# California Long-Term Care Facility Access Policy Workgroup Recommendations Report for State Legislature October 5, 2023

The California State Legislature in 2022 commissioned a workgroup to "develop recommendations regarding best policies and practices for long-term care facilities during public health emergencies, including, but not limited to, visitation policies" (AB 178, Ting, Chapter 45, Statutes of 2022). This report reflects a summary of the discussions and recommendations of this workgroup, known as the Long-Term Care Facility Access (LTCFA) Policy Workgroup.

The California Department of Aging (CDA) will submit this report to the fiscal and appropriate policy committees of the State Legislature. The Legislature is expected to consider these recommendations in its policymaking.

## **Table of Contents**

About the Workgroup	1
Scope and Definitions	3
Recommendations	5
LTCF Access and Visitation for Resident-Designated     Support Persons	5
LTCF Access and Visitation for Health Care and Social Services Providers	16
3. LTCF Access and Visitation for Resident Advocates, Surveyors, and Others	18
Access to Personal Protective Equipment and Other     Emergency Supplies for Visitation	20
5. Process for Grievances and Appeals Related to Visitation Access	22
6. Ongoing Collaboration Between Key Stakeholders	24
Summary of Public Comments	26

## **About the Workgroup**

The COVID-19 pandemic has had a devastating global effect, with U.S. Centers for Disease Control and Prevention (CDC) data showing more than 1.1 million deaths in the United States attributed to the virus from the beginning of the pandemic in 2020 through August 26, 2023. In an effort to contain the spread of the virus in long-term care facilities (LTCFs) – where residents face a higher COVID-19 risk due to the congregate living environment and their advanced age – federal, state, and local authorities around the country established limitations on individuals entering the facilities. These steps limited visitation in LTCFs for extended periods of time, including some prolonged periods where no visitation was able to occur.

Recognizing this, the California State Legislature has asked the Long-Term Care Facility Access (LTCFA) Policy Workgroup to collectively put forth recommendations on how to approach LTCF visitation in states of emergency, with careful consideration of the impact that restricted access has on the mental and physical health of residents and patients, families, and friends.

As defined by the Legislature, the LTCFA Policy Workgroup is comprised of "the California Department of Aging (CDA), the Office of the State Long-Term Care Ombudsman (OSLTCO), the State Department of Public Health (CDPH), the State Department of Social Services (CDSS), and stakeholders representing public health officials, long-term care facility operators and residents, and consumer advocates." A full list of organizations included in the workgroup, representatives for those organizations, and biographies of those representatives is available on the CDA website; see the <a href="LTCFA Policy">LTCFA Policy</a> Workgroup Member Roster.

The workgroup launched on February 8, 2023, with a meeting to review the scope of and process for the LTCFA Policy Workgroup. The workgroup then met four times over the course of five months:

- Meeting 1: March 14 | Recording | Deck | Transcript | Chat Log | Q&A
- Meeting 2: May 30 | Recording | Deck | Transcript | Chat Log | Q&A
- Meeting 3: July 12 | Recording | Deck | Transcript | Chat Log | Q&A
- Meeting 4: August 22 | Recording | Deck | Transcript | Chat Log | Q&A

To inform the discussions, during Meeting 1 the workgroup:

- Examined research on the importance of LTCF visitation and the impact of restricted access (<u>see LTCFA Policy Workgroup Research Summary</u>);
- Heard testimonials from residents and their loved ones on the real-life impact of restricted access during the COVID-19 public health emergency (PHE) (view recording from Meeting 1); and
- Learned from existing LTCFA laws passed in more than a dozen states (see LTCFA Policy Workgroup Summary of State Laws).

Based on these inputs, the workgroup over Meetings 2-4 discussed potential recommendations for policies regarding access to LTCFs during states of emergency. In these discussions, workgroup members weighed the following concepts, which were defined in the kickoff meeting:

- Balance, referring to the relationship between the need for public health protection and the physical health, mental health, and advocacy needs of residents, their families, their friends, and others during emergencies, including their individual rights and autonomy;
- Parity, referring to similarities or differences in visitation requirements that a facility requires for visitors, outside professional staff, and facility staff;
- Regionalism, referring to differences among regions of California; and
- Equity, referring to the imperative to ensure equity in visitation access, with consideration for ageism, ableism, and barriers for historically marginalized communities.

In addition to workgroup discussions, workgroup members provided written feedback on the recommendations on an ad hoc basis and via four Requests for Comment sent to members of the workgroup:

- Request for Comment Survey 1: June 19 | Comments
- Request for Comment Survey 2: July 26 | Comments
- Request for Comment Survey 3: August 9 | Comments
- Request for Comment <u>Draft Report</u>: September 22 | <u>Comments</u> (Summary)

# **Scope and Definitions**

This workgroup examined visitation in LTCFs during states of emergency. The following definitions were used to define the scope of the workgroup and apply throughout this document.

- 1. **State of Emergency**: This workgroup examined LTCF visitation policy during states of emergency defined as follows: A situation that results in a declaration of a state of emergency or local emergency, as defined in Section 8558 of the Government Code, or the declaration of a health emergency or local health emergency, as described in Section 101080 and that triggers a state or local government order to restrict visitation in an LTCF. These situations may include, but are not limited to:
  - a. Disease Pandemics or Epidemics;
  - b. Natural Disasters;
  - c. Bioterrorism Emergencies;
  - d. Chemical Emergencies;
  - e. Radiation Emergencies;
  - f. Other Agents, Diseases, and Threats;
  - g. Power Surge Failures/Blackouts; and
  - h. Facility Infrastructure Breakdowns.
- 2. **Long-Term Care Facility (LTCF)**: For the purpose of these recommendations, the LTCFA Policy Workgroup defined LTCFs as follows:
  - a. Skilled Nursing Facilities (SNFs);
  - b. Intermediate Care Facilities (ICFs);
  - c. Adult Residential Facilities (ARFs) and Other Adult Assisted Living Facilities Regulated by CDSS, including ARFs for Persons with Special Health Care Needs and Enhanced Behavioral Support Homes: and
  - d. Residential Care Facilities for the Elderly (RCFEs) and Other Senior Assisted Living Facilities Regulated by CDSS, including Memory Care Units and Continuing Care Retirement Communities.
- 3. **Staff**: This refers to any individual employed by, or contracted directly with, the LTCF and who provides care to residents.

- 4. **Resident**: This refers to a resident or patient of an LTCF.
- 5. Resident Representative: This refers to an individual who has authority to act on behalf of the resident, including, but not limited to, a conservator, guardian, or person authorized as an agent in the resident's advance health care directive; the resident's spouse, registered domestic partner, or family member, or any other person designated by the resident to act as a representative; and any other surrogate decision maker designated in accordance with statutory and case law.
- 6. **Resident-Designated Support Person** (RDSP): This is an individual selected by a resident or resident representative to provide in-person, on-site support for the resident. RDSPs may include, but are not limited to, friends, family, and chosen family.
- 7. **Chosen Family**: This refers to individuals whom a resident considers family but with whom they may not have a legal or biological relationship.
- 8. **Visitor**: This refers to any individuals who enter an LTCF and are neither a member of staff nor a resident.
- 9. **Compassionate Care**: This is defined as visits for an LTCF resident whose health has sharply declined, who is experiencing a significant change in circumstances, or who is otherwise suffering. This includes, but is not limited to:
  - a. End-of-life and/or hospice care;
  - b. A situation where the resident has stopped eating or drinking, or is experiencing significant weight loss;
  - c. A major change of circumstance, such as a transition to a new LTCF;
  - d. Grief, such as grieving the loss of a loved one; and
  - e. A significant or rapid decline in mental health.

### Recommendations

The sections that follow summarize the discussions and conclusions of this workgroup across six discrete sections, organized by the key questions that the workgroup addressed. Each section contains background, principles, and a policy and practice recommendation, as follows:

- **Background**: This is a summary of the issue and the discussions of the workgroup related to this issue.
- Principles: These statements indicate important concepts related to LTCF visitation that the workgroup jointly seeks to convey to the Legislature.
- Recommendation: Building on the principles, the policy and practice recommendation reflect a specific policy and practice recommendation for the State Legislature to consider in legislative action around LTCFA policy.

The six sections are defined as follows:

- 1. LTCF Access and Visitation for Resident-Designated Support Persons
- 2. <u>LTCF Access and Visitation for Health Care and Social Services Providers</u>
- 3. <u>LTCF Access and Visitation for Resident Advocates, Surveyors, and</u> Others
- 4. Access to Personal Protective Equipment and Other Emergency Supplies for Visitation
- 5. Process for Grievances and Appeals Related to Visitation Access
- 6. Ongoing Collaboration Between Key Stakeholders

# 1. LTCF Access and Visitation for Resident-Designated Support Persons

## 1.1 Background

Across all workgroup meetings, members of the workgroup explored issues related to LTCF access and visitation for family, chosen family, and friends. The following summarizes key themes from the discussion.

### 1. The Need for LTCF Access

In Meeting 1, the LTCFA Policy Workgroup looked at existing research to understand the key roles and benefits of visitation from family, chosen family, and friends. Through this research and the collective lived experience and expertise of the workgroup, it identified several key reasons why it is essential for family, chosen family, and friends to have access to residents, including during a state of emergency.

Firstly, social contact is essential in preventing residents' social isolation and loneliness, which a growing body of research shows has a significant negative impact on physical, cognitive, and mental health. Even before the COVID-19 pandemic, LTCF residents were at a higher risk for social isolation and loneliness. For example, a <a href="systematic review">systematic review</a> published in 2020 in Age and Aging estimated that the prevalence of "severe loneliness" in residential and nursing care homes was 61%, with studies included in the review reporting a range from 9% to 81%. Moreover, a 2020 <a href="scoping review">scoping review</a> published in the Journal of the American Medical Directors Association found positive associations between social connection and LTCF residents experiencing less depression, less anxiety, and less cognitive decline.

Personal experiences shared by members of the workgroup and the public emphasized the importance of visitation from family, chosen family, and friends. Several workgroup members shared how their loved ones experienced serious declines in physical and mental health during periods of restricted visitation. A resident's loved one told the workgroup about her husband's experience of isolation during his facility's lockdown in 2020, in the early days of the COVID-19 pandemic. She said, "On our phone calls, I could tell he was becoming increasingly depressed. He'd say, 'this is no way to live,' and he would cry. He had a drastic decline in both physical and mental health."

Secondly, research shows that family, chosen family, and friends provide frontline care when they visit residents of LTCFs. In a <u>study</u> published in *Health Affairs* in 2022, researchers analyzed data from national household and Medicare surveys to understand the role of "informal caregivers," defined as family members or any unpaid individuals who provided care to the resident and who were not paid aides, employees of the LTCF, or other health or social service providers. It found a high prevalence of receipt of informal caregiving among residents of LTCFs; for example, 65% of nursing home residents received informal caregiving for household activities. It also found

that informal caregivers provide a significant number of hours of caregiving in LTCFs. Among LTCF residents who had a need for informal care and reported receiving it, residential care facility residents received an average of 65 hours per month of informal care, and nursing home residents received an average of 37 hours per month of informal care.

Again, these research findings were echoed in the lived experience of workgroup members, which illustrated the impact of limiting this frontline care during visitation lockdowns. A Long-Term Care Ombudsman in the workgroup shared this story of an LTCF resident with dementia: "Prior to COVID, her husband came to the facility for three meals per day to feed his wife. When the COVID visitor restrictions were enacted, the husband was only able to watch through a window as facility staff fed his wife. He watched with dismay as the staff raced through meals, gave his wife extremely large portions with each bite, causing her to choke, and ended meals before his wife was finished. Over several months of the lockout, the resident lost a significant amount of weight." Another member of the workgroup shared her experience when she was able to visit her mother as a result of her extended advocacy efforts. She said, "What I witnessed as I walked the halls to my mom's room each day was devastating. Residents wandering around in various stages of undress, seemingly panicked, reaching out, crying, help me! Can you please help me? But I couldn't, you know, even in head-to-toe NIOSH-approved [Personal Protective Equipment (PPE)], I had to keep my distance, or I risk everything. If I said something, I could be kicked out. I'd call for staff; no staff was in sight. Cords were regularly pulled for hours with no answer. They just weren't there, there wasn't enough staff. With each passing day, I couldn't help but notice that those people's voices, initially ringing so clear, were slowly fading into this eerie silence."

Thirdly, visitors who do not work for the LTCF have an important role in identifying issues with resident health and well-being, identifying care issues, and advocating for care. Testimonials from workgroup members emphasized the importance of ensuring that someone who does not work for the LTCF is able to access an LTCF resident in person. One workgroup member shared an experience that occurred when she was visiting a friend in an LTCF. She said, "I saw a CNA come out of her room. The CNA was [...] picking up meal trays after dinner. But when I walked into her room, I saw her sitting in her wheelchair. She was crying; her ostomy bag was leaking all over her, all over the floor. Her wheelchair was tracking the contents, and she was completely undressed from the waist down. I had to go find help for her. During lockdown, I would never have had a chance [to know] that was happening to somebody that I love or anybody, and it would have never been reported to [CDPH]."

Altogether, some early academic research suggests that residents of LTCFs experienced declines in physical and mental health during periods of limited LTCF visitation in the COVID-19 PHE. For example, a <u>study</u> published in the *Journal of the American Medical Directors Association* by Mathematica assessed the impact of the pandemic on the well-being of nursing home residents in 2020 and found that long-stay residents had a 15% increase in depressive symptoms and a 150% increase in unplanned substantial weight loss.

## 2. Designating Visitors

Over the course of Meetings 2-4, the LTCFA Policy Workgroup discussed which individuals should be prioritized for visitation in a state of emergency in which a state or local order curtails broad visitation in LTCFs.

The workgroup considered whether to advance recommendations that would prioritize family, chosen family, and friends as "visitors" or as "support persons." The workgroup considered the term "visitor" for these individuals because it would emphasize that no specific care or support is required for visitation. However, the workgroup ultimately determined that the term "support person" would more accurately reflect the important role of such individuals in supporting the health and well-being of residents. However, the workgroup emphasized that the term did not establish a requirement for support persons to provide any specific care or support to achieve this designation.

The workgroup also discussed the importance of not establishing strict limits on the number or range of individuals a resident could see over the course of a state of emergency. Residents, resident representatives, and resident advocates urged the workgroup to ensure in its recommendations that a resident's choice was prioritized and that residents would be able to see multiple loved ones – such as all their children – over the course of an emergency. At the same time, facility representatives and public health officials noted that unrestricted simultaneous access may not be possible in certain emergencies.

Balancing these two concepts, the group agreed on a recommendation that would allow residents to identify the individuals of their choice as Resident-Designated Support Persons (RDSPs), but acknowledged that public health orders may allow or require facilities to limit the number of RDSPs visiting a given resident to one at a time.

In reviewing a draft of this report, some public health officials indicated that there may also be situations where it is infeasible to allow an unlimited total number of RDSPs for a given resident over a period of time in a state of emergency. For example, they indicated there may be situations where the total number of contacts should be minimized to reduce the risk that a serious contagious disease will enter a facility. In addition, some facility representatives noted that staffing and capacity constraints may make it difficult to allow an unlimited number of visitors over a period of time. They recommended that the State Legislature consider a mechanism that would allow a public health order to limit the total number of RDSPs in certain emergencies when such limitations are needed to ensure public health and safety. In Meeting 4, the workgroup had considered and opted not to include in its joint recommendations a limitation on the total number of RDSPs, and these comments from public health officials are included here for Legislative consideration.

In addition, during the workgroup meetings and in reviewing the report draft, representatives of LTCF administrators did raise concerns about the administrative burden of establishing and maintaining records of RDSP designations, noting that such requirements could complicate residents' ability to see the RDSPs of their choice in a timely manner. These representatives favored an approach whereby residents could choose their visitors without establishing an RDSP list, as long as those RDSPs are following the required protocols. At the same time, the majority of workgroup members noted that it would be important during a state of emergency for a facility to know whom to let into the building. Balancing this, the workgroup did not recommend a specific requirement for how LTCFs track designations as long as LTCFs could honor resident choice in visitation.

## 3. Parity and Safety Protocols

In defining the level of RDSP access and protocols for RDSP access to an LTCF during a state of emergency in which state or local orders curtail broad visitation, the workgroup considered multiple options, including an approach where visitor-specific protocols could be established by a workgroup comprised of key stakeholder groups – including public health officials, residents, resident advocates, and LTCF administrators – during a state of emergency. However, the workgroup raised significant concerns about the administrative burden and delays associated with forming protocols in this way during an acute phase of an emergency.

Ultimately, the workgroup agreed on a recommendation in which RDSPs and LTCF staff would have parity in access to facilities and in safety protocols required in order to enter facilities and visit with residents. This reflected the workgroup's position that RDSPs contribute to the care and well-being of residents.

Importantly, however, the workgroup did emphasize that RDSPs should be able to use their own PPE, or other types of appropriate emergency supplies, as long as such equipment meets or exceeds the standards required by LTCF protocols and is in accordance with public health orders and guidance.

#### 4. Hours of Visitation

The workgroup discussed whether to establish minimum visitation hours for RDSPs.

In Title 42 of the Code of Federal Regulations, CFR 483.10(f)(4) <u>states</u> that a resident of an SNF participating in Medicare and/or Medicaid "has a right to receive visitors of their choosing at the time of their choosing, subject to the resident's right to deny visitation when applicable, and in a manner that does not impose on the rights of another resident." In effect, this means that SNF residents may have visitors, including RDSPs, at any time.

However, these federal regulations do not apply to residents of RCFEs and other non-nursing facility LTCFs included in these recommendations. According to California regulations governing RCFEs, residents have the right "to have their visitors, including [Long-Term Care Ombudsman] and advocacy representatives, permitted to visit privately during reasonable hours and without prior notice, provided that the rights of other residents are not infringed upon." Similarly, the California regulations for ARFs state that the facility shall ensure that each resident has the "personal right" to "have visitors, including advocacy representatives, visit privately during waking hours, provided that such visitations do not infringe upon the rights of other clients." As such, current California and federal regulations do allow some LTCF types to establish visitation hours, regardless of whether there is a state of emergency, as long as visitation still occurs.

Although resident advocates in the workgroup endorsed the elimination of visitation hours for all LTCFs regardless of the state of emergency, the workgroup's scope did not extend to LTCF policies outside of a state of emergency, and it was thus considered outside the scope of this workgroup to recommend a change in policy on visitation hours. Instead, the workgroup

recommended that the rules that govern visitation hours outside a state of emergency also apply during a state of emergency, meaning that LTCFs cannot restrict visitation hours because of an emergency.

#### 5. Location of Visitation

The workgroup also discussed the location of visitation, acknowledging that residents during the COVID-19 pandemic often could not see their loved ones in their rooms, even when some visitation was allowed.

The workgroup agreed that visitation should generally be able to occur in a resident's room. In situations where residents share a room, efforts should be made to provide privacy and minimize disruption to residents. However, those efforts should not inhibit visitation; for example, in a situation where both residents sharing a room do not have sufficient mobility to leave the room, visits should be able to occur in the room even if both residents are present.

Ultimately, the determination that RDSPs and LTCF staff would have parity in access to facilities and in safety protocols was considered sufficient to address this issue because it established parity between RDSPs and LTCF staff in the locations where they could interact with residents. Therefore, the workgroup did not develop a specific recommendation specifying the location of visitation.

## 6. Compassionate Care Visitation

The workgroup deliberated whether to include a recommendation for enhanced visitation in situations of compassionate care, which is described in the "Definitions" section of this document.

During the early days of the COVID-19 pandemic, visitation was largely limited to compassionate care situations, in accordance with <u>federal guidance</u> from the Centers for Medicare & Medicaid Services (CMS). Residents and resident representatives in the workgroup shared how challenging it was to receive approval for compassionate care visitation and indicated that loved ones were often denied visitation if residents were deemed to not meet the definition of compassionate care. One workgroup member shared how difficult it was to see her husband at the end of his life. She said, "I started calling the facility and asking and begging for compassionate care visits. And I was again and again denied daily for the compassionate care visits because they were not approved by corporate. And I was told that LA County Department of Public Health wouldn't approve them. I submitted multiple complaints about this, but

to no avail. And it was a nightmare. No one at the facility seemed like it mattered. It wasn't clear that they even noticed, nor would they take responsibility. And I had to stand by helpless as I watched, and listened only on my bad landline, to my husband declining in health. November eighteenth, as if they were handing me a gift, I got a phone call saying, we'd like you to come in for a compassionate care visit, which I greatly appreciated, but [it] shouldn't have just been that day, should have happened a long time ago."

The workgroup determined that it was important to put forth a recommendation that LTCFs take additional measures to enable visitation for compassionate care, namely by lifting restrictions on hours of visitation and number of simultaneous visitors. However, workgroup members stressed that this recommendation should not in any way diminish general RDSP access to visitation, regardless of whether the resident needs compassionate care.

Some workgroup members raised concerns about the use of the term "compassionate care," noting that it often is associated with end-of-life situations and that visits of this type should encompass a range of situations in which a resident's health or well-being is declining or in which they are otherwise suffering. However, existing regulations and guidance, including CMS guidance, use the term "compassionate care" and establish specific requirements around these visits. Therefore, the workgroup opted to use the "compassionate care" term but provide a robust definition that was informed by language used in CMS guidance and laws passed in other states related to "compassionate care."

## 1.2 Principles

Reflecting key takeaways from the discussions summarized above, the workgroup would like to convey the following principles to the State Legislature:

- This workgroup recognizes that family, friends, chosen family, and other visitors are essential to an LTCF resident's well-being and should be considered essential to the resident's care, including in a state of emergency.
- 2. The workgroup emphasizes the importance of resident choice and considers it important for residents to see the range of visitors they choose to see, including in a state of emergency.

- 3. This workgroup recognizes that certain conditions during states of emergency may cause legitimate public health or safety risks that may lead to a state or local order impacting LTCF visitation. In these situations, the workgroup considers it a priority to ensure that residents maintain access to family, friends, and chosen family.
- 4. Building on Principles (1), (2), and (3) above, the workgroup supports the designation of Resident-Designated Support Persons (RDSPs) who can provide in-person, on-site support to LTCF residents during a state of emergency that may impact LTCF visitation as specified in Principle 3 above.
- 5. LTCFs should enable visitation of RDSPs by establishing hours and locations of visitation that are accessible and account for the mobility, accessibility, translation needs, employment hours, travel, and other reasonable determinants of visitation for each individual resident and visitors. In general, visitation should be allowed to occur in the area where the resident lives and/or receives care, although steps should be taken to promote privacy in situations where residents live in a shared room. Regardless of a state of emergency, LTCFs should follow existing federal and state laws related to hours of visitation, as defined in the Background section above.
- 6. In situations requiring compassionate care defined as situations where an LTCF resident is experiencing a sharp decline in health, is experiencing a significant change in circumstances, or is otherwise suffering as a result of lack of visitation visits from RDSPs are especially important and LTCFs should take additional measures to lift any potential barriers to visitation in these situations, which may include lifting restrictions on the number of visitors at any one time.

#### 1.3 Recommendation

In a state of emergency in which a local or state order may curtail visitation due to a legitimate public health or safety risk, the workgroup recommends that Resident-Designated Support Persons (RDSPs) be able to conduct in-person visits with LTCF residents subject to the same safety protocols as LTCF staff.

1. In a state of emergency as defined above, LTCF residents or their representatives can <u>select as RDSPs any individuals</u> who have access to the facility for visitation as long as they follow required safety protocols, as defined in (2) below.

- a. RDSPs may include, but are not limited to, any of the following types of visitors if designated by the resident or their representative: friends, family, or chosen family.
- b. There may not be a limit placed on the number of individuals who may be selected as RDSPs, and residents may select RDSPs they wish to see at any time.
- c. This recommendation is not intended to establish specific requirements on the format or processes, written or otherwise, associated with establishing or tracking RDSPs at the facility level; it is intended to promote resident choice and provide facilities clear guidance on individuals who should be admitted to an LTCF as RDSPs.
- 2. In a state of emergency as defined above, RDSPs shall be required to follow the same safety protocols as LTCF staff in order to enter the facility and cannot be required to follow more stringent protocols than LTCF staff.
  - a. Safety protocols are defined as any measures required in order to protect the health and safety of all individuals during interactions with residents in the LTCF, in accordance with guidance from relevant public health and safety authorities. These may include, but are not limited to:
    - A requirement to don personal protective equipment (PPE) and to receive education on the effective use of PPE;
    - ii. A requirement to test for a contagious disease;
    - iii. A requirement for vaccination against a contagious disease;
    - iv. A requirement to maintain physical distance between individuals;
    - v. A limitation on physical contact; and
    - vi. A limitation on the locations for interactions with residents.
  - b. State or local orders may not require safety protocols for RDSPs that are more stringent than those required for staff.

- c. Where safety protocols require PPE or other types of emergency supplies, RDSPs may procure and use their own supplies for LTCF visitation as long as the supplies meet the minimum standards required in order to follow safety protocols for the facility, in accordance with public health orders and guidance.
- 3. In a state of emergency as defined above, there may be two distinctions in LTCF staff and RDSP access to an LTCF.
  - a. The number of <u>simultaneous RDSPs</u> who may visit an individual resident may be limited to as few as one RDSP per resident at any given time.
    - i. "Simultaneously" and "simultaneous" are defined as occurring at the same moment in time; and
    - ii. This recommendation is not intended to limit a resident's ability to have multiple RDSPs over a period of time (i.e., in a given day), understanding that multiple RDSPs may not be able to visit simultaneously in the case of a legitimate public health or safety risk.
  - b. <u>Hours of visitation</u> for RDSPs must be the same as those required of an LTCF outside a state of emergency. Those requirements vary by facility type, subject to existing federal and state law.
- 4. In a state of emergency as defined above, LTCFs should expand the number of simultaneous RDSPs and the hours of visitation to enable visitation in moments when a resident requires compassionate care.
  - a. Compassionate care is defined as visits for an LTCF resident whose health has sharply declined, who is experiencing a significant change in circumstances, or who is otherwise suffering. This includes, but is not limited to:
    - End-of-life and/or hospice care;
    - ii. A situation where the resident has stopped eating or drinking, or is experiencing significant weight loss;
    - iii. A major change of circumstance, such as a transition to a new LTCF;

- iv. Grief, such as grieving the loss of a loved one; and
- v. A significant or rapid decline in mental health.
- b. The need for a compassionate care visitation may be identified by any member of the resident's care team, the resident themselves, RDSPs, state licensing agency personnel, or the Long-Term Care Ombudsman.

# 2. LTCF Access and Visitation for Health Care and Social Services Providers

## 2.1 Background

In addition to discussing access and visitation issues for RDSPs, the workgroup addressed the need for health care and social services providers to access facilities and provide services to residents.

During the COVID-19 pandemic, health care and social services providers were not always able to come on-site to provide services to residents in LTCFs where those providers did not work. Such providers include, but are not limited to, health care workers, hospice providers, paid caregivers, personal care assistants, care managers, dentists, social services providers, financial planners, conservators, and spiritual care providers.

The workgroup agreed that access for these providers is important, regardless of a state of emergency. In a state of emergency in which a local or state order may curtail visitation due to a legitimate public health or safety risk, the workgroup aligned on a recommendation that would establish parity in access and safety protocols between LTCF staff and service providers who do not work for an LTCF.

## 2.2 Principles

Based on the discussions summarized above, the workgroup would like to convey the following principle to the State Legislature:

1. The workgroup acknowledges that LTCF residents receive critical services from individuals who do not work in an LTCF and considers it important that access to those services be maintained during a state of emergency.

### 2.3 Recommendation

In a state of emergency in which a local or state order may curtail visitation due to a legitimate public health or safety risk, the workgroup recommends that health care and social services providers not employed by the LTCF be able to access an LTCF and, when relevant, conduct in-person visits with LTCF residents, subject to the same safety protocols as LTCF staff.

- 1. In a state of emergency as defined above, health and social services providers not employed by the LTCF may provide services to residents in the LTCF as long as they follow required safety protocols, as defined in (2) below.
  - a. Such providers may include, but are not limited to, health care workers, hospice providers, paid caregivers, personal care assistants, care managers, dentists, social services providers, financial planners, conservators, and spiritual care providers.
  - b. The need for such services may be identified by residents, resident representatives, LTCF staff, the resident's care team, or other individuals.
- 2. In a state of emergency as defined above, health care and social services providers not employed by the LTCF shall be required to <u>follow</u> the same safety protocols as LTCF staff in order to enter the facility.
  - a. Safety protocols are defined as any measures required in order to protect the health and safety of all individuals during interactions with residents in the LTCF, in accordance with guidance from relevant public health and safety authorities. These may include, but are not limited to:
    - i. A requirement to don personal protective equipment (PPE) and to receive education on the effective use of PPE;
    - ii. A requirement to test for a contagious disease;
    - iii. A requirement for vaccination against a contagious disease;
    - iv. A requirement to maintain physical distance between individuals;

- v. A limitation on physical contact; and
- vi. A limitation in the locations for interactions with residents.
- b. State or local orders may not require safety protocols for health care and social services providers not employed by the LTCF that are more stringent than those required for LTCF staff.
- c. Where safety protocols require PPE or other types of emergency supplies, health care and social services providers not employed by the LTCF may procure and use their own supplies for LTCF visitation as long as the supplies meet the minimum standards required in order to follow safety protocols for the facility, in accordance with public health orders and guidance.
- 3. <u>Hours of visitation</u> for health care and social services providers not employed by the LTCF must be the same as those required of an LTCF outside a state of emergency. Those requirements may vary by facility type, subject to existing federal and state law.

# 3. LTCF Access and Visitation for Resident Advocates, Surveyors, and Others

## 3.1 Background

The workgroup also discussed the need to ensure uninterrupted access to LTCFs for individuals not encompassed in Recommendations 1 and 2 but who have access to LTCFs through legal, statutory, regulatory, or similar authority. For example, Title 42 of the Code of Federal Regulations, in CFR 483.10(f)(4)(i)(C), (D) and (F), states that a SNF must provide "immediate access to any resident" for "any representative of the Office of the State long-term care ombudsman," "any representative of the protection and advocacy systems," and "any representative of the agency responsible for the protection and advocacy system for individuals with a mental disorder."

During some periods in the COVID-19 pandemic, individuals who have legal, statutory, regulatory, or similar authority to enter an LTCF experienced periods of restricted access when state and local orders curtailed visitation. The workgroup agreed that future state and local orders curtailing visitation should not prevent visitation for these individuals. As with Recommendations 1 and 2, the workgroup agreed to establish that these individuals have the same access and follow the same safety protocols as LTCF staff in a state of emergency where broader visitation is curtailed.

## 3.2 Principles

Based on the workgroup discussion summarized above, the workgroup would like to convey the following principle to the State Legislature:

 The workgroup recognizes the importance of the work that resident advocates, surveyors, licensing agency staff, and individuals in similar roles conduct in LTCFs, and acknowledges the importance of ensuring that these individuals have continued access to LTCFs during a state of emergency.

### 3.3 Recommendation

In a state of emergency in which a local or state order may curtail visitation due to a legitimate public health or safety risk, the workgroup recommends that individuals who have access to enter LTCFs through legal, statutory, regulatory, or similar authority be able to access an LTCF and, when relevant, conduct in-person visits with LTCF residents, subject to the same safety protocols as LTCF staff.

- 1. In a state of emergency as defined above, individuals who have access to enter LTCFs through legal, statutory, regulatory, or similar authority may access the facility and, when required by law or otherwise relevant, visit with residents in the LTCF as long as they follow required safety protocols, as defined in (2) below.
  - a. Such individuals may include, but are not limited to, regulators, government surveyors, long-term care ombudsmen, patient advocates, patient representatives, law enforcement officials, and others.
- In a state of emergency as defined above, individuals who have access
  to enter LTCFs through legal, statutory, regulatory, or similar authority
  shall be required to follow the same safety protocols as LTCF staff in
  order to enter the facility.
  - a. Safety protocols are defined as any measures required in order to protect the health and safety of all individuals during interactions with residents in the LTCF, in accordance with guidance from relevant public health and safety authorities. These may include, but are not limited to:

- i. A requirement to don personal protective equipment (PPE) and to receive education on the effective use of PPE;
- ii. A requirement to test for a contagious disease;
- iii. A requirement for vaccination against a contagious disease;
- iv. A requirement to maintain physical distance between individuals;
- v. A limitation on physical contact; and
- vi. A limitation in the locations for interactions with residents.
- b. State or local orders may not require safety protocols for health care and social services providers not employed by the LTCF that are more stringent than those required for LTCF staff.
- c. Where safety protocols require PPE or other types of emergency supplies, health care and social services providers not employed by the LTCF may procure and use their own supplies for LTCF visitation as long as the supplies meet the minimum standards required in order to follow safety protocols for the facility, in accordance with public health orders and guidance.
- 3. <u>Hours of visitation</u> for individuals who have access to enter LTCFs through legal, statutory, regulatory, or similar authority must be the same as those required of an LTCF outside a state of emergency. Those requirements may vary by facility type, subject to existing federal and state law.

# 4. Access to Personal Protective Equipment and Other Emergency Supplies for Visitation

## 4.1 Background

In its meetings, the workgroup discussed the need to ensure access to emergency supplies – including, but not limited to, PPE, vaccines, and testing equipment – for RDSPs.

During the COVID-19 pandemic, state, county, and local authorities directed the distribution of PPE, testing equipment, and vaccines during periods when these supplies were extremely limited. In doing so, they prioritized certain populations – including LTCF staff and residents – to receive supplies based on risk factors and job requirements. However, the loved ones of LTCF residents were not consistently prioritized for these supplies in order to enable visitation.

Although measures have been taken to improve the standing supply of PPE and avoid limited access in the future, the workgroup in its discussions acknowledged that these measures do not eliminate the possibility of experiencing a period of limited supply of PPE and other emergency supplies. The workgroup agreed that if this situation were to occur again, RDSPs should be considered among the priority populations for emergency supplies. This prioritization would reflect the workgroup's overall principle that RDSPs are essential to the health and well-being of LTCF residents.

## 4.2 Principles

Based on the workgroup discussion summarized above, the workgroup would like to convey the following principles to the State Legislature:

- 1. The workgroup considers it essential to include RDSPs among the priority populations for PPE and other emergency supplies during a situation in which there is limited access to those supplies, as is already standard for LTCF staff.
- 2. The workgroup also seeks to ensure that RDSPs are able to procure and use their own supplies for LTCF visitation as long as the supplies meet or exceed the minimum standards required in order to follow safety protocols.

### 4.3 Recommendation

In a state of emergency in which the emergency supplies are limited across the board and in which state, county, and local authorities are involved in supply distribution, the workgroup recommends that state, county, and local authorities consider RDSPs to be among the top priority populations for any emergency supplies required in order to adhere to LTCF safety protocols.

1. Emergency supplies may include, but are not limited to, PPE, vaccination, and testing equipment.

- 2. Facilities should provide emergency supplies to RDSPs to the extent that those supplies are available at the time of visitation and have been made available to the facility by federal, state, or local entities for this purpose.
- 3. Nothing in this recommendation would deprioritize or inhibit access to emergency supplies for LTCF staff.
- 4. In case of extreme limitations on emergency supplies, the workgroup recommends that state, county, and local authorities consider compassionate care visits to be among the highest-priority situations for any emergency supplies required in order to adhere to LTCF safety protocols.
  - a. Compassionate care is defined in Recommendation 1.

## 5. Process for Grievances and Appeals Related to Visitation Access

## 5.1 Background

In its meetings, the workgroup discussed the importance of clear communications and a timely grievance and/or appeals process related to visitation.

Members of the workgroup shared how, during the COVID-19 pandemic, it was difficult to understand residents' rights to visitation. Various federal, state, and local entities govern rules related to visitation in LTCFs, and there was no simple source of information for residents and their loved ones to understand their visitation rights. The workgroup agreed on the importance of ensuring that clear communication about visitation policies be accessible to residents and loved ones.

The workgroup also agreed on the importance of a fair and timely grievance and/or appeals process to ensure the equitable implementation of its recommendations. Resident advocates specifically emphasized that this process should ensure a rapid response and resolution of issues to ensure that RDSP access to residents is preserved. The workgroup acknowledged that licensing agencies for LTCFs have existing grievance and appeals processes that may be leveraged and modified for this purpose. Understanding that additional work is needed to develop the operational details of a grievance and/or appeals process for RDSP visitation, the workgroup did not specify whether licensing agencies should develop a new

process or modify an existing process for this purpose. Instead, the workgroup opted to specify what this process should contain and recommend that licensing agencies develop or modify a process to achieve this outcome.

During Meeting 4, the workgroup expressed concern that the cost of implementing a grievance and appeals process might impact progress on the recommendations in this report. Residents and resident advocates in the workgroup urged that the state adopt a transparent process in developing the grievance and appeals process related to these recommendations.

## 5.2 Principles

Based on the workgroup discussion summarized above, the workgroup would like to convey the following principles to the State Legislature:

- 1. All policies and practices related to LTCF visitation must be implemented equitably, with consideration for ageism, ableism, and barriers for historically marginalized communities.
- 2. All policies related to visitation must be clearly communicated in a manner that is accessible to all individuals who may need that information.
- 3. To ensure that policies are implemented equitably, residents and their loved ones must have access to a timely grievance and/or appeals process to address their concerns and ensure equitable access to visitation.

#### 5.3 Recommendation

The workgroup recommends that state LTCF licensing agencies provide clear communication on LTCF visitation standards and an accessible process for submitting grievances and appeals in situations where visitation is not made available as defined in this workgroup's recommendations.

- 1. To promote clear communications of policies:
  - a. State LTCF licensing agencies should clearly post on their websites, in languages that are accessible to all who may need the current policies for visitation in LTCFs, the safety protocols that LTCF staff and visitors must follow, in accordance with Recommendations 1-3.

- b. Facilities should clearly post visitation policies in the preferred languages of their residents and visitors in visible locations within and outside the facility.
- Facilities should conduct proactive outreach with RDSPs in their preferred language to provide timely updates on visitation protocols.
- d. All communications related to visitation whether by state licensing agencies or by facilities must meet accessibility standards, be written in plain language, and be available in languages accessible to all who need the information.
- 2. To promote equitable implementation of those policies:
  - a. The state LTCF licensing agencies should develop a detailed process for grievances and appeals within six months of legislative action on these recommendations, or as soon as practicable. In doing so, it should:
    - i. Consult key stakeholders, including residents, RDSPs, and resident advocates, in the development of the process; and
    - ii. Release the proposal for public comment prior to finalizing it.
  - b. The process will include specific timelines for responding to grievances and appeals.
  - c. The process should include a method for rapidly responding to a situation in which an RDSP was not able to visit a resident in accordance with the policies posted on the state LTCF licensing agencies' websites.

## 6. Ongoing Collaboration Between Key Stakeholders

## 6.1 Background

In its meetings, the workgroup discussed the need for ongoing collaboration in policymaking related to LTCF visitation.

Some members of the workgroup noted that collaborative policymaking in which state officials consulted residents and resident advocates on LTCF visitation was inconsistent during the COVID-19 pandemic. They advocated

for a recommendation to promote ongoing collaborative policymaking related to LTCF visitation during a state of emergency.

## 6.2 Principles

Based on the workgroup discussion summarized above, the workgroup would like to convey the following principle to the State Legislature:

 It is important to ensure that those most impacted by LTCF visitation policies have input in the development of those policies, even in a state of emergency.

### 6.3 Recommendation

In a state of emergency in which a local or state order may curtail visitation due to a legitimate public health or safety risk, the workgroup recommends that a representative group of stakeholders be convened at regular intervals to discuss issues related to LTCF visitation and provide a collaborative forum for those impacted by the policies to provide feedback to licensing agencies and other key decision makers.

- A representative group of stakeholders would at minimum include residents; resident representatives; resident advocates; long-term care ombudsmen; LTCF operators and staff; select experts from the fields of gerontology, geriatrics, and long-term care medicine; the California Department of Public Health (CDPH); local public health departments; and the California Department of Social Services (CDSS).
- 2. The group should represent the diverse needs of the residents in all types of facilities impacted by these recommendations.

# **Summary of Public Comments**

To ensure an open, transparent, and accessible process, all LTCFA Policy Workgroup meetings were held publicly. Throughout all meetings, members of the public had the opportunity to provide comments and submit questions.

Members of the public provided feedback on workgroup discussions and the development of materials through more than 50 comments submitted verbally and via the written Q&A tool in the workgroup meetings. In Meeting 1, members of the public emphasized the importance of caregivers and loved ones visiting residents in person, and the challenges visitors encountered accessing loved ones during COVID-19. In Meetings 2 and 3, members of the public voiced concerns about any principle or recommendation that may allow safety protocols or visitation parameters that are different from those required for staff and that might restrict visitation.

During Meeting 4, a complete set of draft policy and practice recommendations were discussed, and public comment was taken throughout. Members of the public suggested that the workgroup specify that Resident-Designated Support Persons (RDSPs) be subject to the same safety protocols and be granted the same access to LTCFs as "direct care staff" for visitation during a public emergency. Members of the public expressed support of the workgroup's final recommendations – which were refined during Meeting 4 – that outlined the designation of RDSPs, parity in access and safety protocols, and recommendations to prioritize PPE for RDSPs.

All submitted public comments are available on the LTCFA Policy Workgroup website.