COTA
For older Australians

Submission to the Royal Commission into Aged Care Quality and Safety

Lessons of the COVID-19 crisis for Aged Care Reform

Submission 1

Prepared by

COTA Australia

July 2020

COTA Australia

COTA Australia is the national consumer peak body for older Australians. Its members include State and Territory COTAs (Councils on the Ageing) in each of the eight States and Territories of Australia. COTA Australia and the State and Territory COTAs have around 40,000 individual members and supporters and more than 1,000 seniors' organisation members, which jointly directly represent over 500,000 older Australians.

COTA Australia's focus is on national policy issues from the perspective of all older Australians as citizens and consumers and we seek to promote, improve and protect the circumstances and wellbeing of older people in Australia. Information about, and the views of, our constituents and members are gathered through a wide variety of consultative and engagement mechanisms and processes.

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Preface

The following submission was largely prepared before the full extent of the current crisis in parts of the residential aged care system in Victoria, and in greater Melbourne in particular.

COTA has been and is closely involved in advocacy for the interests of aged care residents and their families, discussion with the Aged Care Quality and Safety Commission on measures it should take, discussions with sector representatives, and representations to and discussions with the State and Federal Governments. Unfortunately, at this date this is an ongoing and still escalating situation.

We have made some references to the current situation within this submission, but our observations in this submission substantially relate to the experience across all jurisdictions during the first wave of COVID-19 prior to recent events in Victoria. There were two major COVID-19 outbreak events – Dorothy Henderson Lodge, which we believe was well managed; and Newmarch House, which certainly in some respects was not. Another major issue was visitor lockdowns, in relation to which COTA played a major role, and this is explored in this submission.

After the first wave many people congratulated the aged care provider sector on managing the impact of the pandemic. COTA is on the record as being cautious about that judgement. We said we thought the ”jury is out” because there had been such a low rate of community transmission that the system and individual providers had not been much tested. The current experience in Victoria is bearing that out.

While COTA’s views about the future development of aged care are unlikely to be varied, in the broad, by the COVID-19 experience, and indeed they are in the main reinforced, the experience of an actual situation, rather than anticipation and forecasting, always creates additional learning. We are in the midst of processing the current experience and expect to have some details of our views about lessons for the future impacted by our reflections on it.

As we prepared to email this submission the Commission announced it will extend the deadline for COVID-19 submissions. We will submit this, but we will have more to add in relation to the lessons that should be learnt for aged care from the COVID-19 experience in a follow up submission.

Ian Yates AM
Chief Executive **31 July 2020**

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Introduction

Australia has managed the COVID-19 pandemic well relative to many other nations in the world. A high level of testing, banning of international travel, social distancing and restrictions to social gatherings, informed by public health expertise and strong political leadership, have reduced demand on the health system and resulted in low numbers of confirmed cases and mortality rates.

This statement remains true comparatively even despite the "second wave" being experienced in Victoria at the time of this submission. That "second wave" is currently having quite tragic outcomes for residents in many aged care facilities and there is a deeply concerning risk that this could spiral further out of control, despite now very substantial assistance and interventions federally.

However, for older Australians throughout the country restrictions and health risk are not at an end. So, this submission is feedback at a point in time and further review will be required. Whilst the community in general returns to a more normal life in most jurisdictions – even though slowed now by concerns about the Victorian second wave spreading - for many older Australians requiring care and support, the COVID-19 experience is still being lived out.

While at COTA Australia we hear some positive stories and experiences from consumers and their families, it is unfortunate that most of the stories we hear reflect, frustration, anger and heartbreak. The impact of COVID-19, the experiences of consumers and response from providers has demonstrated the urgent need for aged care reform and reinforces the current and planned work of the Royal Commission.

The COVID-19 experience for consumers and their families has clearly focussed the spotlight on the over institutionalised approach to aged care in Australia. This approach often results in poor consumer engagement. It is accompanied by inadequate communication and promotes a culture that results in some consumers being fearful and reluctant to complain or provide feedback about poor practice and service neglect.

The response to the pandemic has provided lessons and insights for aged care reform at the community and service delivery level and at a structural or big picture level.

At the community and service level this includes inadequate infection control training and preparedness, gaps in service communication and information processes, inconsistent home care service delivery and pricing, increasing concern about loneliness and the mental health of vulnerable older people in the community, access to respite, and challenges related to access and use of technology.

At the structural or big picture level this includes challenging ageist attitudes and emphasising human rights, strengthening quality assistance, regulation and compliance, reforming service governance and culture, clarifying and improving coordination between aged care and health care, supporting funding and service flexibility by learning from local service responses and expanding consumer engagement mechanisms.

We have been strongly reminded of the critical importance of raising the consumer voice and its place in transforming the aged care system.

Over Institutionalisation of Aged Care in Australia – Residential Aged Care Visits

COVID-19 has shone another light on the Royal Commission's diagnosis that aged care is over institutionalised Through the experience during COVID-19 in relation to Visitor access to residential aged care, which we explore here.

Many providers responded quickly and forcefully to the initial COVID-19 wave to reduce risk by isolating residents from visitors, by banning visitors (often with no or little notice). However there were many cases in which the impact of this move on the emotional and psychological health and wellbeing of consumers, and indeed in many cases their physical health, was not given the same attention. The approach of far too many providers to visiting restrictions was inflexible, lacked provision for compassionate circumstances and involved limited or no capacity or planning to respond to regular care needs of residents who had been partially dependent on family visits.

In response to the initial wave of COVID-129, which included initially one and later two outbreaks and deaths in residential aged care in Sydney facilities, we saw many if not most aged care homes across the country implementing blanket "lockdowns" with no provision for visitation on compassionate grounds, including end of life, or reasonable assessment of risks, incorporating appropriate safeguards. We note that the term "lockdown" is deceptive. Homes are not locked down – that would involve management and staff being confined. Rather they are in "lockout" mode with regard to visitors.

Some family members, carers and friends of older people living in residential care play a significant role in their care. Its unfortunately a minority, but numbers are not insignificant. This role can include supplementing or enhancing care provided by providers. During the initial stages of the residential aged care lockdown, many residents were denied support from their relatives, carers and friends who were prevented from seeing their loved ones often with little or no communication. This led to stress, frustration, loneliness and disconnection. It also acted to increase risk by compromising the health of vulnerable residents. Limited and poor communication and information provided by residential services left many families and friends confused, frustrated and worried about the health and wellbeing of relatives in residential care.

As one family member stated

> *"by controlling time, duration and space for social visits, providers have effectively removed resident freedom and rights and removed transparency. Surely this is not the intention."*

There are many examples of the impact of blanket lockdowns including this one:

> *"Whilst physical safety is important, the impact of this severe measure on the mental health of these residents must also be strongly considered. With our elderly 99-year-old parent (mother), who is mobility challenged and extremely fragile, we worry about her mental well-being. Two of her children have spent the last few years assisting in feeding her lunch and evening meals, brushing her teeth, and keeping her stimulated. We are also often able to pick up signs of*

changing health and advise staff. Mum doesn't seek out friendships with other residents. She desires and finds comfort in the company of her family. Without her family, we are afraid our mother will feel forgotten and become depressed and basically give up."

On 16 March 2020 National Cabinet announced guidance on restricted visits to residential aged care. In line with general public health measures this included not permitting visitors who had cold and flu symptoms or had returned from overseas or had contact with others with COVID-19. There was also guidance on the nature of visits including limiting visit duration time and numbers of visitors, conducting visits in areas to limit transmission, demonstrating evidence of influenza vaccination, not permitting children and practicing physical distancing. The National Cabinet guidelines also advised providers to make exemptions on compassionate grounds and to facilitate other communication mechanisms to compensate for reduced numbers and duration of visits. It also made it clear that in cases of outbreaks, full lockdowns would occur.

In the weeks following the National Cabinet announcements, COTA and other consumer organisations such as OPAN, National Seniors and Dementia Australia, and also the Aged Care Quality and Safety Commission, collectively received thousands of complaints from distraught relatives unable to visit or even have contact with loved ones, including family members who had attended daily for care and support, and including end of life situations. We heard from consumers themselves ("I'm in a prison") and their families that many providers were implementing a full exclusion approach. Others were implementing lockdown but making allowances on compassionate grounds. Another group of residential care provider maintained a strict set of restrictions but did not preventing visits, only severely limiting them.

Lockdowns and approach to visits received increasing media focus and there were also complaints to , members of parliament and Ministers. Medical practitioners Were expressing concern about the directly perceived mental and physical health impacts of resident isolation.

Faced with a situation in which the vast majority of providers had committed to full lockdown COTA Australia and other consumer bodies took a joint position arguing that compassionate exemptions were essential to the Australian Health Protection Principal Committee (AHPPC) and through them to National Cabinet. However National Cabinet was not prepared to accept that visitor exclusion should continue in the way providers had enacted it, without any strategy for emerging from it.

On 21 April 2020, the Prime Minister expressed the National Cabinet's significant concerns about the impact of restrictions over and above those recommended by the National Cabinet on the health of residents. The views of National Cabinet were largely rejected by aged care providers, quite publicly. This lead to additional comments made by the Prime Minister on Friday 24 April, on behalf of the National Cabinet, that if providers did not voluntarily comply with guidance to allow visits then the Government would regulate that providers would be required to seek an exemption from practices going beyond the AHPPC rules and would need to have sound grounds for this exemption to be granted.

The issue was increasingly being played out in the media as a standoff between providers and the Federal Government and National Cabinet. In response, on Monday 27 April COTA Australia initiated the move for an Industry Code on Visitors to address this situation more constructively, to be endorsed by consumer organisations, provider peaks, and National Cabinet. The Code would govern

the rights and responsibilities of providers and consumers (including family, friends and carers) regarding visits.

Our initiative was supported by other leading consumer bodies, so we then approached a provider peak on Monday evening to test the idea and also floated it with government. With active support from Minister Colbeck and the Department, a couple of industry peaks, and some leading providers, a Draft Code was developed through some intense negotiations and within 72 hours, on Thursday evening 30 April, we had a "Consultation Draft" endorsed by four consumer peaks, seven provider peaks, and sent to AHPPC and National Cabinet which were meeting the next day.

On Friday 1May the Prime Minister and Minister Colbeck announced the National Cabinet's adoption of the Industry Code (albeit it was still a Consultation Draft) as well as a COVID-19 funding package for providers (the story of which is for another day).

Over the following week both consumer and provider peak bodies undertook consultation with their members and the public regarding the Draft Code. A substantial quantum of feedback was received, most of which was positive (apart from the Anti-Vaxers objecting to the requirement for visitors to be vaccinated against the flu), with a number of constructive suggestions. Further negotiations proceeded late that week and over the weekend and the final version of the Industry Code for Visiting Residential Age Care Homes during COVID-19 was agreed on Monday evening and released Tuesday morning with a joint Media Release. Minister Colbeck followed with a Media Release indicating the government's endorsement of the Code. Initial implementation of the Code by many providers saw an improvement for many consumers and their families and a more consistent approach to visitor access in aged care homes. COTA Australia received considerable feedback from older people that the Code has been effective in enabling visits and improving relationships between families and friends and facilities. However, COTA Australia continues to receive reports of restrictive behaviour and poor outcomes for consumers and families.

The Code has been further reviewed with changes to reflect better outcomes for consumers particularly in relation to length of visits and facilitating real human contact. The Code was substantially revised after the release of new AHPPC guidance on 19 June and subsequent major changes to State and Territory Health Directives after that. The revised Code was reissued on July 3, 2020 and is available on COTA Australia's website at https://www.cota.org.au/agedcarevisitors . The Code is currently being revised to include the new Victorian Health Directive issued in the context of the current situation of community lockdown. We note that the Directive closely follows the Code in respect of compassionate provisions.

In hindsight, the full impact of implementing such long-term restrictions on consumers had, in many cases, not been considered or planned for by providers. Many providers have experiences with restricting visitation for short term situations such as managing influenza or gastroenteritis outbreaks. Applying the same response in COVID-19 was a limited institutional response without looking forward and this did not include broader strategies that focused on the experience of and impact on the consumer of a lockdown with no exit strategy.

The residential care response to residential aged care visits during COVID-19 has highlighted the flaws in the institutional model responding to the care needs of older Australians.

Consumers fearful and reluctant to complain or provide evidence of poor practice

COTA Australia receives, and through the COVID-19 has continued to receive, a significant number of reports indicating that older Australians accessing care and their families, carers and friends, are fearful and reluctant to provide feedback or complaints. COVID-19 has highlighted that they have little confidence in protections offered against reprisals for providing feedback and some are fearful of repercussions.

- *Kim told COTA Australia that she reluctantly cancelled all her mum's medical appointments, including those with her psychiatrist and oncologist, after the home advised her that if her mother left the residential premises, she would be isolated for two weeks upon her return. Kim's attempts to reason with the home's general manager, were meet with a blanket "no exemptions in any circumstance" response. Kim said she entertained the prospect of contacting the Aged Care Quality and Safety Commission but was nervous that this might have negative care and support repercussions for mother. She is now considering having her mother stay with her, but afraid that she will not be able to arrange for community nursing support.*

In another case

- *"They have told me it's a privilege that I can see my husband now. I don't want to rock the boat, I'm afraid they will take away my privileges."*

Fear of reprisals based on previous experiences was a common theme amongst those who were reluctant to complain.

- *A family member said that he was extremely nervous about complaining to the aged care home where his father, who had advanced dementia and high care needs, resides because of his father's alleged past emotional and physical outbursts supposedly directed at staff; a situation that has never fully been resolved. The son explained that although he is upset about the lack of collaboration around the lockdown, he is afraid that if he complains the home might ask him to consider moving his father to another facility, or his father may be treated unfairly. He is afraid that his father will again be subjected to forcible restraint.*

- In another case, a carer expressed her frustration and concern about making complaints. "I don't feel I can take this further as a complaint. I'm already enemy number 1 as far as they are concerned."

This reflects institutionalisation and a paternalistic power imbalance preventing an understanding of reform issues and is contrary to good practice. It highlights the importance of supporting older people to share their stories and perspectives.

Community and Service Delivery

Gaps in planning for increased infection control

Residential aged care providers generally responded quickly to protect older people from the spread of COVID-19 through isolation measures directed at visitors and activities. At the end of the first phase of COVID-19 it was widely said that the sector had done well in preventing COVID-19 outbreaks in residential care, and that this reflected sector improvements in infection control after major issues in earlier years.

COTA Australia's view, however, was that the very low incidence of COVID-19 infection and low loss of life in Australia was primarily a function of public policy measures such as international border closures, restrictions on movement and gathering; and community physical distancing and hygiene measures reducing the level of community transmission. We therefore said publicly that we thought the jury was out on sector preparedness.

Experience in Melbourne as we write appears to show that there are at least significant holes in sector preparedness and capacity. As in other aspects of aged care quality performance it appears that infection control readiness and mitigation capacity is variable across the sector. This is not a surprise to us, regrettably.

Experience during the first phase of the crisis did reveal that a minority of facilities had inadequate infection control practices and plans potentially leading to disease outbreaks; and insufficient training in the use Personal Protective Equipment (PPE) which could have had severe impacts in the case of more outbreaks, as demonstrated in Newmarch. Amongst the feedback received by COTA Australia from consumers and families were concerns about the lack of or misuse of PPE.

A survey conducted by the Aged Care Quality and Safety Commission in mid-March 2020 found that around one-quarter of services signalled that they have further work to do on putting in place arrangements to ensure sufficient supplies of protective equipment, hygiene and cleaning products in anticipation of increased need.

Allied health professionals report that many residential care facilities are not equipped to ensure the level of hygiene and physical distancing practices to protect residents from COVID-19. This is reflected in the lack of PPE, insufficient handwashing stations throughout the facility and small group rooms to conduct activities with sufficient physical distancing, and incorrect PPE practice.

COTA is concerned about the view presented by providers and their representatives that residential aged care should not be expected to implement and manage stringent infection control because facilities are not hospitals, have different staffing arrangements and provide a 'home-like' environment. This argument is counter to developing staffing, design, cohort management and resident transfer solutions to ensure older people are safe from a variety of infections to which they can be exposed in residential care, and indeed is not consistent with the Aged Care Standards.

If we are going to continue to provide support and care to many of our most frail, chronically ill, immunocompromised and at risk citizens in congregate care facilities then we have to recognise that disease prevention and control are essential and not inconsistent with a 'home like' environment

but do have significant implications for facility design, staffing and training, management and governance.

More evidence and review are required to fully understand and assess the adequacy of infection control preparedness in residential aged care across Australia to respond to COVID-19 and future pandemic situations and public health risks. It is essential that the lessons of the two homes in NSW in the first phase and the large number of providers in Melbourne in their second phase which have experienced large outbreaks is documented and learnt from, and that the overall preparedness of the sector is reviewed in depth.

Impact on consumers of inadequate infection control

In residential aged care, in addition to feedback on the use of PPE many families reported to COTA Australia poor infection control practices that they have witnessed such as staff touching and moving between residents without any attention being paid to hand hygiene and/or the wearing of masks.

- *"The nurse helped three other residents before assisting my father to reposition himself in the chair. At no time did I see her wash her hands."*
- *"the worker who supported my mother, who is 91 years old and suffering from respiratory failure, to make her way onto the balcony was wearing a mask, although it was hanging about her chin."*
- *Another daughter advised that her mother had complained that the nurse who takes residents' blood pressure does not wear a mask and "uses the same blood pressure sleeve for several residents without any attention to sterilising between uses."*

Even with excellent infection control practices, some providers have failed to safely enable residents to access appropriate areas and services within facilities (e.g. walking in a garden), contributing to confusion, inactivity and unnecessarily disrupting routines. In some cases, there is evidence of minimal or no effort to provide mental stimulation and meaningful activities for residents.

Many families told us about the importance of family visits, social interactions and routines for their loved ones. The stories and quotes below from consumers and families highlight some of the situations consumers and their families find themselves in now and the negative impact of overly institutionalised responses:

- *"My father has Alzheimer's disease and has been in an Aged Care facility for a year and a half. Prior to coronavirus, one of my brothers or I would visit Dad six days a week for roughly two hours at a time. We would regularly end our visits with walking Dad out to the dining room for dinner, which he enjoyed & he had become familiar with the men on his table. Since the facility went into lockdown, one of us has rung him every day and it has become apparent that Dad's daily routine has fallen apart. He has stopped going to the dining room for meals and simply stays in his room all day. During last week's phone conversations Dad was very angry, threatening to kill himself and begging for us to get him out of the facility.*

We suspect that Dad desperately needs some social interaction added back into his daily routine for his mental

- *Sarah, a health care professional, understands the need for some controls but is concerned about her mum's mental health. In addition to disallowing Sarah and her brother to visit their mentally agile mother, the home has stopped all activities, communal dining and residents' visits to other residents' rooms. Sarah is upset that not only has the home stopped their mother's visits from family but have also banned her from direct communications with her friends at the home.*

- *"As her dementia has advanced my aunt has forgotten English and has reverted to her mother tongue, Mandarin. She is unable to converse with other residents, but still enjoys being around them. Only one staff member can communicate verbally with my aunt. However, she works as a casual. My aunty is alone in her room all day and all night as the nursing home has cancelled all family visits and social activities including communal dining. Her severe arthritis prevents her from using and or holding a phone.*

- *" Although my father has advanced dementia, he remains physically active. In the past the aged care facility has agreed with us that keeping him physically engaged in activities, especially gardening, is important to managing his emotional wellbeing and behaviour without overdoing the medication. However, now he is being kept in his room. As is the home, we are aware that this will result in him becoming difficult. We are very concerned about how the home will deal with his outbursts."*

Importance of effective communication processes with consumers, families and friends

Poor or no communication with older Australians, families, friends and carers by some residential care providers has fuelled frustration, anxiety and concerns. Scenes portrayed in the media of confused and angry people standing outside of facilities worried about their loved ones, in many cases, reflected a breakdown in communication. COTA Australia received many calls and emails from families commenting on lack of communication from residential aged care providers. A small sample of the stories we heard at COTA Australia below encapsulate the situations and feelings of families and friends in being isolated from loved ones without compassion.

- *The lockdown was imposed without any communication with families. "The home just told us not to visit. No discussion. When I phoned to discuss why an absolute lockdown was being enforced, I was told, "you can stand at the front entrance and talk through a glass door." That's all they offered. Then the person added that is the home's new visitation policy and that it would be reviewed when the general manager was ready to do so. I was made to feel that I was being selfish and not prepared to put my grandmother's health first."*

- *"On April 28th, I received an email from the nursing home that had been written by the CEO on the 9th April explaining the reason for the lockdown. I'm disappointed with the delay of communication and angry that my request to see my dad was turned down."*

- *In another instance, a granddaughter's request to see her nan on compassionate grounds was initially granted. However, when she arrived at the facility two hours later, she was denied access because she wasn't one of two people that the home had now nominated as her visitors. The granddaughter then phoned the named family members only to find out that they had not been advised that they were the nominated visitors. "I tried to reason with the manager of the home, and then asked to speak with the general manager. The manager refused to tell me who the general manager was or how to contact him. She said that contact with the general manager was made by her and her only. Later that day, the family members found out they were Nan's "nominated" visitors. "As yet, I have not been able to visit."*

These stories demonstrate a lack of understanding of the role of the consumer at the centre of service delivery. They also highlight poor preparation for a crisis situation particularly on the importance of planning communication and information processes prior to the event. The pandemic experience highlights the importance of the input of consumers (including families and friends) in the development of effective communication content and strategies.

As one family member asked, why were we not involved in the decision. The example below emphasises not only the need for engagement with consumers, but also the importance of how the communications are made and considering the style of tone of messages.

- *"It is our loved one who is being kept in lockdown. We appreciate the emphasis on physical safety but know that our mother overall health depends on her contact with her family. There is nothing we would do to upset her or put her in danger. If only the facility invited us to help with deciding what happens during the time of coronavirus. We can be trusted."*

On a more positive note, we also heard about the performance of providers who had developed good communication strategies and were able to put them to good effect. Unfortunately, from the feedback we received at COTA Australia substantial number of providers did not practice a person centred, principles and compassionate approach to visits and enforced isolation of residents.

- *"My husband was emailed by the head nurse to advise that the facility would implement a lockdown within 24 hours. The nurse explained why the lockdown was being imposed and that special arrangements would be in place to assist up to two family members to meet in their loved one's room for pre-arranged short visits twice a week, for residents to communicated electronically with their family and friends, and that longer visits would be permitted on compassionate grounds. The nurse asked my husband if he had any suggestions for how the home could provide his mother special assistance during the lockdown. We were impressed and pleased with the approach taken by the home – my husband felt relieved knowing that his mum is being sensitively cared for (she has only been in permanent care for 5 months)."*

- *"On the 30 April, after a little pleading, the nursing home said I could take my aunt's tiny dog to the home for a short visit. Being able to have Louie on her lap and stroke him was one of the very few pleasures left in her life. On the 2 May, my aunt, who was blind and deaf, had a significant fall and sustained multiple injuries. Her advanced care directive indicated that she did not wish to be hospitalised. No family member was able to visit on the 2nd. However, on*

compassionate grounds the family were able to visit on 3 and 4 May (with no restrictions on our time). My aunt passed away on the afternoon of 4 May surrounded by her family."

- *"The staff at my husband's nursing home are fantastic. They are doing all they can to ensure we have contact with our loved ones. Sure, it is not ideal, but they are doing their very best to support all involved and reassured that our mother is well. I applaud their efforts."*

Effectiveness of service delivery and consistency in pricing of home care

We have heard much about the impact of the COVID-19 pandemic in residential aged care. The impact on aged care at home is still unfolding. The lack of service planning and policy attention on home care, in part due to the focus on issues in residential care, is of considerable concern. Most people receiving aged care services are living in their own homes and utilise local health and other social support services.

In feedback COTA Australia has received from consumers and their families, there is some evidence of inconsistency in home care service provision with local providers implementing various and contrasting rules, guidelines, practices and price increases in delivering services. These practices include reducing hours of service without discussion or agreement abandoning the principle of consumer choice and control. There have also been reports of some providers significantly increasing hourly rates for services and of blanket increases to cover COVID-19 expenses that are then billed as case management. There have also been numerous enquiries from aged care consumers regarding clarification of why providers can still levy service charges although providing no service/s.

- *As one older person communicated to COTA Australia, "I phoned to query the additional costs that appeared on my statement only to be told that the increase was necessary to cover the extra administration involved. This is incredibly confusing as, apart from a call twice a week, I am receiving no services."*
- *In another instance, the older person was advised by their service provider that a slight increase in the administrative cost was necessary to help pay for the additional staff required to replace those on sick leave.*
- *Another case where a provider added $85 per week for additional case management services "until this situation is over."*

These reports of inconsistent or poor home care delivery practice highlight how little we know about the safety, health and wellbeing of older people currently receiving or waiting for home care packages. Care at home has received relatively little attention in comparison to residential aged care. However, at COTA Australia we are concerned by the lack of focus on supports at home. We know from our interactions with older Australians and the outcomes of a number of our projects[1] it

[1] https://www.cota.org.au/information/home-care-today, https://www.cota.org.au/information/self-management-in-home-care/increasing-self-management-home-care-project/, https://www.cota.org.au/policy/state-of-the-older-nation/

is the overwhelming preference of older Australians to live at home and access supports to be able to do so for as long as possible. Demand for government subsidised and privately funded supports for care at home will continue to grow. More investigation and review are required to better understand how the COVID-19 experience has impacted on home care service delivery and to ensure consistency and quality that enables consumer choice and control.

Understanding and responding to loneliness, social disconnection and mental health of older people

The social distancing measures implemented during the COVID-19 crisis have compounded the loneliness and social disconnection of some older people living in the community and in residential aged care, potentially leading to significant mental health issues. Existing research demonstrates that social disconnection puts older adults at greater risk of depression and anxiety and reports to COTA Australia during the crisis have confirmed this.

The self-isolation measures, implemented to ensure public safety, disproportionately affect many elderly individuals whose only social contact is out of the home, such as at day-care venues, community centres, and places of worship. Those who do not have close family or friends and rely on the support of voluntary services or home care, are placed at additional risk, along with those who are already known to be lonely, isolated, or secluded.

Over the past few months, online technologies have been harnessed to provide social support networks and a sense of belonging to support vulnerable older people. However, this is limited for people with poor access to or no literacy in digital resources.

The COVID-19 experience has highlighted that interventions enabling more frequent telephone contact with significant others, close family and friends, voluntary organisations, or health-care professionals, or community outreach projects providing peer support throughout the enforced isolation. The development of COTA Australia's Older Australians COVID-19 Support Line is an example of this. The support line provides advice, support, referrals and connection to older people and receives funding from the Australian government.

The required public response to COVID-19 in Australia highlighted the extent of loneliness and mental health issues experienced by older people across a range of living circumstances. Understanding and responding to this is an important element of service reform and should result in changes to current service practice and new initiatives. Families have highlighted the challenges of technology for older Australians below:

- *"My mother has advanced Parkinson's and a degree of dementia related to her Parkinson's. Before COVID 19, I visited my mother at least three times per week and my sister would visit on the weekend. I was devastated when I was unable to visit her in her room. The window visits are very frustrating as mum finds it hard to comprehend and communicate effectively. Talking on the telephone is also difficult as her voice is very soft and croaky. Sometimes she can manage FaceTime, but this too is becoming more difficult. I requested but was told that that she cannot be taken out onto the balcony, where she could sit with her plants and get some fresh air. Since the lockdown she has been more confused and anxious, and I am scared she is slipping away."*

- *"My dad's aged care facility has been in lockdown since the 17th March and whilst I understand the home's wish to protect the residents from Covid-19, I am concerned for the morale of the residents. They look forward to their visits from family and friends. My brother and I miss our time with my dad. We have only had 5 Skype sessions in the whole time as dad needs the staff to set these up. Also, we feel worried about the effect of these sessions on dad. He keeps asking to come home as he misses his children, granddaughter and great grandchildren greatly. He cries saying he is desperately lonely and wants to see his family."*

Access to Respite

Our current information indicates that, whilst there is some respite available linked to residential care, generally the provision of respite care is very limited. While the closure of social support group activities and outings to adhere to various advice in relation to social distancing and restrictions is impacting on the health and wellbeing of those participating this has also left many carers without the respite that these activities provide. Cottage respite appears not to be available at all and carers report that in-home options or other alternatives are mostly too expensive. The lack of emergency respite is particularly concerning as this could lead to carer burn out.

- *"My partner, who is eight months pregnant, is the primary carer for her 86-year-old grandmother. Acting on the advice of her GP my partner has made numerous inquiries about short term respite for her grandmother. However, unless she agrees to place her grandmother in permanent aged care post respite, it appears that respite is not available."*

- *"After breaking my ankle and arm, my husband and I looked for aged care respite for his mother. Although you read about this and see it advertised in aged care facility brochures, within our local area respite does not seem to exist. However, two homes were prepared to offer respite if we agreed to seeing this as the precursor to a permanent age care placement. We are unsure if this always occurs, or is a special response to COVID-19?"*

Technology: access, capability, cost – source of inequity and disadvantage

Research indicates that under COVID-19 physical isolation conditions, older Australians are more likely to suffer social isolation and several studies have already established a link between internet connectivity and reduced social isolation in older people.

Residential aged care services should have the capacity to, or be supported to, bridge the digital divide. However, many older people in the community, who utilise home care packages and home care support, do not have this capacity. COTA Australia welcomes initiatives by the Australian Government and state governments that seek to enable older people to socially connect through technology.

Many older Australians who have access to the appropriate equipment and capability have embraced technology and have become tech savvy. This has greatly enhanced and improved their social connection and has been particularly important during the COVID-19 pandemic period. A recent report found that 21% of older Australians have used a new technology for the first time and

29% have increased their social media use to stay connected.[2] However, others, often from low income communities, do not have the capacity to access technology and need support to be more digitally literate.

Whilst technology has facilitated some solutions, it is not the panacea and doesn't replace in person or in room contact. There is a genuine digital divide where some older Australians are not able to access or utilise technology. Some consumers are not able use technology due to their health issues (e.g. acute arthritis) or it is inappropriate for the purpose (e.g. you can't feed your parent by internet). Technology should complement but not replace face to face contact with family, carers, friends and important others.

- *"For our dad in aged care, the stimulation that he gets from family visitors over the last 4.5 years is irreplaceable and since the complete lockdown, his mental health has deteriorated badly as well as his overall physical health. Now he is always anxious and scared."*

As the care needs of older Australians increase or become more complex, some families supporting aged care residents have found encouraging the use of technology difficult:

- *"We have tried various technologies to interact with Nan including the phone, iPad zoom calls, windows of love etc. However, none of these worked due to her dementia and her not knowing how to use computers. She has also forgotten how to use her mobile."*

More consumer engagement and research are required to understand and respond to the digital divide to improve access to care and to enhance social connection, health and wellbeing. This is particularly important as the physical distancing of older people from others is likely to continue for some time.

Maintaining critical ongoing health care for older Australians during a public health crisis

COTA Australia has received reports that some older Australians have not been receiving critical and important ongoing health care during the pandemic period, particularly services provided by allied health professionals (e.g. physiotherapy) that support recovery, reablement and independence.

During the height of the pandemic, the Deputy Chief Medical Officer Richard Kidd reported that there had been a 30 percent drop in clients attending allied health professional services and this was particularly acute for services with a larger older client base. There was also a 40 percent decline in pathology tests. Allied health professionals are particularly concerned about testing and ongoing health care for type 2 diabetes, heart disease and kidney disease which disproportionately impact on older people.

In some areas, this is because some health services have made business decisions to close. In other cases, older people have the strong perception that they are at risk of contracting COVID-19 if they receive these services or that they are a burden on a stretched health system.

[2] Global Centre for Modern Ageing, Finding a Silver Lining Report 1

Telehealth has the potential to address some service delivery issues arising from physical distancing. However, reports provided to COTA indicate that its effectiveness has been limited particularly if the consultation is limited to a phone call. Our information is that most communication with doctors was via a phone call with no visual interaction due to older people not having the relevant software or because of the practice approach of the GP. The result of this is that older people were missing out on general examinations, where, in typical times, many health needs are detected, and treatment provided.

There is evidence of confusing information and advice to older people about accessing health services. Older people were being told not to attend the clinics at the height of lock-down due to the risks involved but that phone appointments were available. Older people were still advised not to attend even when general public information indicated it was safe to attend health services. The mixed messages generally led to many older people not seeking treatment and advice. This impact is being felt for those living in the community as well as in residential aged care homes.

Increased Elder Abuse

There is evidence from support phone lines across the country that indicate a significant increase in the prevalence of elder abuse during the pandemic crisis. Some help lines have recorded increases in calls regarding elder abuse of up to 15 percent.

It is estimated that between 2 and 14 percent of older Australians experience elder abuse in any given year, with the prevalence possibly higher. It is hard to know the exact figures because elder abuse often takes place behind closed doors and out of public view.

Some older people have been at heightened risk of elder abuse during physical distancing restrictions because they were in lockdown in the same house as the perpetrator, or unable to get to the usual places where they could seek help. In this environment, older people are less likely to report abuse or can interpret abuse as a communication issue. Financial pressures on families and higher levels of mental health issues in the community across age groups may be some of the contributing factors during the pandemic period.

Reports have included circumstances where older people are living with families and forced to live in one room and not permitted to leave that room. Families have removed the decision-making capacity of older people, falsely determining that this is safer for them.

An increase in family violence during the pandemic period has been highlighted in the media and by advocacy groups. Elder abuse is often linked to this and can be seen as a form of family violence. Elder abuse can take many forms: financial, physical, psychological, emotional, sexual and neglect. It can happen to anyone regardless of background.

Important recently announced initiatives by Australian governments to address elder abuse are welcome developments.

Further investigation and research are required to know more about the extent of elder abuse perpetrated on consumers of aged care services and potential related reforms to address this issue.

Big Picture Reform

Confronting ageist attitudes and emphasis on human rights

COVID-19 has highlighted the need for continued reform and a focus on consumer centric service systems including aged care. During this pandemic period, this has been particularly evident in residential aged care but also applies to home care. Challenging ageist attitudes in the community and emphasising human rights is critical to addressing this.

The calls to COTA Australia over this period of the COVID-19 pandemic have shown that Older Australians have received many negative and disempowering messages and some providers have contributed to this including: that older people are a burden on others and the system, they are fortunate to receive care, they must suspend normal activities and not leave their room or the house, are selfish and create difficulties for service staff and younger people, they should not make their own decisions and do what you are told. At the centre of some of this behaviour are ageist and paternalistic attitudes infantilising older Australians and reducing their experiences to a transaction. This is not news to the Royal Commission and is highlighted in Neglect, the Commission's interim report.

More broadly, we see a debate being played out in the media pitting generations against each other. Headlines such as "Young v old, investors vs spenders"[3] and "Coronavirus economic fallout could see tens of thousands of apprenticeship places disappear"[4] have become more prevalent and fuel the arguments that the economic impacts of measures taken to curb the COVID-19 pandemic benefit older Australians and detrimentally impact younger generations. The COVID-19 pandemic has shone a very strong spotlight on the ageism that already exists in our community. Language such as "grey tsunami", "burden", "boomer privilege" unnecessarily emotionally charge and fuel these debates.

COTA Australia advocates for a society that values older people and their contribution. This should be underpinned by Human Rights legislation to be enacted that removes discrimination based on age. Supporting this is the development of a campaign that starts from a foundation of valuing older Australians and their lifetime contribution to society and includes a suite of social marketing initiatives to promote the value and ongoing contribution of older people.

Maintaining and enabling quality assessment, monitoring and compliance

From what we heard from consumers and their families and previous positions, the pandemic experience has reinforced the need to strengthen quality assessment, regulation and compliance to address neglect and poor practice. There has been a significant increase in complaints to the Aged Care Quality and Safety Commission related to the COVID-19 pandemic. COTA Australia supports the strengthening and widening of the powers of the Aged Care Quality and Safety Commission. We want to see more inspections and timely and effective use of a range of regulatory measures in aged care.

[3] O. Guerrera. "*Young v old, investors v spenders: Readers debate a universal aged pension*", The Age, 30 May 2020. https://www.theage.com.au/politics/federal/young-v-old-investors-v-spenders-readers-debate-a-universal-aged-pension-20200527-p54wua.html

[4] M. Atkin. "*Coronavirus economic fallout could see tens of thousands of apprenticeship places disappear*", ABC Online, 29 May 2020. https://www.abc.net.au/news/2020-05-27/coronavirus-fallout-could-see-apprenticeships-positions-fall/12283648

The unprecedented nature of the COVID-19 crisis has challenged the capacity of services to continue to provide quality services and the assessment, monitoring and compliance activities of the Aged Care Quality and Safety Commission. Aged care consumers have high expectations of the regulator in monitoring and ensuring quality outcomes in care.

- *"are there going to be more inspections … now, due to lock out?"*

In the likely event of residential aged care services remaining in a "restricted visiting" situation well beyond physical distancing restrictions are lifted for the community, it is vitally important that poor service practice is addressed, and, where necessary, sanctioned. It is also critical that standards in home care are maintained and poor practice addressed. Further work will be required to respond to these changing circumstances and to ensure that a high level of quality assessment, monitoring and compliance is achieved.

Governance of aged care services: Consumer focused service culture in and beyond a crisis

The COVID-19 experience has highlighted the established need for reform to the governance of aged care services, particularly the incorporation of effective consumer engagement to improve outcomes for older people.

Some services have demonstrated leadership, innovation and the implementation of effective plans during the pandemic period ensuring that older people are safe and enabling consistent and ongoing communication as well as the continuation of regular health and personal care to consumers. However, COTA Australia has received reports through its contacts and networks, that many older people, families and supporting friends have been left frustrated, stressed, confused and anxious after their interactions with services. Some evidence indicates that older people have been informed that they are "privileged" to receive a service and have been left uncertain about what aspects of their care would continue. Many older people have not received the necessary reassurance and supportive communication about the importance of their ongoing care needs.

The work of the Royal Commission in investigating and recommending reform to the governance of aged care services should examine the capacity of services to effectively engage and communicate with consumers to improve service culture, practice and outcomes.

The COVID-19 experience has highlighted both excellent and poor consumer engagement, community and other service relationships, crisis preparedness and risk management. Some providers' actions demonstrated an openness and readiness to work with consumers and their family carers to implement the required restrictions in ways that acknowledged as far as possible the holistic needs of all affected. For example, from the beginning of the pandemic some aged care homes initiated testing of staff and provide lessons in the wearing of PPE, allowed pre-arranged visits in communal rooms set up to accommodate social distancing requirements or several short visits in a resident's room throughout the day. Another area where many providers showed compassion and flexibility was in not restricting family visits for older people receiving palliative care or who were close to death.

However, this was not the case for all and too many providers bypassed any discussion with residents and families and devised their own version of 'lockdown' without any possibility for amelioration. As one family member explained, when she visited the facility after being telephoned to be informed that her 99-year-old, bed bound, mother's health had suddenly deteriorated, and asked permission to see her mother in her room, the facility refused.

- *"They point to the rules, 'Whilst in lockdown the following restrictions apply to all visitations:*

1. *one family member once only during the week*
2. *no visits in the resident's rooms*
3. *an appointment must be made*
4. *the visit will be for half an hour only*
5. *no contact between a family member and the resident*
6. *the visit will take place in a communal room which will be cleaned after each half hour visit."*

Improving coordination between Aged Care and Health Care

The pandemic experience has highlighted the well-established issue of a lack of policy clarity and service coordination between aged care services and the health system. One example of this is the initial inadequate supplies of PPE equipment in residential aged care services and a lack of training and preparedness in the use of this equipment.

There is also confusion regarding decision making and actions related to the removal of residents from residential facilities and transfers to hospitals in the event of a disease outbreak. There appears to be different and contrasting approaches to this in state and territory jurisdictions which adds to the confusion for consumers.

- *At one facility, a daughter was advised that if she took her mother out of the facility to her medical appointment at the nearby local hospital that on return less than two hours later her mother would be required to self-isolate in her room for 14 days. Moreover, during that time the mother would be permitted no visits. The daughter found this news most distressing as her cousin living interstate had had no re-entry conditions imposed by her father's residential facility after she had accompanied him to see his medical specialist at the practitioner's consulting rooms.*

Another area of confusion was the different strategies adopted by hospitals and residential aged care homes. Whilst in hospital a family carer could be with an older person. However, once the older person returned to the aged care facility this was no longer allowed.

- *"During the lockdown I was unable to visit my husband at all, except for two serious falls, when he was admitted to hospital. I could see him there, to explain his medical condition, and give permission (as Enduring Guardian) for medical treatment. Staff were sympathetic and allowed me to stay overnight at the hospital with him."*

- *"My mother, aged 90 and suffering from advanced dementia. Prior to the current lockdown I was visiting her once a week, then this stopped. She is currently in hospital for surgery after breaking a hip in a fall last Friday. I have been able to visit her freely in hospital after not seeing her at all (and more importantly, her not seeing me) for six weeks. She is due to return home today and under the present restrictions I don't know when I will see her again."*

Funding and service flexibility in local community planning and knowledge

Some services have demonstrated flexibility in their service practice to respond to local and regional needs. The willingness to do things differently and utilise funding in new ways to meet the needs of older people has produced some positive outcomes and has highlighted the importance of enabling local solutions. More review of this could assist the Commission's investigation of funding arrangements and governance.

Examples of local approaches have included the development of tailored technological activities, phone contact lines and follow up and organisation of food parcels in collaboration with local businesses.

Some community organisations have had their staff and volunteers involved in helping older people unfamiliar with technology to order groceries online, whilst others have assisted older people with laundry, gardening and keeping medical appointments.

More evidence is required in understanding the service experience of older Australians at the local level during the pandemic period. Whilst there is insufficient information, some reports indicate innovative approaches responding to distinct local needs whilst others reflect service inertia.

Knowledge of effective local solutions is important in developing consumer focused service delivery, improving data collection and can provide useful examples of the involvement of consumer in co-design.

The capacity and ability of aged care services to understand and connect with local services and to respond to local issues is critical in ensuring the health and wellbeing of older people, addressing mental health issues arising from loneliness and isolation and supporting self-management.

Knowledge of the location and circumstances of older people who live alone, have insufficient access to technology or poor technological literacy and have limited, poor or no family and friendship networks can enable and drive effective local responses.

Improving communication, information and public messaging for older people

During the pandemic crisis, particularly in the initial stages, COTA Australia is aware that many older people were confused about how to respond and conduct their lives. Some older people, living in the community, thought, because media told them, they were unable to go outside into the backyard or go for a walk. Others had the perception that they needed to forego their regular health and personal care because they would burden the health system or put themselves at risk. The initial lockdown approach in residential aged care and poor communication by some providers contributed

to this. In addition, the contrasting approaches to this in state and territory jurisdictions and levels of communication added to confusion for consumers.

There is an opportunity to review how public messaging to older people could be improved. This would include examining the coordination, consistency and tailoring of information to support and reassure vulnerable older people and the role of government and aged care services play in providing this information.

Adequacy of data collection and measurement

The experience of the pandemic raised concerns for policy makers, sector leaders and government about how little we know about care service coverage, quality of care and the health and wellbeing of older people, particularly those living at home, when general physical distancing is applied.

This raises questions about the appropriateness, effectiveness and implementation of data collection and measurement, both during a public health crisis and in more typical circumstances.

Whilst the Royal Commission is examining this, it should consider how data collection and measurement could be improved, particularly if lockdowns and restrictions for older people continues or if a future crisis arises.

Strengthen the consumer voice

The COVID-19 experience has above all further emphasised the need and importance of capturing and responding to the consumer voice to improve aged care services. More insights from consumers will assist our understanding of what worked well during the crisis including service innovations, communication strategies and practical responses. Strengthening the capacity to record, learn from and respond to consumer experience will also enable effective policy and service reform to address service gaps, develop service guidelines and procedures and improve service quality.

We need more and expanded platforms of consumer supports that educate, engage and empower consumers locally and at the national level. The pandemic experience has shown that, more than ever, there is a need to hear the consumer voice.

End