

Aged care facility is a residential facility in which a person resides, where they receive personal care or nursing care, or both, with appropriate staffing to meet residents' nursing and personal care needs. These facilities also provide meals and cleaning services, furnishings, furniture, and equipment for residents.

Aged Care Quality and Safety Commission (ACQSC) began operations on January 1, 2019, as the primary government agency responsible for monitoring aged care in Australia. It replaced the Australian Aged Care Quality Agency and the Aged Care Complaints Commissioner. It accredits, monitors, assesses, and receives complaints regarding government-subsidized aged care services.

Australian Health Practitioners Regulation Agency (APHRA) is a governmental body supporting the national boards of health professions. It accepts complaints about practitioners' behavior placing the public at risk or practicing their profession in an unsafe way.

Australian Department of Health develops and delivers policies and programs and advises the Australian government on health, aged care, and sport. It seeks to ensure better health for all Australians.

Chemical restraint is restraint that is, or that involves, the use of medication or a chemical substance for the purpose of influencing a person's behavior other than medication prescribed for the treatment of, or to enable treatment of, a diagnosed mental health condition or intellectual disability, a physical illness, or a physical condition.

Commonwealth Ombudsman assesses complaints about the actions of Australian government agencies and private sector organizations it oversees, to consider if the actions were wrong, unjust, unlawful, discriminatory, or unfair.

Dementia is the loss of cognitive functioning—thinking, remembering, and reasoning—and behavioral abilities to such an extent that it interferes with a person's daily life and activities.

Informed Consent is a decision made with a full understanding of the purpose, risks, benefits, and alternatives to a medical intervention, in the absence of pressure or coercion.

Person-centered care is care focused on an individual's unique qualities as a person. Such care builds and nurtures relationships between the individual and others.

Pharmacists and chemists are used interchangeably in Australia to refer generally to professionals trained and authorized to dispense medicines. However, formally, a pharmacist is qualified to prepare and dispense medicines, and a chemist is a broader term for an expert in chemistry. Chemist can also refer to a drugstore.

Power of attorney is a legal document in which one person nominates and gives legal authority to another to act on affairs on their behalf.

Quality Assessors conduct assessments in aged care facilities and have the authority to enter and search facilities. They work for the ACQSC (above) and are distinct from ACQSC complaints officers.

Risperidone is an antipsychotic medicine that is used to treat schizophrenia in adults and children who are at least 13 years old. In Australia, it is permitted for the treatment (up to 12 weeks) of psychotic symptoms, or persistent agitation or aggression unresponsive to non-pharmacological approaches in patients with moderate to severe dementia of the Alzheimer type. Risperidone is not approved by the Food and Drug Administration (FDA) in the United States for the treatment of behavior problems in older adults with dementia.

Royal Commission of Inquiry into Aged Care Quality and Safety was created by the Australian government in September 2018. It is holding hearings across the country and accepts submissions from the public to learn about aged care. It will conclude its activities in April 2020 with a final report making recommendations for improving aged care services.

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*No Memorandum (0925-2019)

September 23, 2019

Hon Richard Colbeck
Minister for Aged Care and Senior
Australians, Minister for Youth and Sport
Department of Health
GPO Box 9848
Canberra ACT 2601
Australia



CC: David Hallinan, Acting Deputy Secretary, Ageing and Aged Care
Dr. Bernie Towler, Commonwealth's Principal Medical Adviser

Re: Human rights and aged care facilities in Australia

Dear Mr. Colbeck:

Human Rights Watch is an independent, nongovernmental, human rights organization that conducts research and advocacy in over 90 countries on a range of human rights issues, including on the [rights of older people and the rights of people with disabilities](#). Our work is grounded in objective, in-depth research on human rights problems. We use our research to draw attention to important human rights issues and to offer concrete recommendations to improve human rights protection.

We are currently conducting research on human rights concerns linked to aged care facilities in Australia. Our primary focus is on the use of chemical restraints among older residents with dementia. We are examining the broader obstacles to effective regulation and the enforcement of residents' rights under domestic and international law.

We are writing with some questions about the role of the Department of Health in regulating aged care facilities. We had the pleasure of meeting with some of your staff in July 2019, and I will also be visiting Sydney and Canberra in mid-October and would value the opportunity to meet with the Department of Health again to discuss our findings.

Our key areas of concern include the use of chemical restraints -- meaning any drug or drugs used for the needs of the institution and not required to treat medical symptoms; staffing levels adequate to meet older people's support needs; staff training to provide quality support

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to older people with dementia; and the adequacy of the Aged Care Quality and Safety Commission complaints system.

We have interviewed current residents' families and visited some aged care facilities in three states in Australia. We do not anticipate identifying any specific facilities in our report. Our preliminary findings include:

- Staff in facilities are giving older people with dementia medications to alter their behaviors for the needs of facility rather than to treat medical symptoms;
- Procedures for administering drugs used as chemical restraints, including the use of PRN ("as needed") prescriptions, leave much discretion to facility staff;
- Aged care facilities are not seeking informed consent for the use of medications from individuals or their legally designated representatives under powers of attorney;
- Some facility staff, residents, and families are not knowledgeable about the medications' risks and about alternatives to their use;
- Some family members of people with dementia in nursing homes described difficulty in access, communication, and resolution of complaints through the Aged Care Quality and Safety Commission;
- There is low staffing that may not always be able adequately support people with dementia in some nursing homes; and
- Australia's laws and regulations fail to prevent the use of chemical restraints, which are prohibited under Australia's commitments under international human rights law.

As part of our ongoing research and to ensure thorough and objective reporting, we are contacting you with some questions.

1. By what means has the Department of Health become aware of chemical restraint as a problem in aged care facilities? What kinds of issues have been raised?
2. How does the Department of Health monitor for chemical restraint in aged care facilities? What have the findings and results of that monitoring been in 2017, 2018, and 2019?
3. What information does the Department of Health have about the Australian Health Practitioner Regulation Agency's efforts to ensure older people in aged care facilities' freedom from chemical restraint?
4. What mechanisms are in place to ensure free and informed consent to all medical treatment in aged care facilities? How does the Department of Health respond to concerns that people in aged care facilities do not always receive medication with free and informed consent by the individual receiving medication or treatment or by that person's legal health care proxy?
5. How does the Department of Health use international human rights standards to protect older people's rights in aged care?
6. How does the Department of Health monitor the implementation of the Minimising Restraint Principles 2019?

7. Why has risperidone been permitted for use in older people with Alzheimer's disease, despite the warnings listed in the product information on the Department of Health's Therapeutic Goods Administration's website regarding increased health risks?

We kindly ask for your response to these questions by October 7, 2019, so that we may incorporate your response into our report and into any other publications or statements Human Rights Watch issues on this topic.

Finally, I would like to request a meeting to discuss issues of mutual concern during my upcoming trip to Australia in mid-October. I can be reached by phone at [REDACTED] or by email at [REDACTED]

Sincerely,

A large black rectangular redaction box covering the signature area.

Bethany Brown
Researcher on Older People's Rights
Human Rights Watch



Australian Government
Department of Health

Ref No: MC19-015676

Bethany Brown
Human Rights Watch
GPO Box 4278
SYDNEY NSW 2001

Dear Ms Brown

Thank you for your correspondence of 23 September 2019 to the Minister for Aged Care and Senior Australians and Minister for Youth and Sport, Senator the Hon Richard Colbeck regarding the use of chemical restraint among residents in aged care with dementia. The Minister has asked me to reply.

The health, safety and wellbeing of older people who reside in aged care services is of paramount importance to the Australian Government.

To assist with your research on this matter, I have set out your questions and the Department of Health's (the Department's) responses below:

1. *By what means has the Department of Health become aware of chemical restraint as a problem in aged care facilities? What kinds of issues have been raised?*

In January 2019, the Australian Government announced that physical and chemical restraint was to be better regulated, as part of its ongoing reform agenda to improve quality and safety in aged care.

Prior to this announcement, the Government funded two separate projects, 'RedUse' and 'HALT,' at a total cost of \$4.1 million (2013 to 2016) aimed at reducing the use of sedative and antipsychotic medications in residential aged care facilities.

The 2017 RedUse study found over a third of residents (37%) were taking a sedative medication daily. Specifically, 22% were taking an antipsychotic and 22% of residents were taking a benzodiazepine.

The Aged Care Quality and Safety Commission (the Commission) also captures data associated with its regulatory and complaints functions. From 1 July to 31 December 2018, medication management was one of the five most frequent 'not met' outcomes in residential care audits, and the most complained about issue. This data indicates that prescribers and aged care workers need better information about the effectiveness and use of medicines in aged care settings.

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Telephone: (02) 6289 1555

2. How does the Department of Health monitor for chemical restraint in aged care facilities? What have the findings and results of that monitoring been in 2017, 2018, and 2019?

The Commission assesses the use of chemical restraint during complaint handling processes and accreditation, and as part of assessment and monitoring activities. During these processes, complaints officers and assessors will seek evidence of the actions taken by providers to minimise the use of restraints at their service and, where restraint is used, to ensure that it is in accordance with legislative obligations. This evidence is gathered through observation, reviewing records of care, interviews with consumers and their representatives and enquiries of management, staff, health professionals and others at the service.

Available Data:

From 2014 to 2019 (as at 31 March 2019), a total of 264 complaints were received which raised issues about chemical and/or physical restraints. Table 1 provides a breakdown.

Table 1: Complaint issues received about chemical and/or physical restraint, per calendar year.

	2014	2015	2016	2017	2018	2019
Chemical restraint	0	0	7	11	44	18
Physical restraint	39	34	41	22	31	17
Total cases	39	34	48	33	75	35

3. What information does the Department of Health have about the Australian Health Practitioner Regulation Agency's efforts to ensure older people in aged care facilities' freedom from chemical restraint?

The Australian Health Practitioner Regulation Agency (AHPRA) provides operational support for the 15 health professionals Boards (the Boards) including the Medical Board of Australia and the Nursing and Midwifery Board of Australia.

AHPRA is an independent authority with its legislation based in complementary legislation enacted in each state and territory. This law means that the 16 health professions are regulated by nationally consistent legislation under the National Registration and Accreditation Scheme.

Each of the Boards sets standards to provide guidance to their profession as to what is expected of their practice. For medical practitioners this includes a *Good Medical Practice: a code of conduct for doctors in Australia* (the Code). The Code includes requirements for informed consent.

AHPRA operates a notification (complaints) process whereby other practitioners, family or community members can make a complaint against a registered practitioner if they have concerns about a practitioner's practice. Registered health practitioners and employers of registered health practitioners must inform AHPRA if they have formed a reasonable belief that a registered health practitioner has behaved in a way that constitutes notifiable conduct.

In addition the Commission makes referrals to AHPRA, if it is aware that a health professional's conduct has breached the applicable standards.

Once received, AHPRA and the relevant Board assesses the complaint and where indicated, initiates an investigation into the practitioner. This can result in restriction or suspension of a practitioner's registration to practice.

AHPRA publishes an annual report which provides data on notification and outcome of investigation against health practitioners.

4. *What mechanisms are in place to ensure free and informed consent to all medical treatment in aged care facilities? How does the Department of Health respond to concerns that people in aged care facilities do not always receive medication with free and informed consent by the individual receiving medication or treatment or by that person's legal health care proxy?*

The responsibility for seeking informed consent of the consumer or their family for prescription medications, including psychotropics, rests with the prescriber (rather than the residential aged care provider). An approved provider has no power to impose the obligation to seek informed consent on visiting medical practitioners or nurse practitioners; this is a matter for AHPRA and the relevant professional board.

If a person has a concern about the conduct or performance of a registered health practitioner, they can lodge a notification with AHPRA. Alternatively, they may contact a health complaints ombudsman in the relevant State or Territory. AHPRA and the National Boards are responsible for making sure that only health practitioners who have the appropriate skills and qualifications to provide safe, ethical care are registered to practise.

Minimising the use of restraint in aged care homes requires a multi-pronged approach; including regulation, educative activities; clinical governance; and improved data capture.

Providers of aged care homes have specific legislative responsibilities in relation to the use of chemical restraint. These regulations require providers to inform the consumer's representative around the time of administering the medication.

In addition, the Australian Government's Aged Care Clinical Advisory Committee acknowledged there is a need for more effective education about the appropriate use of antipsychotic medications and benzodiazepines in aged care homes, and also about appropriate management strategies for behavioural and psychological symptoms of dementia.

The Department has recently engaged an external agency to undertake user testing on what messaging and delivery modes will be effective for a range of audiences (prescribers, pharmacists, aged care workers (including nurses), families and decision makers) and to develop core messaging for each of these audience groups on the appropriate use of antipsychotics and benzodiazepines in residential aged care. It is envisaged that core messaging will cover the following topics:

- Appropriate use of these medications
- Consent and the role of substitute decision makers (relates to all medications)
- Appropriate alternative management strategies for behavioural and psychological symptoms of dementia which need to be considered the first line approach and maximised before medications are considered.

5. How does the Department of Health use international human rights standards to protect older people's rights in aged care?

The Australian Government is working to build a fully integrated, sustainable aged care system, that is genuinely consumer centric. Supporting the human rights of aged care consumers is a core part of the reform agenda.

The Committee on Economic, Social and Cultural Rights¹ noted the right to health in all its forms and at all levels contains the following four interrelated and essential elements:

- Availability
- Accessibility
- Acceptability
- Quality

These elements are reflected in the Australian Government's ongoing reform agenda to improve quality and safety in aged care through regulatory and non-regulatory measures. In the 2015-16 Budget, Government committed to the development of a Single Aged Care Quality Framework, including a single set of consumer focussed quality standards, which apply across all aged care programs.

Significant developments were announced in the 2018-19 Budget, many of which have already been delivered. These measures included:

- the introduction of a new independent Aged Care Quality and Safety Commission from 1 January 2019;
- measures to improve aged care quality protection, including: establishing a robust risk profiling approach, developing options for a serious incident response scheme, and developing a clinical governance framework (delivered in July 2019);
- measures to provide greater transparency of quality in aged care, including: introducing a performance rating system for the new Aged Care Quality Standards (the Quality Standards), the development of an open disclosure framework to support provider compliance with the new Quality Standards (delivered in July 2019), and the continued development of a single Charter of Aged Care Rights (commenced 1 July 2019); and
- funding to residential aged care providers to assist their transition to the new Quality Standards.

As well as improving the safety and quality of aged care services, these measures will protect the rights of consumers to access aged care services that are respectful of ethics and culturally appropriate.²

¹ Committee on Economic, Social and Cultural Rights, *General Comment No. 14: The right to the highest attainable standard of health*, UN Doc E/C.12/2000/4 (2000).

² *Ibid* at 12(d).

Under Standard 1 of the Quality Standards, providers are required to demonstrate that each consumer is treated with dignity and respect, with their identity, culture and diversity valued. Standard 1 highlights the importance of the consumer being able to act independently, make their own choices and take part in their community.

More senior Australians are choosing to remain in their own home for longer. The Australian Government is committed to supporting this choice, as well as promoting the right to health. The Committee on Economic, Social and Cultural Rights' commented that public health facilities, goods and services have to be available in sufficient quantity. The Department's data (as at 30 June 2019) indicates that 125,117 Australians have access to a home care package compared with 99,932 at the same time last year – this is a 25 per cent increase in just one year. In addition, the Australian Government is delivering \$150 million over 3 years to enable more senior Australians to access entry-level home support.

6. How does the Department of Health monitor the implementation of the Minimising Restraint Principles 2019?

From 1 July 2019, the *Quality of Care Amendment (Minimising the Use of Restraints) Principles 2019* amended the *Quality of Care Principles 2014* so that providers have specific responsibilities in relation to the use of physical and chemical restraint.

As part of its complaints function, when the Commission has grounds to believe that the practices of a provider may be in breach of their responsibilities under the Principles, the Commission engages with the service and expects them to act immediately to ensure they are meeting their responsibilities. Where this does not happen or where the issue itself is serious and/or the capability of the provider to implement actions that it has committed itself to is in question, the Commission can instigate the process of issuing formal directions to the provider.

The use of chemical and physical restraint is assessed under a number of the Quality Standards, which came into effect on 1 July 2019. The Quality Standards specifically require providers who deliver clinical care to have a clinical governance framework in place that includes minimising the use of restraint and organisational wide governance systems for regulatory compliance that includes compliance with the Principles on minimising the use of restraint (Standard 8).

Several Quality Standards are relevant, including:

- Standard 1: consumer dignity and choice, whereby the consumer is supported to take risks to live the best life they can
- Standard 2: ongoing assessment and planning with consumers
- Standard 3: personal care and clinical care which is best practice and responsive to consumers' changing needs. Providers must also demonstrate effective management of high-impact or high-prevalence risks associated with the care of each consumer, including restrictive practices. If an organisation uses restrictive practices such as physical or chemical restraint, these are expected to be consistent with best practice and used as a last resort, for as short time as possible and comply with relevant legislation.
- Standard 4: a service environment that is safe and comfortable and promotes the consumer's independence, function and enjoyment

- **Standard 8: organisational governance where the organisation's governing body is accountable for delivery of safe and quality care.**

The Commission notifies any finding of non-compliance with the Quality Standards to the Department. The Department may take regulatory action, including imposing sanctions. This action is aimed at protecting current and future care recipients' health, welfare and interests as well as returning the provider to compliance. Information about aged care providers and compliance action, including current and expired sanctions, is available at www.myagedcare.gov.au

The Commission has developed a *Self-Assessment Tool for Recording Consumers Receiving Psychotropic Medications* that provides details of the type of information that the Commission will seek to review when undertaking assessments of aged care services against the Quality Standards, and as part of that, monitor how services are effectively overseeing the use of restraints. The Commission wrote to all residential aged care providers in June 2019 with the Self-Assessment Tool to support their process of continuous improvement in relation to the standard of care and services.

The Commission has also developed the *Guidance and Resources for Providers to support the Aged Care Quality Standards* (2019) booklet which contains information about minimising the use of restraint within both Standard 3 (Personal and Clinical Care) and Standard 8 (Organisational Governance). This tool contains reflective questions and examples of actions and evidence that providers can consider demonstrating that restraint is only used as a last resort, and references to relevant resources and tools from the Department and Dementia Australia.

Further information is available on the Commission's website at: www.agedcarequality.gov.au/providers/assessment-processes/minimising-restraints-use

Further, the Commission is establishing a new clinical pharmacy unit aimed at reducing the misuse of medicines in residential aged care. The goal of the Clinical Pharmacy Unit will be to improve the quality of life, quality of care, and safety of consumers of aged care services by reducing the misuse of medicines, with a particular focus on minimising inappropriate use of psychotropic and antibiotic medicines. The unit, which will report to the Commission's Chief Clinical Advisor, will deliver improved clinical outcomes for consumers by working effectively with residential aged care facilities to promote coordinated and effective use of existing quality use of medicine initiatives; developing and promulgating evidence-based guidance material and encouraging collaboration between medical and other health practitioners.

7. *Why has risperidone been permitted for use in older people with Alzheimer's disease, despite the warnings listed in the product information on the Department of Health's Therapeutic Goods Administration's website regarding increased health risks?*

The Therapeutic Goods Administration (TGA) is responsible for ensuring that therapeutic goods available for supply in Australia are safe and fit for their intended purpose.

The TGA regulates medicines through a number of different mechanisms, one of which includes classifying the medicine based on different levels of risk to the person taking them.

The Pharmaceutical Benefits Advisory Committee (PBAC) - an independent, expert advisory body - provides advice to the Australian Government on the listing of medicines on the Pharmaceutical Benefits Scheme (PBS).

When considering a medicine for listing, the PBAC is required to take into account its safety, clinical effectiveness and cost-effectiveness. Clear and reliable scientific evidence is required to show that the medicine is clinically effective, is unlikely to cause more harm than good, and that the benefit it offers warrants the money expected to be expended across the Australian community when compared with alternative treatments. The PBS restrictions reflect the circumstances in which a medicine was determined to be effective for the entire eligible patient population.

Australian guidelines acknowledge that non-pharmacological therapies are the first line treatment for behavioural and psychological disturbances in patients with dementia. However, if pharmacological therapy is required to control hallucinations, delusions or seriously disturbed behaviour, risperidone is considered first line therapy.

Risperidone is currently listed on the PBS for treatment of behavioural disturbances in dementia of the Alzheimer type, characterised by psychotic symptoms and aggression. A further restriction requires that patients must have failed to respond to non-pharmacological methods of treatment.

The listing of a medicine on the PBS does not indicate that it is appropriate or safe for all patients. All aspects of patient care, including recommendations about appropriate treatments, remains the responsibility of the treating physician.

Thank you for raising this matter.

Yours sincerely

A solid black rectangular box redacting the signature of David Hallinan.

David Hallinan
A/g Deputy Secretary
Ageing and Aged Care
27 October 2019

II. HRW Letter to the Australian Health Practitioner Regulation Agency

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*In Memoriam (1975–2019)

September 23, 2019

Martin Fletcher
Chief Executive Officer
Australian Health Practitioner Regulation
Agency
GPO Box 9958
Canberra
ACT 2601
Australia



Re: Human rights and aged care facilities in Australia

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As part of our ongoing research and to ensure thorough and objective reporting, we are contacting you with some questions.

1. By what means has AHPRA become aware of chemical restraint as a problem in aged care facilities? What kinds of issues have been raised?
2. What efforts has AHPRA made to ensure older people in aged care facilities' freedom from chemical restraint? How does it monitor for chemical restraint practices among prescribers?
3. What percentage of complaints to AHPRA have been related to issues of chemical restraints in 2017, 2018 and 2019? In what percentage of these complaints has AHPRA found issue with a prescriber's practice?
4. What mechanisms are in place to ensure free and informed consent to all medical treatment in aged care facilities? How does AHPRA respond to concerns that people in aged care facilities do not always receive medication with free and informed consent by the individual receiving medication or treatment or by that person's legal health care proxy?
5. How does AHPRA use international human rights standards to protect older people's rights in aged care?

We kindly ask for your response to these questions by October 7, 2019, so that we may incorporate your response into our report and into any other publications or statements Human Rights Watch issues on this topic.

Finally, I would like to request a meeting to discuss issues of mutual concern during my upcoming trip to Australia in mid-October. I can be reached by phone at [REDACTED], or by email at [REDACTED]

Sincerely,

[REDACTED]

Bethany Brown
Researcher on Older People's Rights
Human Rights Watch

III. HRW Letter to Aged Care Quality and Safety Commission

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*In Memoriam (1933–2019)

June 25, 2019

Janet Anderson
Aged Care Quality and Safety Commissioner
Aged Care Quality and Safety Commission
GPO Box 9819
ACT 2601
Australia



CC: Viv Daniels, National Manager, Complaints Operations

Re: Human rights and aged care facilities in Australia

Dear Ms. Anderson:

Human Rights Watch is an independent, nongovernmental, human rights organization that conducts research and advocacy in over 90 countries on a range of human rights issues, including on the [rights of older people and the rights of people with disabilities](#). Our work is grounded in objective, in-depth research on human rights problems. We use our research to draw attention to important human rights issues and to offer concrete recommendations to improve human rights protection.

We are writing with some questions about the role of the Aged Care Quality and Safety Commission (ACQSC) complaints system. I will also be visiting Sydney and Canberra in mid-July and would value the opportunity to meet with you to discuss our project and get your insights.

We are currently conducting research on human rights concerns linked to aged care facilities in Australia. Our primary focus is on the use of chemical restraints among older residents with dementia. We are examining the broader obstacles to effective regulation and the enforcement of residents' rights under domestic and international law.

Our key areas of concern include the use of "chemical restraints" -- meaning any drug or drugs used for the needs of the institution or discipline and not required to treat medical symptoms, and that are not in line with the resident's will and preferences; staffing levels adequate to support older people's support needs; staff training to provide quality support to older people with dementia; and the adequacy of the Aged Care Quality and Safety Commission complaints system.

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We have interviewed current residents' families and visited some facilities in three states in Australia. We do not anticipate identifying any specific facilities in our report. Our preliminary findings include:

- Older people with dementia often do not have adequate access to state services to support them in their choice to live at home;
- Aged care facilities are not seeking informed consent for the use of medications from individuals or their legally designated representatives under powers of attorney, and some facility staff, residents and families are not knowledgeable about the medications' risks and about alternatives to their use;
- Procedures for prescribing drugs used as chemical restraints, including the use of PRN ("as needed") prescriptions, leave much discretion to facility staff;
- Some family members of people with dementia in nursing homes described difficulty in access, communication, and resolution of complaints through the Aged Care Quality and Safety Commission;
- Facilities are giving older people with dementia medications to alter their behaviors for the needs of facility rather than to treat medical symptoms;
- There is low staffing that may not always be able adequately support people with dementia in some nursing homes; and
- Australia's laws and regulations fail to prevent the use of chemical restraints, which are prohibited under Australia's commitments under international human rights law.

As part of our ongoing research and to ensure thorough and objective reporting, we are contacting you with some questions related to our research.

1. What steps does the ACQSC take to publicize its existence and its role? What steps does it take to ensure the public knows how to file a complaint?
2. What steps does the ACQSC take to ensure that people can access a member of the complaints staff to file a complaint in a timely manner?
3. What steps does the ACQSC take to ensure adequate coverage in each office for managing incoming complaints and addressing open cases?
4. On average, how many hours does it take a complainant to file a complaint?
5. Have you received complaints about difficulties accessing your services? What kinds of issues have been raised? How have you responded to these complaints?
6. In what percentage of complaints does the ACQSC advise residents and/or their families to meet on their own with facility staff through an "early resolution" (quickly without a formal process) or through a service provider resolution (referring the complaint to the service provider to address)?
7. Does the ACQSC proactively seek out whether people may be chemically restrained based on the types of complaints it receives, even if that is not the initial complaint made, such as with a complaint about neglect or weight loss?
8. How does the ACQSC follow up on complaints to ensure compliance?

In what percentage of complaints does the ACQSC make referrals to Australian Health Practitioner Regulation Agency; the Coroner; the Department of Health; the Police; or the Health Complaints Entities for further resolution of complaints?

9. What mechanisms are in place to prevent retaliation by a facility for a complaint made against it?
10. How and how often is the ACQSC required to report on its complaint resolutions to the public? To policy makers?
11. How does the ACQSC use international human rights standards to protect older people's rights in aged care in its resolutions of complaints?
12. Do you track staffing ratios at the facilities for which you receive complaints? How often do you find a connection between a problem specified in the complaint which could have prevented or ameliorated by improved staffing?
13. How will you monitor the new Aged Care Quality Standards, set to go into effect on July 1, 2019? How will you communicate that to policymakers and the public?
14. How do you believe that the effectiveness of the ACQSC could be improved?

We kindly ask for your response to these questions by July 26, 2019, so that we may incorporate your response into our report and into any other public comments Human Rights Watch issues on this topic.

Finally, I would like to request a meeting to discuss issues of mutual concern during my upcoming trip to Australia in mid-July. I can be reached by phone at [REDACTED], or by email at [REDACTED]

Sincerely,



Bethany Brown
Researcher on Older People's Rights
Human Rights Watch

IV. HRW Exchange with Aged & Community Services Australia

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 Marc Winkler

June 5, 2019

Aged and Community Services Australia
 Pat Sparrow
 Chief Executive Officer
 Suite 3, Level 6, 24 Collins St
 Melbourne VIC 3000, Australia
 Phone: (03) 9108 0750



HRW.org

CC: Darren Matthewson, Director Strategy and Policy

Re: Human rights and aged care facilities in Australia

Dear Ms Sparrow:

Human Rights Watch is an independent, nongovernmental, human rights organization that conducts research and advocacy in over 90 countries on a range of human rights issues, including on the [rights of older people and the rights of people with disabilities](#). Our work is grounded in objective, in-depth research on human rights problems. We use our research to draw attention to important human rights issues and to offer concrete recommendations to improve human rights protection.

We are currently conducting research on human rights concerns linked to aged care facilities in Australia. Our primary focus is on the use of chemical restraints among older long-term residents with dementia. We are examining the broader obstacles to effective regulation and the enforcement of residents' rights under domestic and international law.

Our key areas of concern include the use of "chemical restraints" -- meaning any drug or drugs used for the needs of the institution or discipline and not required to treat medical symptoms, and that are not in line with the resident's will and preferences; staffing levels adequate to support older people's support needs; staff training to provide quality support to older people with dementia; and the adequacy of the Aged Care Quality and Safety Commission complaints system.

We have interviewed current residents' families and visited some facilities in three states in Australia. We do not anticipate identifying any specific facilities in our report. Our preliminary findings include:

- Older people with dementia often do not have adequate access to services to support them in their choice to live at home;
- Aged care facilities are not seeking informed consent from individuals or their legally designated representatives under powers of attorney, and some facility staff, residents and families are not knowledgeable about the medications' risks and about alternatives to their use;
- Procedures for prescribing drugs used as chemical restraints, including the use of PRN prescriptions, leave much discretion to facility staff;
- Facilities are giving older people with dementia medications to alter their behaviors for the needs of facility rather than to treat medical symptoms; and
- Australia's laws and regulations fail to prevent the use of chemical restraints, which are prohibited under Australia's commitments under international human rights law.

As part of our ongoing research and to ensure thorough and objective reporting, we are contacting you with some questions related to our research.

1. How does your association engage on policy or legislative measures affecting your members at the federal and state and territory levels? What specific policy or legislative measures are currently priority areas for you?
2. Would you support a requirement for aged care facility staffing ratios that are adequate to support older people's needs, without chemically restraining them in aged care facilities?
3. What would be required for older residents of facilities affiliated with your association to have the choice to live independently in the community with appropriate services and supports? What information do facilities affiliated with your association collect related to this issue?
4. What is the policy of your association on the use of chemical restraints? How does your association provide advice or support to affiliated facilities regarding the use of chemical restraints to control behavior? Does your association track the use of chemical restraints in its facilities? If so, what do those results show?
5. Does your association issue guidance about including explicit permission to use restraints in admissions contracts? What percentage of the facilities affiliated with your association use restraints agreements in admissions contracts?
6. What data do you gather regarding complaints made to the Aged Care Quality and Safety Commission about facilities affiliated with your association? What percentage of complaints are resolved to the satisfaction of the facilities affiliated with your association? How do you believe that the effectiveness of the Aged Care Quality and Safety Commission could be improved?

We kindly ask for your response to these questions by July 10, 2019, so that we can incorporate your response into our report and into any other public comments Human Rights Watch issues on this topic.

Finally, I would like to request a meeting with Aged & Community Services Australia's officials to discuss issues of mutual concern during my upcoming trip to Australia in mid-July. I can be reached by phone at [REDACTED] y email at [REDACTED]

Sincerely,

A large black rectangular redaction box covering the signature area.

Bethany Brown
Researcher on Older People's Rights
Human Rights Watch

7 July 2019

Human Rights Watch
GPO Box 4278
Sydney NSW 2001
Attention: Bethany Brown

Re: Human rights and aged care facilities in Australia

How does your association engage on policy or legislative measures affecting your members at the federal and state and territory levels? What specific policy or legislative measures are currently priority areas for you?

We engage through a variety of means, including:

- Through involvement in sector reference groups, for example:
 - Clinical Governance reference Group – Aged Care Quality and Safety Commission
 - Sector Consultative group - Aged Care Quality and Safety Commission
 - Additional Services Reference group - DoH
 - Risk Advisory Group – DoH
 - Home Care Pricing reference Group – DoH
- Direct engagement with government and relevant Ministers
 - Direct engagement by CEO and Executive Director Strategy and Policy
 - Through our Government Relations Roles – Federal and State levels
- Through the National Aged Care Alliance (NACA) - The National Aged Care Alliance (the Alliance) is a representative body of peak national organisations in aged care, including consumer groups, providers, unions, and health professionals, working together to determine a more positive future for aged care in Australia. <https://naca.asn.au/>
- **Priority Policy Areas:**
 - Sustainability and viability of the sector
 - Submissions (Residential and Home Care) to the Aged Care Royal Commission (ACRC) - see attached
 - Submission on the proposed New Funding Model
 - Restraint and Psychotropic Medication Position Papers - see attached
 - Workforce
 - Home Care Reform Changes
 - Single Quality Standards and Charter of Rights implementation – Home Care and Residential Care

ADELAIDE 1st Floor Building 3, 22/54 St Donalds Road Mile End SA 5001 (08) 8236 791	BRISBANE Level 3, 19 Lang Pde Hilton QLD 4004 (04) 470 940	CANBERRA Level 1, 10 Theopol Ct Deakin ACT 2600 (02) 6282 7827	HOBART 19 Brisbane St Hobart TAS 7000 (03) 6305 0246	MELBOURNE Suite 3, Level 6, 24-26 Collins St Melbourne VIC 3000 (03) 9268 0750	PERTH Level 3, 25 Wythers Dr Clyburne Park WA 6007 (08) 9244 8233	SYDNEY Level 6, 8 Rider Blvd Rosedale NSW 2158 (02) 8764 0400
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Would you support a requirement for aged care facility staffing ratios that are adequate to support older people's needs, without chemically restraining them in aged care facilities?

ACSA actively advocates for adequate funding for the aged care sector, we argue the inadequacy of current funding in our recent submission to the Royal Commission into Aged Care Quality and Safety – see our Residential Care Submission to the ACRC attached and previously noted.

We have a proactive position on appropriate use of restraints (including a restraints minimization approach) and appropriate use of psychotropic medications - see our two position papers attached and previously noted.

We do not support fixed staffing ratios in residential facilities for a variety of reasons, including:

- Facilities and variable acuity levels, both within facilities over time and between different facilities;
- Fixed ratios do not account for the variety of differing service models within the sector; and
- Fixed ratios do not account for other factors such as building design, technology etc.

.....however we support appropriate staffing levels underpinned by an appropriate skills mix and timely access to a responsive external health professional and specialist workforce.

What would be required for older residents of facilities affiliated with your association to have the choice to live independently in the community with appropriate services and supports? What information do facilities affiliated with your association collect related to this issue?

The ability of people to remain living in the home of their choice in the location of their choice is dependent on the availability of supports, predominantly being:

- Commonwealth Home Support Program (CHSP) – adequate resources and capability in our basic support program that focused on independence and wellness;
- Uncapping of the Home Care Package program so older people can have access to the appropriate care and support when they need it and as their needs change (currently 129,000 older people in a national waiting list – (see attached Summary of recent data report also see our ACRC Home Care Submission);
- Privately purchased services where a reliable market can be supported.

What is the policy of your association on the use of chemical restraints? How does your association provide advice or support to affiliated facilities regarding the use of chemical restraints to control behavior? Does your association track the use of chemical restraints in its facilities. If so what do those results show?

ACSA has a proactive approach to restraint minimisation and the appropriate use of psychotropic medications in the sector as demonstrated by our Position Papers –attached and previously noted.



PATRON: THE HON MICHAEL KIRBY AC CMG
ABN 48 609 882 288

We raised this important topic for discussion at the inaugural Aged Care Quality and Safety Commission Sector Consultative Forum in June 2019.

These Position Papers have been made available to our members.

They have also been made available to the Aged Care Quality and Safety Commission – at their request.

We have also made contact with the newly appointed Chief Clinical Advisor of the Aged Care Quality and Safety Commission on this topic, providing her with our Position Papers and both us and her committing to ongoing engagement on this important topic

Does your association issue guidance material about including explicit permission to use restraints in admissions contracts? What percentage of the facilities affiliated with your association use restraints agreements in admissions contracts?

ACSA addresses the issue of consent in relation to restraints in our Position Papers on Restraints and Psychotropics.

We do not manage resident agreements, this is a relationship between providers and residents.

Consent in relation to restraints is addressed directly in the relationship between service providers, residents and their next of kin.

This area is oversighted by the Aged Care Quality and Safety Commission as part of their role as regulator of the Aged Care Quality Standards.

Consent is also addressed via the *Quality of Care Amendment (Minimizing the Use of Restraints) Principles 2019*. ACSA communicated this incoming legislative change to its members.

What data do you gather regarding complaints made to the Aged Care Quality and Safety Commission about facilities affiliated with your association? What percentage of complaints are resolved to the satisfaction of the facilities affiliated with your association? How do you believe that the effectiveness of the Aged Care Quality and Safety Commission could be improved.

We do not monitor such complaints data, and we don't believe such granularity of data is even available.

Yours sincerely

A solid black rectangular box used to redact the signature of Pat Sparrow.

Pat Sparrow
Chief Executive Officer

V. HRW Exchange with Leading Age Services Australia

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June 4, 2019

Leading Age Services Australia
Sean Rooney
Chief Executive Officer
PO Box 4774
Kingston ACT 2604
Australia



CC: Tim Hicks, General Manager, Policy and Advocacy

Re: Human rights and aged care facilities in Australia

Dear Mr. Rooney:

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We kindly ask for your response to these questions by July 10, 2019, so that we can incorporate your response into our report and into any other public comments Human Rights Watch issues on this topic.

Finally, I would like to request a meeting with Leading Age Services Australia's officials to discuss issues of mutual concern during my upcoming trip to Australia in mid-July. I can be reached by phone at [REDACTED] or by email at [REDACTED]

Sincerely,

[REDACTED]

Bethany Brown
Researcher on Older People's Rights
Human Rights Watch

3 July 2019

Bethany Brown
Researcher on Older People's Rights
Human Rights Watch
GPO Box 4278
Sydney NSW 2001
Address

Dear Ms Brown

Re: Human rights and aged care facilities in Australia

Thank you for your letter of 4 June outlining your current research focus and for the kind invitation to meet. Unfortunately LASA's CEO Sean Rooney is on annual leaving during July.

I note you had a number of questions regarding data from providers. We do not routinely collect this type of information from our members. Information on how we support and advocate for our members on issues of policy can be found on our *website*.

LASA's position on restrictive practices, including chemical restraint, is captured in our *response* to the Australian Law Reform Commission *Elder Abuse - A National Legal Response* and in our *Statement* to the Royal Commission in Aged Care Quality and Safety. In LASA's view, the principle that restraint should be a last resort is widely accepted across the sector. There are few age services providers that would not support the principle of minimising the use of restraint. However, there is variation in the way that providers are able to operationalise the principle of minimising restraint.

To assist providers in minimising their use of restraint LASA has actively supported initiatives to reduce the use of both physical and chemical restraint including the use of the *DECISION-MAKING TOOL: Supporting a Restraint Free Environment in Residential Care* and as a member of the steering committee of the *'Reducing Use of Sedatives' (RedUSE) Project* to promote the appropriate use of sedatives, in particular antipsychotics and benzodiazepines both of which were referenced during the expert testimony during the recent Royal Commission hearing in Sydney.

I wish you well with your research.

Yours sincerely

Tim Hicks
General Manager, Policy and Advocacy

Leading Age Services Australia Ltd
ABN: 71 156 349 594
www.lasa.asn.au