



Long-Term Care Facility Access (LTCFA) Policy Workgroup Meeting
March 14, 2023

(AUTOMATED ZOOM CAPTIONING)

[SLIDE 3]

12:32:14

NELSON SHEYA: Alright, hello, and welcome to meeting number one of the California Long-Term Care Facility Access Policy Workgroup. My name is Nelson Sheya, with the California Department of Aging, and I'll be kicking off today's meeting. But first I'll walk you through some housekeeping items. If you need any assistance during today's meeting, please type your question into the Q & A box located on the Zoom panel at the bottom of your screen. And during today's event, live closed captioning will be available in 11 languages and live American sign language interpreting is available. Next slide please.

12:32:47

[SLIDE 4]

Public participation. So CDA is committed to ensuring an open, transparent, and accessible process. All workgroup meetings will be held publicly and are subject to the Bagley Keene Open Meeting Act. And all sessions of this workgroup will be made public, and will be, and we will reserve time for public comments.

Last, all meeting information and materials will be posted on CDA's website, and we will drop a link into the chat in a bit.

12:33:15

[SLIDE 4]

Okay, how to participate for workgroup members. You may participate by making verbal comments or submitting comments via the chat. For verbal comments please raise your hand by clicking the reactions icon and select raise hand. You will then be added to the speaking queue.

So, throughout the meeting CDA will take comments and questions from workgroup members. And when sending comments via the chat, make sure you are sending them to everyone. Chat comments will be recorded and reviewed by CDA staff. Next slide please.

12:33:43

[SLIDE 5]

Participation for members of the public. You will participate by making verbal comments during the public comment period, or throughout the meeting in the Q & A box. To make a verbal comment, please click the raise your hand icon, or press star 9 for attendees participating over the phone. You may also submit comments and questions using the zoom Q & A box. Again, all comments will be recorded and reviewed by CDA staff. With that I'll pass it over to Brandie. Thank you.

12:34:19

[SLIDE 6]

BRANDIE DEVALL: Thank you, Nelson. Welcome to the Long-Term Care Facility Access Policy Workgroup meeting one. My name is Brandie Devall, and I am an attorney at CDA. Thank you to our workgroup members, and members of the public, for joining this meeting. Before I review the agenda I would like to provide a reminder of the purpose of this workgroup. Commissioned by the California legislature the Long-Term Care Facility Access Policy Workgroup will develop recommendations for policies and practices regarding access and visitation to long-term care facilities during states of emergency, with consideration for the impact that restricted access has on the mental health of residential families and friends and on the physical health and safety of residents. Next slide, please.

12:35:28

[SLIDE 7] Now that we are reminded of this workgroup's purpose, let's look at the agenda for today. As Nelson noted, this is the first of 4 meetings of this work group. We will start by recapping some background about the scope of this workgroup, and edits we made to that scope based on feedback received during the kickoff session. Then we will cover 3 important topics as we advance towards developing recommendations for visitation and access policies in long-term care facilities. We will start by covering key research on long-term care facility access and visitation, highlighting the impact of visitation on the physical, and mental health, of

residents and loved ones, and discussing the effects of restricted visitation. We will then open up the meeting for long-term care residents, and family members of residents, to share testimonials about their experience of visitation generally, and during the COVID-19 pandemic. In our last section of the meeting we will look at long-term care facility visitation policies across the country that have been passed in response to COVID-19. This section will focus on strategies that other states have used in their visitation laws, and it will include discussion of approaches we may consider in making recommendations here in California. Once that overview is provided, members of the public will have an opportunity to give comments. Next slide, please.

12:37:22

[SLIDE 8] I would now like to introduce my colleagues, who will be presenting throughout our meeting today. We have Mark Beckley, who is the Chief Deputy Director at CDA. And Juliette Mullin, Senior Manager from Manatt Health. Next slide. Thank you.

12:37:39

[SLIDE 9] On this slide is a full list of organizations participating in this work group. CDA will post a list of the representatives for these organizations to our website after today's meeting. We will also be including workgroup member bios, that have been submitted to CDA. So, if you haven't sent your bio in, we invite you to do so before the next meeting. At this time, I'd like to invite representatives from these organizations to just drop us a little message in the chat. Please introduce yourself, provide your name, title, and the organization that you're from. And I'll give just a few seconds while you all drop your hellos into the chat. Oh, good, yes, hi, hi, Eric. Oh, good. Maitely. Lots of stuff coming in pretty quickly. Great. Yeah. The Ombudsman. Great. Thanks guys, please keep saying hello. And we're going to keep moving the program along. As I turn it over to Mark Beckley for a background and a recap of the kickoff meeting that we held on February 8th.

12:39:30

[SLIDE 10]

MARK BECKLEY: Great. Thank you Brandie, and good afternoon everybody. Thank you so much for attending today's workgroup meeting. And thanks to all of you who are able to attend last, the last kickoff meeting as well. We really appreciate the level of engagement and participation as

well as all the comments and research items that you sent to us after the first kickoff meeting. And in particular, for this meeting I'd really like to thank all the workgroup members, and members of the public for residents, for friends, family members, or chosen family of residents of long-term care facilities, who will be providing their testimony today about their experiences and living in or having a loved one in a facility during the COVID pandemic. Your testimony is really at the heart of what this workgroup is attempting to accomplish. And it's really going to be critical to inform the recommendations of this workgroup going forward. So, thank you all for being so comfortable to share your testimony with us today.

12:40:33

I'd also like to thank our partners at Manatt for conducting extensive research on peer reviewed studies and articles on loneliness and isolation for older adults and long-term care facilities specifically, and on the effects of prolonged isolation can have on individuals health and well-being. They have only conducted extensive research on other state laws that have been acted and provided rights for compassionate care, and the visits for residents. And these are ideas and activities that California also may want to consider. Unless, I, you know, wanna thank everybody for providing your feedback. And what we're really interested in hearing today is your feedback on where you think that this workgroup should go next. After you hear the research on the state laws and on, you know, the detrimental effects of loneliness in isolation. We're really interested to hear what you'd like to focus on in the next workgroup meeting. So, as you're listening to discussion, just kind of keep in the back of your mind what are the areas that really resonate to you, in terms of options for consideration, as well as areas of further research and study that you'd like to focus on next. So, in my portion of the presentation, what I'd like to do is go through a recap of the scope considerations.

12:41:55

So, in the last meeting we have heard a lot of very valuable input in terms of additional scope considerations. And what we've done is we've updated our scope to incorporate several of your additional recommendations. For areas where we haven't adopted the scope, will provide a reason for why those additional scope considerations for not adopted. Okay, next slide.

12:42:18

[SLIDE 11] So, as a reminder, the Long-Term Care Facility Access Policy Workgroup will consider a range of the following categories: visitors,

purpose of visitation, long- term care facilities, and emergencies. The following slides will outline the elements that may be considered in the scope of the work group. Next slide.

12:42:40

[SLIDE 12] So, considerations for visitors. The workgroup will consider a range of visitor types in its recommendations, including those listed on this slide. I won't read through the entire slide, we did go through these categories last time, and we do have the meeting minutes and video available from the last meeting. So, if you are interested in getting a recap, I invite you to visit last meetings materials.

But what I do wanna highlight here is areas where we've made expansions. So, we have expanded the type of providers, healthcare, social services, and other service providers, such as hospice providers, conservators, and financial planners, and we explicitly called out patient advocates, which was a key recommendation that we heard from in the last meeting. And I also want to remind all of us that this is not a definitive list of categories to be used in policy recommendations, it's simply lists the range of different visitor types that this workgroup may consider. Okay, next, slide.

12:43:47

[SLIDE 13] The next category that we considered was visitation purposes. So, we will develop policy recommendations that could apply to a range of different visitation purposes. Some of the updates that we made to this section are feedback that we received on expanding the definition of health care visits, and visits to other facility types. We also added an additional category for advocacy visits, which again, was a key recommendation that we heard from the last workgroup visit. Again, this is not a definitive list, but this is a list of the scope that we have heard so far in our input and feedback. Okay, we will move to the next slide.

12:44:32

[SLIDE 14] Facility types. So, in the last month's meeting we also heard recommendations for different types of facilities that we should also consider. So, we've called out a number of facility types that we were asked about in the kickoff meeting, explicitly noting that the workgroup may consider other facility types as well. We did receive a couple of questions in the kickoff meeting about whether pediatric care facilities would be included in the scope. We referred back to the bill language and really this workgroup is convened to really consider visits to older adult residents as

well as persons with disabilities. So, not included, we're at adolescence or pediatric facilities. We also feel that that would really require a different set of stakeholders. Stakeholders with different levels of expertise than what we have on this workgroup, and that those types of facilities would really be best suited with a different convening. Okay, next, slide.

12:45:43

[SLIDE 15] So, scope considerations. We also looked at emergencies. So, what types of emergencies should this workgroup consider. And we've expanded the list to also include specifically local regional emergencies. For example, local, flu outbreaks, blackouts, power surge failures and emergency power shut offs, domestic terrorism, such as mass shooting, cyber-attacks, as well as facility infrastructure breakdowns, so such as, burst pipes, electrical outages. Move to the next slide.

12:46:27

[SLIDE 16] And then Key Principles. And on this one I really do want to go through each of our 4 key principles again and note areas where we've made some updates. So, because these are really the principles that are gonna be guiding our work, going forward, so it's important that we always keep this in the front of our mind when we're thinking about this work, and think about the recommendations that will be making. So, balance. Balance refers to the relationship between the need for public health protection versus physical, mental, and advocacy needs for residents, their families, their friends, and others during emergencies, including their individual rights and autonomy. I'll flag here that we added the importance of individual rights and autonomy based on the feedback we received numerous comments, really highlighting that as an essential principle. The next principle is parity. This refers to similarities or differences in visitation requirements that a facility requires for visitors, outside professional staff, and local facility staff. The next principle is regionalism. Which refers to differences among all regions of California and allows for flexibility and policies. And then finally, equity. This is a new principle that we added again, based on your feedback from last month's kickoff meeting. And this refers to the imperative to ensure equity and visitation access with consideration for agism and ableism and barriers for historically marginalized communities, making sure that these communities get served and are recognized in these recommendations. We will revisit these principles again later in the meeting and provide an opportunity for recommendations and additional principles for consideration.

12:48:12

I'm now going to turn the presentation over to Juliette Mullin, who is one of our consultants at Manatt Consulting to talk about the research that Manatt has conducted on isolation, loneliness, and state laws and statute recommendations, Juliette.

12:48:28

[SLIDE 17]

JULIETTE MULLIN: Great. Thank you, Mark. Before we get started I will just note that I have dropped in the chat a summary document that covers all of the different pieces of research that we will touch on today.

The research that we're about to walk through is research conducted by the Manatt team doing a broad literature review of the available peer-reviewed research on long-term care facility visitation, and then the impact when visitation is restricted. I also wanna thank many members of the workgroup for submitting studies, articles, and reports related to long-term care, visitation, and access. Those are also reflected in the presentation today, and all of those reports and studies are available in the link that I dropped in the chat. We've included a brief summary of each article and a link to click through and actually read the article itself. So, with that, if you go to the next slide.

12:49:29

[SLIDE 18] So, at a high level, what we'll do today is we'll walk through some of what's available in the research to help us understand the impact of restricted visitation and to help us understand the importance of visitation. And in doing that, we really looked at 2 core questions in our literature review. So, the first is what are the key roles of visitors, and the benefits of visitation in long-term care facilities. So, this really looked at before COVID, during COVID. What are the roles that visitors have? What are the benefits of visitation? And then we look at the impact of restricted visitation. We'll have that baseline to refer to of what does it look like when you have visitations?

There are 2 core findings that we'll delve into in this section. One, that even before the pandemic, long-term care facility residents were at a higher risk of social isolation, and loneliness. And that studies show the importance of social connection, to combat social isolation and loneliness. That's kind of the first big bucket of findings we'll go through. The second is looking at the

role that friends, family, and chosen family provide in providing care and support to residents in facilities. So, we'll actually look at the role they play as caregivers in long-term care facilities.

And our second section, once we've established that baseline about visitation, we'll look at what happened when visitation was restricted during COVID-19. And one of the key, kind of top line takeaways there, is that research around the impact of restrictive visitation is still early, but some early studies do show there may have been some adverse effects of having restrictive visitation. So, we'll dive into all of these questions.

We'll invite folks to participate and comment in the chat as we go, and then we will also pause at the end of the review of the research, for folks to both weigh in and react to the research that was included here, and add any additional major points that you feel were not covered in the research covered today. One request is for workgroup members to please, when you comment for everyone to see if you could use the everyone setting instead of the host and panels, that everyone, including members of the public, can see the chat. Next slide, please.

12:52:09

[SLIDE 19] So we're gonna focus in first on what were the key roles of visitors and the benefits of visitation. Next slide.

12:52:18

[SLIDE 20]

So first of all, what we found in the research, and a number of folks also sent us articles around social isolation, as looking at generally a growing body of research, really points to significant physical and mental health impact of the social isolation and loneliness. And so, as a reminder for everyone, social isolation is generally considered an objective measure of a lack of social contact, whereas loneliness is subjective, feeling of being lonely. The 2 concepts are, of course, very intertwined, but those are the definitions and the differences between the 2.

A major, 2020, meta-analysis, published by the National Academies of Sciences, Engineering, And Medicine summarized the major impacts of social isolation and loneliness among older adults. Those include a number of adverse effects in terms of the physical health of an individual who is feeling lonely and experience in social isolation. Those include an increase in the risk of cardiovascular disease and strokes, a reduction in functionality

as measures, measured by ADLs, and a reduction in quality of life. That meta-analysis also showed major impacts on the mental and cognitive health of individuals experiencing social isolation and loneliness. Specifically, it found that there was an increase in reported levels of clinically significant depression and anxiety, a decline in global cognition, processing speed, executive function, and visuospatial abilities, and it found an increase in the risk of dementia. So, that study is linked in the summary of studies we've dropped in the chat. It is kind of a very large report, with a lot of detail in it, and encourage folks to refer to that for more information on the impact of social isolation and loneliness, and the different studies that have looked at that over the years. To go to the next slide.

12:54:24

[SLIDE 21] So? Why? Why this look at social, and social isolation and loneliness? Because the research does show that long-term care facility residents have a high risk of social isolation and loneliness. A systemic review published in 2020, in Age and Aging, estimated that the prevalence of severe loneliness in residential and nursing care homes was approximately 61%.

Now this is a systematic review, so it looks at a range of studies, and those studies reported a range between 9% and 81%. So there, there is a range out there in the research they found that the general prevalence across all of those studies came out to about 61%.

The flip side of that is a 2020 scoping review, published in the Journal of The American Medical Directors Association, did find a positive association between having social connection and long-term care facility residents during the less depression, less anxiety and less cognitive decline so this points to a potential of having social connections in long-term care facilities, mitigating some of the risks associated with the higher risk around loneliness in long-term care facilities. To go to the next slide.

12:55:47

[SLIDE 22] So, this next piece of research here sort of shifts from social isolation and loneliness to look at the role that loved ones provide in actually giving essential care to residents in long-term care facilities. So, a study published in Health Affairs in 2022 found, looked at, it looked at data from the Medicare survey, the national household surveys to understand the role of informal caregiving in a number of settings. So, it looked at it in nursing homes, residential care homes, and community dwellings. It defined informal caregiving as family members or unpaid individuals

providing care to the resident, who was not a paid, a paid aide, an employee of the long-term care facility, or another service provider. What the study found is that the prevalence of informal caregiving was actually higher among residents in long-term care facilities compared with residents in community dwelling, compared to older adults in community dwelling sites. So, for example, it found that 65% of nursing home residents received informal caregiving for a household activities. If you take a look at the study itself, you'll be able to see a breakdown of different types of caregiving needs, and the older adults received that kind of caregiving and long-term care facilities. Another big finding of the study is not just that informal caregiving is really prevalent in long-term care, it's also that there is that informal caregivers of residents in long-term care facilities provide a significant number of hours of caregiving. So, looking at the different types of long-term care facility residents, the study found that 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 of informal care. To go to the next slide.

12:57:51

[SLIDE23] That wraps up the very, very high-level summary of the research around long-term care facilities, visitation, the benefits it has and the role that it plays in a long-term care facility. Again, we do invite folks to read and go through the full summary document which highlights each of the studies, and we'll have a moment at the end of this section for people to chime in and add any additional points they think are critical for this group to consider on that front. Before we get to that, we are going to look at what happened when the visitation was restricted during COVID-19. And we'll begin with a brief overview of specifically how this visitation is restricted in the state of California. If you go to the next slide.

12:58:40

[SLIDE 24] So we want [inaudable], and by first establishing how long-term care facility visitation policies are set in California. And I think the key piece, the key piece to highlight on this slide is that for any individual long-term care facility there are a number of different factors that will determine that long-term care facility's visitation policy. You can kind of see the cascade here of regulations, guidances, and public health orders from federal to state to county, down to the facility. We'll begin at the top by noting that the centers for Medicare & Medicaid services as well as Centers for Disease Control will establish national rules and regulations related to long-term care facility visitation and infection control measures. At the state level, the

California Department of Health and the California Department of Services, Social Services will build on those federal guidances. And as the licensing agencies for the different facilities we're looking at in this workgroup, we'll establish statewide visitation guidance for the entities that they regulate. And another level down on each county also has a county public health department that will establish public health orders and roles that are specific to that county. And then long-term care facilities will establish their specific visitations, policies and practices in accordance with regulations and guidances from all of the entities involved. So, what we're really doing in this slide is acknowledging that there are a number of different layers involved in long-term care facility access policy settings. And we are gonna focus in on this next slide specifically on what happened at the state level, which is to say, the California Department of Public Health and the California Department of Social Services during the pandemic. But will acknowledge that there would have been variation between counties and long-term care facilities kind of based on what you see on this slide here. Next slide.

[SLIDE 25] So, this slide pulls up at a very high level and walk through the progression of long-term care visitation policies during COVID-19 in the state of California. Now, I imagine most folks that have joined us today will know that there were a number of different, number of different steps in the process, and a lot of different guidances offered at the state level around long-term care facility visitation. What we've done here is applied some of the major milestones around how long-term care facility visitations policy evolved, as the pandemic evolved from March of 2020, to as recent as January of 2023. So, we'll start with March of 2020, and we'll note that California, as I imagine everyone here knows, issued a statewide shelter in place order in March of 2020. That same month CDPH authorized long-term care facilities to update visitations policies to implement CMS guidance that quote, that directed them to quote, "restrict visitation for all visitors, and non-essential healthcare personnel except for certain compassionate care situations such as end of life situations." In June of 2020, following a CMS reopening guidance, CDPH notified long-term care facilities that they could reopen to visitation if there were no new COVID cases among staff and residents over the past 14 days, and COVID incidents in the community was decreasing. So that represented a major point in time, and a major development in the development of long-term care, facility visitation policies in the pandemic in California. I will note there were a number of additional guidances issued over time, but the next one that we'll highlight for the purpose of the workgroup today is guidance issued in August of 2021. And this issued new guidance permitting indoor

visitation subject to specific COVID-19, safety protocols, and those protocols included vaccination and testing requirements. So, this guidance really opened up visitation more than it had been in March, of, in June of 2020, for individuals who are vaccinated, or who had, and or who had been tested within a certain window. We'll sort of fast forward in the progression to the most recent, I believe guidance, issued by CDPH, which was issued in January of this year, so just a couple weeks ago, and it issued new guidance, allowing indoor visitation without vaccination or testing requirements, but that did maintain certain safety protocols, such as self-screening for symptom and exposure.

13:03:48

[SLIDE 26] And I will acknowledge, before I keep going here, a comment in the chat that also noted that as we think about the levels of long-term care facility visitation, there are also city public health departments to consider, so, thank you for that addition. At that note, that is also a layer of long-term care facility visitation policy settings to consider. So, this I think this is our last slide in this section. And this slide really looks at now that we've established that visitation was restricted during COVID-19, what was the impact of that restriction? So, this looks at peer reviewed research related to the impact of restricted visitation and social distancing measures in COVID-19. And I think what we would call out at a high level is that you know, the research on this is still early, but there are 3 key findings that we would highlight and would refer people to the document on our website if you would like to read the additional detail around all of the studies made. But there are 3 key findings that I will highlight. So, the first is a 2022 study in *Scientific Report*, in which University of Rochester researchers did find a link between states with stronger social distancing measures, and that included, that was not limited to restricted long-term care facility visitations and lower weekly rates of new confirmed COVID-19 cases and related deaths among long-term care facility residents and staff. In a 2021 study of the *Journal of The American Medical Directors' Association*, Brown researchers found that 29% of long-term care facility residents in a 2020 national Medicare survey reported feeling lonelier during the pandemic than in the weeks prior to the pandemic. And this last piece is a study published in the *Journal of The American Medical Directors Association*, again, and this is Mathematica researchers who found some adverse effects associated with restricting long-term care facility access in spring of 2020, including a significant increase in unplanned and substantial weight loss that was sustained even for residents who did not get COVID-19 and after visitation restrictions we implemented. If you go to the next slide, please.

13:06:28

[SLIDE 27] All right, so we will now open up for some conversation here, and what we'd love to hear from folks is, you know, what are the key implications of these research findings for long-term care facility visitation, what are the additional benefits and roles of long-term care, facility, visitation, and what are the known impacts of visitation restrictions? I am seeing a couple questions in the chat about access and visitation in 2020, and just noting that there were different types of I'm just going to read them. There's one question, are we sure that there was access in 2020? Are we talking about window visits or compassionate end-of-life situations there? So, I think, what I'll respond to at a high level on that one is, what we walk through today is the state level guidance that was issued by CDPH. But as we noted, there were a lot of different layers that were impacting what happened around visitation in specific facilities and counties. And so, I think, to the question about whether there was access, and I see a second comment about remembering zero access. I think that speaks to a couple, a couple pieces, and I'll invite folks to weigh in and chime in on this one as well. It speaks to the different layers at which policy was that, and may also speak to what was happening in the community. With COVID rates, because I think you'll recall the slide indicated visitation was allowed in very specific situations but if those situations weren't present in the community, visitation potentially have not been permitted, but I will invite folks to raise their hand and provide verbal comment, and anyone that wants to weigh in on that piece, I welcome that. I can see there are hands raised, but for some reason I can't see who they are. Oh! Here we go! We have Mark, who's raised his hand. Mark, please take yourself off mute.

13:08:45

MARK BECKLEY: Visitation was allowed during 2020, my recollection, if we have anybody from CDPH or DSS on the workgroup who wants to speak more to this. My recollection was, there were allowances for outdoor visits, and I can't recall if there is allowances for indoor visits, but I do remember in the fall of 2020 is when some level of visitation started happening.

13:09:23

JULIETTE MULLIN: Thank you Mark. And then I see Melody Taylor Stark, with her hand raised.

MELODY TAYLOR STARK: I was just trying get off of mute.

JULIETTE MULLIN: No problem.

MELODY TAYLOR STARK: Hi! I'm just wanting to follow up, and I think part of what was happening is some of the visitation might have been allowed on paper, but it wasn't happening. Compassionate care visits were not happening, window visits were not happening. I belong to several Facebook groups, and we were hearing from people in those groups that you know, even when they were bringing the documentation in from the state, or showing it to staff, or calling the administrators, and so forth, they were being told well, corporate won't allow us, or no DPH, you know, even if, even if they had right down to the detail, the county or the city information, the visits were still being denied, and even compassionate care visits, which I experienced myself were being denied. So I think while it's being reported that they were allowed, on paper they really weren't happening in in real life. So, I think that's where some of the questions, and then notations are coming from, because we were, you know, constantly hearing and experiencing ourselves during that time that we knew that we were allowed access, but we weren't being given access, so, thank you.

13:10:55

JULIETTE MULLIN: Thank you, melody we appreciate that comment, and definitely understand that this statewide guidance, there were several layers below it that that would have impacted what visitation looked like in facilities at that time. So, that's very helpful thank you. And I'm also I'll just note there's also a comment in the chat that not only with facilities have set their own visitation policy, but those visitation policies might also have been impacted by staffing levels. I will go to the next in line, Jayleen Richards from Solano, Public Health.

13:11:32

JAYLEEN RICHARDS: Hi Jayleen Richards with Solano Public Health, and I'm also representing the County Health Executives Association of California, and thank you for having these discussions. Just from the public health perspective, just want to remind folks that public health and local health jurisdictions, focus on community health. And during this last public health emergency we were really focusing on mitigating negative outcomes for vulnerable populations. We understand and we appreciate there is an important mental health component to allowing visitors in a long-term care facility, and restricting visits to high-risk people in long-term care facilities isn't done lightly, but this last public health emergency was definitely a new disease. It was an unknown disease, and people needed time to figure out

what was the best strategy to protect the most vulnerable populations, and one of those populations were folks who were in long-term care facilities. People in long-term facilities are in that age group that was at highest risk for COVID-19 adverse outcomes as well as death. And we saw a lot of that in this last emergency, needing time to figure out how to respond. In Solano County we worked closely with our long-term care facilities on how to have safe visits with their family members. We train staff and visitors on how to put on personal protective equipment as well as take it off. We helped long-term care facilities go through guidance and orders, and how to implement that at the local level. So, a lot of those things helped to get us to a place where visitors could be in the facilities. I just wanted to provide that feedback thank you.

13:14:12

JULIETTE MULLIN: Thank you I really appreciate you saying that, lifting that up, and I think one note, I'll maybe make before we go to the next comment. One part of what Mark did at the outside of this meeting is sort of frame up work, and note that this is about how we wanna, how we wanna think about this moving forward. It's not necessarily about, you know, COVID-19, and so appreciate definitely your comments Jayleen, that's helpful context an important note around the balanced concept we'll talk about later. And we'll kind of encourage folks to think about this globally, not just in the context of COVID-19, as we start to talk about recommendations as well. Thank you. next in our line we have Anissa Davis.

13:15:02

ANISSA DAVIS: Hi! Thank you for taking my question and my comment. I wanted to just echo what my Solano, I believe a County of Solano colleague said regarding the balance, and the pressures that public health was facing. And, I wanted to just clarify, I believe it was Melody's comment, who was saying that even when they had the paperwork from the local health jurisdiction saying, or the state saying that this was allowed, that it was the facility that was having, you know, restrictions. So, I don't think it was just a layering of restrictions at different levels. I think it's actually, you know, wanna highlight like, implementation of the allowances at the facility level probably played a role as well. Whether it was because of staffing or other, you know, issues that were going on at the facility level. So, I just wanted to kind of put that out there.

And then I just had a question, is there, so I just don't understand how, if a state law is passed regarding long-term care facility visitation, I don't understand how that interacts with federal regulations at the CMS level. So, if that could be addressed at some point thank you.

13:16:31

JULIETTE MULLIN: Thank you, we appreciate that comment. I think I will abstain from commenting on the federal question, unless, Mark, you'd like to make a comment there before we move on.

13:16:41

MARK BECKLEY: Yeah, I mean, what I can say about the federal level is, you know, federal laws, regulations, will always trump state, right. So, you know, if we enact a law and say the federal government enacts a more stringent standard, we would be subject to, the more stringent standard set by the feds. But there, if the feds set a lesser standard, and you know the state, you know, decides to impose something more restrictive, I think the state can always do that. But that's my understanding of the way that the federal state relationship operates in general.

13:17:22

JULIETTE MULLIN: Thank you. Next in line we have Blanca Castro.

13:17:27

BLANCA CASTRO: Yeah good afternoon Blanca Castro, State Long-Term Care Ombudsman. I just wanted to, for the conversation add that, what with the data, with the Long-Term Care Ombudsman Program has shown, and I will share with this group and with the public, is that I think there was, because of the different layers of direction, there was confusion, and, with providers, and so, I think there's gotta be a balance of even just pointing out that yes, maybe in on paper there was a law or a guidance from CDPH that came down, and maybe the public health, local public health was consistent with the state, but because there was so much information happening, and this is one of the lessons biggest lessons learned is just having that clarity of, as Mark described, how do we simplify and streamline that information to the public? Because I do think that there was a, you know, some providers just rather wanted to, and you know, in some cases wasn't necessarily that they didn't have enough staff, but they wanted to err on the side of, you know more, more protections with the residents. And so, there is just so much information coming out and at providers, that I think that

also, and we did see that in our role. Yes, there were some places where, you know, there was interference with Ombudsman, and so that really is why we were, we elevated the conversation with the legislature, and the governor, you know, signed legislation to reinforce that Ombudsman had a specific role. So, really happy to see that we're having this conversation, and just trying to uncover from all of this, the information we have. But I think what you'll see with the data is in 2020 the kind of complaints that, that started to really come out were not until this recent year, in 2021, where people were then complaining, all right I'm tired of the restrictions, and these policies, and those we started to see that, as you know, rising in terms of importance for residents.

13:20:12

JULIETTE MULLIN: Thank you Blanca. Right, I think that covers all of our workgroup members who had their hands raised. I do see there are some hands, oh, I see one more, but I'll say one thing first, and then I'll take a last comment, as you see, some hand raise, some hands raised for members of the public. We are gonna move on to the next topic for a moment, but we will come back and provide an opportunity for public comments shortly, and you are, of course, welcome and invited to drop comments throughout in the Q & A section. I will invite Anna Acton comment.

13:20:53

ANNA ACTON: Thank you. Good afternoon, so just really appreciate our public health friends weighing in, and just kind of bringing me anyways back to where we were at that point, right, in 2020, when we had no idea what we were faced with, and then seeing the tremendous impact of COVID-19 on individuals that were in these facilities. Just by far, being disproportionately impacted. And how do you balance that with your, when you're dealing with the pandemic, that you don't know right. We were learning we're building the plan as we're flying it. We didn't know what, and we were learning as we go, and I would guess that a future pandemic may be very similar, right. And how can we take the lessons, quote unquote, learn from this incident and make them actionable pieces that we can apply to the next disaster, and whatever form it comes based on the scope of this workgroup. And it just reminded me of my dear friend whose father passed away in an institutional setting, and with the restrictions on visiting him, being the only one that could visit. He had a disability himself, went home to take care of himself, and his father passed away, while other family members were in the waiting room. Or the woman who got out of the facility to go onto hospice so she could die with her family at home. Or the

individual who had no communication with the outside after having a stroke, and being in an institution when the pandemic hit, and not being able to get even just basic telecommunication capabilities in place without a lot of effort to communicate with outside. And so, these are the real people, right. And so, to your questions on key implications, you know, I think someone put it in the chat, I think it was a Tony who, you know I think, one of the ah ha moments for me on the research was how much we rely on the informal caregivers for individuals in those institutional settings. So, I think that's a key piece for us in this workgroup, right. How do we put into place policies, procedures, focus to ensure those informal support somehow become a priority, rights, with access, and for overall well-being. The benefits and roles of the visitations are obviously for the individuals in it, but I will tell you are equally important for those informal caregivers as family members. There was a lot of mental health, and with not being able to see, and access, and be with loved ones in their final moments, or just over extended period of time. So, I just wanted to add that piece in before we went to the public comment thank you.

13:23:47

JULIETTE MULLIN: Thank you, appreciate that. And I think it's a very nice transition about how do we take the research, the experience, and translate that into how we do this in a future scenario. What we'd love to do now, if we could go to the next slide.

13:24:07

[SLIDE 28 and 29] I wanna, acknowledge before we get into this section, first of all, thank you for all the great comments, the highlighting of the importance of balancing the public health needs, and the needs of residents inside their facilities. The importance of informal caregiving, as you noted Anna, and I saw a lot of comments in the chat around what it looked like in practice perhaps, and some challenges around enforcement, some challenges around it looking different for different facilities. So, all of this are very helpful inputs and I think we can all see how this might help build toward the recommendations we would make for policies moving forward around, how we might approach long-term care facility visitation in a future situation like the COVID-19 pandemic. We just spend some time on the peer reviewed research, we spent some time hearing about the policies. What we'd like to do before we start to talk about policy options and solution, what we'd like to do is really spend some focus time in hearing the lived experience. It is a critical element of this workgroup's charge, is to really understand how long-term care facility visitation impacts the

residents, the loved ones of residents, and the staff of long-term care facilities. And so what we'd like to do now is invite first the residents loved ones and staff who are on our workgroup to provide their story and share their story of visitation in long-term care facilities. That can be the experience that they have before COVID, if that's what they're, their experience was, or if it could be an experience of what it would like for them during COVID. And so, we'll take the time now to spotlight the experience. And I'm gonna, we're gonna begin I think, and I'm gonna turn to our CDA comms team here, we're going to begin with a recorded story provided by one of our workgroup members who has not able to be here today. And, I believe that it's from Mercedes Vega. We'll share the video.

13:26:40

[VIDEO – PICTURE OF FAMILY]

MERCEDES VEGA: My name is Mercedes, and today I am gonna ask that you not just hear my voice, but really listen to the voice that I am representing today, which is the voice of my brother Manuel Vega, who is a resident in a skill nursing facility here in California. He's someone who during the time he was able to, helped his neighbors and his community, and he was very proud of the work that he did, helping, you know, construct, a much very needed infrastructure here in LA. You know, I believe my brother Manny, and residents like him deserve to be safe at all times. He deserves to have his family with him during difficult moments. My brother cannot talk, move much, or care for himself. He relies on my mother, and my family, and I to interpret his needs and make the best health care decisions for him. Unfortunately, we cannot do that when we're not physically there for a long period of time. My brother was a victim of a crime. Someone stole his life and ours in instant, and I won't go into details, but unfortunately, these are the conditions in some of our communities here. It's like we go from one public health crisis to another one. And it's never just one life, this changed us all completely. The only thing that brought us comfort in all of this was being able to be part of my brother's care, and I think that's how many of us caregivers feel. Going to visit my brother has been the highlight of my days. We watch movies together, we listen to music, I help him with range motion therapy, etc. We as caregivers and family members, we give up parts of our lives to care for our loved ones. We make big sacrifices because family is important to us. That's what it takes, and we cherish them. The way most of us learn about the health, the long-term care system, it's a bit daunting, though. The lack of equality options, knowing, you know, we can no longer have our family members with us when we, like we did before, and the ups and downs of their health,

and the challenges of under staffing are hard to bear for all of us, you know. I changed, I changed my entire life, I gave up a lot to be next to my brother, and I wouldn't change it, change that for anything. But it just seems like it didn't matter in a way for a while, because I was still prohibited from seeing him for almost 2 years. You know, I decided to stay here, and instead pursued my Master, my Master's in Public Health, here in California, because this whole experience taught me so much that I longed to be part of the solution. And I'm hoping that sharing this with you will be part of that. As graduates, we took an oath to protect the most vulnerable. And I think protecting residents in long-term care means allowing their loved ones to be physically there with them, even during closures, because we're essential to their lives. The consequences of closures are part of the reason why the health of our loved ones decline. We now live with these painful realities, that we can only hope will get better. I urge you all, here, who are attending, to consider the countless data, prior to, and during the pandemic that's been, that's demonstrating the crisis and these facilities that without a doubt were exacerbated, by isolation, and by not allowing family members to be there in person to protect them. Today, I'm really hoping that we bring back the essence of this bill, and what it represents, because it's still relevant today. You know, we have a lot of guidance and orders that are allowing, and, for visitations, but unfortunately, there's still countless facilities that are prohibiting and restricting visitation times, to this day. You know, a lot of us who have family members in long-term care we've been following and trying to keep up with the DPH, local, state, and federal guidance, we're very adherents, we're very pro public health, of course, and we appreciate the work that's gone into helping respond to these, you know, to this crisis. And I just wanna reiterate that we come from informed places, but most importantly, here today is our testimony and our firsthand experience. This should serve as feedback to resolve this policy issue and learn from the past, and just, and do better. Now! I would love to see California demonstrate that we're not in ageist or ableist state or society, and that we can model policy, that the benefits, the aging population and disabling population, because our loved ones matter too. Thank you very much, that is all that I have for today, and again, I appreciate everyone's who is here making the efforts to come to a consensus that will be benefit and improve the outcomes for our loved ones. Thank you.

13:34:45

JULIETTE MULLIN: Thank you, Mercedes, for sharing that story. I know you weren't able to be with us today, but we very much appreciate you

preparing the video and having the opportunity for us to watch it today. We have a few other members of our workgroup who are residents of or loved ones, of residents of long-term care facility residents who have also prepared some remarks around their experience in long-term care. I see mainly that you just came on video. So, I'm wondering if I can have. If I can ask you to go next, is that okay?

13:35:24

MAITELY WEISMANN: Yeah, sure, sorry my dogs are barking in the background they're loud.

JULIETTE MULLIN: Not a problem.

MAITELY WEISMANN: Sorry, okay. My name is Maitely Weismann. I'm a family caregiver and co-founder of Essential Caregivers Coalition. Since, as far back as I can remember, I've been a caregiver for my mother. Starting in her twenties, my mom navigated increasing challenges related to a car accident resulting in a traumatic brain injury, quadriplegia, and aphasia. She now requires support in nearly all activities of daily living, which I would typically provide to a substantial degree. That support includes helping her to eat, drink, bathe, dress, organize her belongings, manage bathroom needs, mobility, transfers, verbal communication, and other regular tasks. However, when pandemic policies imposed visitor restrictions in her facility, they failed to recognize my family caregiving role as essential. My mother moved to California in early 2020, and have been residing in large and small RCMC, memory care homes ever since. Before she moved, I decorated her new room to make it feel cozy and soft, just like home, from the moment she entered, right down to the velvet hangers in your closet, and the lavender aroma from her humidifier. I ensured her new home would accommodate her cat, Hector, too. There were activities and new friends to make, the caregiver seemed attentive, and unrushed. I was there nearly every day. At first, she loved it, and then the lockdown came. Initially I thought it would be a short time before we figured out a safe way to enter. I went online looking for NIOSH proof PPE to be helpful. I also found an adjustable height stand for an iPad and some goofy theatrical costumes to make the most of our video visits. We can make them fun for a while, you know, by playing dress up and matching, we'd be wearing matching boas and heart-shaped glasses, for example. But despite that, as daily video visits progressed, I witnessed my mom's demeanor and quality of life rapidly deteriorate. She became agitated withdrawn, depressed, and ultimately unresponsive. Overwhelmed staff didn't seem to have the time to recognize these changes, nor bruises, rashes, visibly poor hygiene,

lethargy, signs of dehydration, and delirium. My questions about those changes led to hospital visits, which soon increased for unusually high or low blood pressure, severe weight loss, dehydration, contusions, a broken clavicle, aspiration, pneumonia, and recurrent CDIFF. All in the first year of isolation measures. I watched my mom's struggle to survive due to family caregivers being miscategorized as mere visitors. This is not to say I was standing idly by; I was unrelenting in my advocacy. After months of persuasive effort and supportive actions, I thought surely management would understand the importance of allowing me in, and by now they should know me well enough to trust that I take infection control seriously. My only concern was to bring my mom back to baseline. It really didn't matter if I had to wear 10 layers of PPE to do it, I just knew she needed me, and I would be there for her anyway I could. As a designated support person for my mother with ADA accommodations I could always stay to support her in hospital. This did not change during even the worst spikes of the pandemic. Sure, nurses were uneasy with my presence at first, but they quickly grew to know and appreciate the value of my support. In fact, thanks to some of those nurses, I learned to properly don and doff extensive PPE in a hospital's COVID unit before they had enough. Well, they weren't fast enough with PCR test turnarounds in the beginning of the pandemic, so they couldn't rule out COVID yet. She had aspiration pneumonia, but we were in the COVID unit. All told, I stayed with my mom in the hospital on at least half a dozen different occasions, each time for at least several days. Yet, for the first 6 months of the lockdown I could not set foot in her long-term care home. That is, until a respected news outlet wanted to film me, and mom during one of our first outdoor visits, on premises. After the journalist contacted the care home for permission, I was miraculously granted access to her in the privacy of her own room, 2 full days a week. Soon later that turned into daily visits, around the clock. As far as I could see, I was the only family member inside. 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-one NIOSH approved 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. Chords 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, they were slowly fading into this eerie silence. During all that time my mom nor I, neither of us, contracted COVID, but she ultimately lost what fluency she had left in her verbal communication. She experienced serious physical and cognitive health declines during her prolonged absence of family

support. She's still here today, but her voice and her words, disregarded for so long, are now lost forever. And, I'm an example of what could have gone right. If we were just working together. Thank you.

13:42:43

JULIETTE MULLIN: Maitely, thank you so much for sharing those comments, and for sharing your experience with the workgroup today. I've seen a few people in in the chat, and in the Q & A comment that this work has to be driven by residents of long-term care facilities and the loved ones of residents and long-term care facilities, and so we deeply appreciate you sharing the story as this workgroup considers this recommendations for the future. Thank you.

I understand Nancy and Melody have both, are both also prepared to share their stories today. I'm happy to call on someone, or someone, if you would like to volunteer to go next. Melody I see you raising your hand.

13:43:36

MELODY TAYLOR STARK: Happy to. Thank you so much. I'm Melody Taylor Stark. I'm a long-term care advocate, chosen family member, and my husband, who passed, was also in a nursing home for close to 5 years. It's a little more emotional because it's the anniversary of lockdown, and remembering, remembering the day that I saw my husband in the morning, and hugged him and left for work and, was called later in the day tell me that I couldn't come back to see him that night. During lockdown, unlike greater society for the most part, the options for virtual visits, and phone visits, and creative safe ways for in-person visits. I remember working here at home and seeing some families out in front of my house, where like across the street from each other, but they were playing a game, so there was some sense of community and connectedness. And that didn't happen, for people in long-term care, and for many of their loved ones outside. Long-term care negatively affected, my loved ones, as well as me. Prior to lockdown, I saw them every day. Staff knew me, staff appreciated the support to my loved ones, and also to the staff nurses, housekeeping, whoever it was, I was part of that community. And with that group of my loved ones, my friend Pat, who's a chosen sister, she has no biofamily involvement. I saw her like I did the others, every single day, we were close. I helped to support her, I helped to teach her to advocate, to learn to advocate for herself. During co COVID vid we lost contact with each other,. Her rooms kept changing, and when I would call no one seemed to know which room she was in or what the phone number was. She also had lost

my phone number, it was written down somewhere, and she was asking staff for it, which I found out after. No one gave it to her. I even called the facility, and said, hey, could you give my phone number to Pat? And she never received it. So, we had all that time of disconnect. All of a sudden I lost a friend; she lost a friend. After gaining access back to the facility, she told me how she deals with severe depression, and that many times during lockdown the isolation was so unbearable. She didn't feel like she wanted to live, and she didn't feel like she was being taken care of, and she felt that no one would help her contact me. Fast forward to today we visit in person, by phone, regularly, I bring in some meals to share, sometimes she said that some of the best times that she's had. She's bedridden, which creates other challenges. And in addition to all of that I'm also back there to help her advocate. Recently her pain medications ran out, and she was asking where they were, and she was being told, we're working on it. And she was without them for 4 days. And I don't know how much longer that would have gone on, but I was able to contact the DON and say, you know, somebody's got to do something, somebody needs to help out, and within 12 hours she had her meds back. And so, like Maitely was saying, we do a lot more than just, you know, bringing flowers and candies and chocolate there's some hands, some hands on, some real support that we're giving to these people that we love.

Joan is another chosen sister, and Joan has no known biofamily. She's deaf, which presented even further challenges during lockdown with communicating with her. In the facility I talked to the administrator many times, and gave some ideas on how to facilitate some communication by video chat with me and Joan, which we did one time. I hold up written cards, and she would write back on a whiteboard, and, but at least she got to see me, and she was very happy, but that was only once during lockdown, and it was for 15 minutes, not 16, not 15 min, 15 seconds the camera was shut off at 15 minutes. After being able to resume in person visits with her, she told me how lonely and helpless she felt during that time, and how awful it was to be locked up, and she was just in her room and feeling that nobody cared for her. Fast forward to today we visit regularly and bring some dinners to share with her as well. Good time. For advocacy, about 6 weeks ago I went over about 5 30 at night, and as it was walking towards her room, I saw a CNA come out of her room, CNA was picking up meal trays just like normal 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 at that was happening to somebody that I love or anybody, and it would have never been reported to DPH. It has been. So, there's this bigger picture of caring for each other, and the connectedness that needs to take place. We're not dealing with widgets, we're dealing with real people. Friendships are also formed in long-term care, and the residents not only lost communication with people outside of the nursing home, they lost communication with each other. They were not even, staff were told, they were not even allowed to tell for example, my friends Pat and Joe, how's Joan doing, how's Pat doing? We're, we can't tell you. Pat and Joan were also friends with my husband Bill, and no one even told them that he had passed until after I was, be, able to be back into the building, which was a year after lockdown.

And that brings me to my husband, Bill. Bill was an upbeat, optimistic person. He had post-polio syndrome, and a philosophy of play the cards that you're dealt. I come by the nursing home for my daily good morning, and a hug, and a kiss for my husband. I come back to work, I come back after work, we'd spend evenings together. I was also with him on weekends. My philosophy is, where I am right now, is "house", and with Bill was "home". Friday nights we had a date night where I'd pick up take out for dinner, and staff even knew, one of the, one of the tables in the activities room that was ours, and they put a tablecloth and flowers on it so that we could have our date night. Well, the day of lockdown was a Friday, and I ordered take out, and a couple of hours later I had to call the restaurant and cancel. I figure out what I was going to do, thinking it was only going to be a few weeks. Of course, we all know a few weeks isn't what happened with COVID, but I'm especially glad that just hours before that lockdown I stopped by the nursing home and hugged and kissed my husband. After lockdown Bill had no contact with me except for a bad landline phone. Something was wrong with his cell phone, and there was no one to help him with it, leaving no option for a phone chat. And I saw somebody in chat talk about technology that's needed in nursing homes, and here's an example. I tried all possible means to have more contact with him, but everything, including window visits, and this facility has ideal settings for winter visits, we're denied. The administrator said they did not have approval from corporate, and they reported they had no approval from Department of Public Health to even have window visits. On our phone calls I could tell he was becoming increasingly depressed, he'd say, this is nowhere to live, and he would cry. He had a drastic decline in both physical and mental health. Reports of this to the facility garnered no response. They placed the blame on LA DPH for blocking in-person family support. When window visits were finally allowed at the end of August, which was 5

months after lockdown, the window visits were limited to one time per month, for 15 minutes, that's it. And that 15 minutes again was 15, not 15 and 15 seconds, they were right there, pulling him out of the area when that, when that 15 minutes was up. I noticed during one of the visits that he had blood under his nails, that wouldn't have happened should I have been able to get in a visit. He was, he was scratching at some lesions that had appeared, and I had to put in a complaint to DPH about that, to get it addressed. I reported it to the administrator, I reported it to the charge nurses, I reported it to the DON, and it was 6 weeks, and took a report to DPH to get it addressed. Several weeks before his death, Bill was interviewed by phone, by a reporter from the LA Daily News, and he admitted, this corona virus is nothing to fool around with. But he said that didn't make it, make briefly seeing me once a month through a window, or the social isolation any easier. If, he said, I'm in essence in a cell room. I've got TV and the newspapers, but that's it. I can't be happy. At the end of October Bill was diagnosed with pneumonia. It was discovered by me during a phone call on that bad landline. And I wondered, how did I notice that when staff, working with him daily, didn't notice any of the symptoms. And it may be even more concerned at what kind of care he was receiving. He was hospitalized the beginning of November and re-mitted to the nursing home on November the eleventh. Calls from the nurses at the end of the day for status updates, one nurse in particular, who's an excellent geriatric nurse, who recognized the signs, was indicating he was rapidly declining. She was reviewing his pulsed with me, so that when the time came, I wouldn't be in a crisis situation, and forget what was written in there. So, at that point the first phone call that indicated that 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 or 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 shouldn't have just been that day should have happened a long time ago. So I came in and through had the full PPE the gown, mask, shield, hand, sanitizer, everything, and I wouldn't do it any other way, because I got to see my husband. Staying 6 feet away, he was happy to see me in person. Bill, smiled, and he blew kisses, and I heard happiness in his voice for the first time in a long time.

Again those 15 minutes, well started out with the person facilitating the visits, standing at his doorway watching us have the visit. And I told her we could have a private visit, and I would make sure to be safe, which they knew. Anyway, 15 minutes was up, came back, hauled me out of the room, and as I was leaving, I noticed staff coming in to do some up close and personal support for him. Wearing the exact same PPE I was wearing, yet his wife of 20 years had to stay 6 feet away. I purposely didn't go near him and hug him because I was hoping I'd get to come back next day, and I knew if I did, that they wouldn't allow me in. In retrospect, I would have done that. That night Bill was readmitted to the hospital as his systems for shutting down. I got a call a couple of days later that he had passed. So, I'm glad I hugged him that day, when I found out lockdown was happening, but I did get to hug him one last time, and it was when I carried his ashes from the car to the church for his funeral. The protocols thought to protect Bill failed Bill, and failed many others. Together with this workgroup I know we can do better, and I trust we will be able to ensure moving forward other residents don't lose their life sustaining right to meaningful human connection when the next lockdown occurs. And I will close with, last night I was able to attend a memorial vigil for long-term care, lockdown anniversary, and there was a poem, was read, and I was allowed to share it, and I will put that in the chat and I encourage you, to read it, it, was from a resident in long-term care facility. Thank you. I appreciate that this group is coming together, and I look forward to the good things that it will do for people in long-term care. Thank you.

13:58:07

JULIETTE MULLIN: Melody, thank you for sharing that very powerful and personal story about your experience with your loved ones and long-term care during COVID-19 pandemic. I know we have one more member of our workgroup that prepared comments today. I'm going to turn it to Nancy Stevens. If you're available to speak.

13:58:37

NANCY STEVENS: Hi. I'm not sure how much time we have left. It's not safe for me to talk right now. It's something that happens often, especially when I'm in meetings or have a visitor. They just open my door and are chatting right in my doorway.

JULIETTE MULLIN: Okay Nancy.

NANCY STEVENS: That's so I, yeah, it's not really safe for me to disclose a whole lot. I can just say that a lot of abuse and neglect happened and continues to happen. A lot of people are being medicated when visiting our, the restrictions are, I'm sorry I can't talk. I'm so sorry.

13:59:31

JULIETTE MULLIN: That's all right, Nancy we can clearly understand no, no, we completely understand thank you. And perhaps we can see if there's an opportunity at another time.

NANCY STEVENS: Okay. Yeah. Thanks.

JULIETTE MULLIN: At another time, and I will just note Nancy is a resident of a long-term care facility, and thank you for your willingness to provide your story, and we'll see if there's another opportunity.

I will take a moment, I know we have one additional workgroup member who, who's not able to be here today, who provided some written remarks to Blanca. So, Blanca I would love it if you could share their experience on their behalf.

14:00:12

BLANCA CASTRO: Yes, absolutely thank you, Juliette. So this, this testimony comes from the Long-term Care Ombudsman in San Luis Obispo, Karen Jones. And she shared this because of a resident, a couple that she worked with. We received a call in June 2019, from the male husband of a female resident. They had been married for more than 50 years. The residential had experienced a severe stroke that left her paralyzed in both arms, and unable to speak well. She had dementia, and required full assistance with eating. Prior to COVID, her husband came to the facility for 3 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 a 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 significant amount of weight. Her husband had almost no risk of contracting COVID. He rarely visited stores and worn an N95 mask whenever he was around other people. He lived alone and did not socialize with people outside of the nursing home. The facility staff were at much greater risk of bringing COVID into the facility, and yet her husband was not allowed to help ensure his wife was able to eat with dignity. Her husband was very willing to wear any level of

PPE in order to help feed his wife. Eventually we were able to work with CDPH and facility staff to ensure that her husband could enter the facility to feed his wife. But it was a struggle. My greatest frustration as a Long-Term Care Ombudsman during the COVID restrictions is that PPE works for everyone, not just paid staff. The virus cannot tell who gets a paycheck and who is an unpaid visitor. Restrictions should be based on science and not position. Thank you for convening this workgroup, and I look forward to participating. Best wishes, Karen Jones, San Luis Obispo, Long-Term Care Ombudsman Program Manager and Executive Director. Thank you.

14:03:01

JULIETTE MULLIN: Thank you, Blanca, for sharing that story on behalf of Karen Jones. I wanna just take a moment to pause and thank deeply and sincerely all of the loved ones of residents and residents on our workgroup. For first of all, being part of this workgroup and developing solutions and working with this workgroup over the coming weeks. But specifically for sharing your stories today, you're very personal and powerful stories. You know that this workgroup, as you can see in the chat, deeply appreciates this.

14:03:43 I know we are running a little bit behind, but I do want to take a moment and invite anyone who's joined us as members of the public today, who are residents of, or loved ones of residents of a long-term care facility. If you would like to provide a brief story about your experience in long-term care. We'll just take a moment right now to welcome that and get that opportunity to share your story as well. And I see Teresa Palmer, you have your hand raised. We will.

14:04:21

TERESA PALMER: Yeah can you hear me?

JULIETTE MULLIN: Ask our team. Yeah, perfect we can hear you. Thank you.

14:04:26

TERESA PALMER: I don't know if my video is on, but, I, I'm a mostly a retired nursing home doctor, and my, my mother, had dementia and needed 24-hour care. And in 2017, after attempting to care for her at home for 14 months, we were completely worn out. And we did find what we felt was the best nursing home in the city to put her in, in San Francisco, and she did well there. She was very social, even though she was 99 she was

ambulatory with the walker everyone at the nursing home, knew her. And she, she basically thrived. We manage to get family visits about 3 times a week and take her out for dinner, and she remained the heart and soul of our extended family. Until March thirteenth, when the person that was going to visit her was turned away, and because I have rheumatoid arthritis and I'm immunosuppressed I could not take her home and have caregivers running in and out of my house, and I could not even pretend to be the one to visit her, although other family members were willing. We lived through a year of this I managed to fast talk the nursing home into 3 times a week, zoom visits, where she could visit the extended family, and she was bright enough to benefit from that. The only reason I got those visits is because someone had written it into the care plan, and when they refused it, they were ordered by the Ombudsman to follow the care plan. Most people got once a week or once every 2 weeks visits which we're cancelled whenever the nursing home felt like it. She began to decline and lose weight by early 2021 I began to ask for more visits, but wasn't able to get them, and finally, after a significant weight loss and her taking to bed, I insisted. I got in after a couple of days of visiting. I realized it wasn't psychological was physical I took her to the emergency room She was, dehydrated and malnourished, and had a big pancreatic tumor, and I got her hospitalized, and then took her home for hospice care. I thought she was imminently terminal, but she actually lived for 10 weeks because the big problem was, she was dehydrated and malnourished because no one had noticed that she wasn't eating, or no one thought it was worth it to put that effort into someone as uppy and frail as she was, and this was in a very good nursing home, where the nurses, whereas conscientious as one could expect. But there just were not enough of them. and because I have a professional degree, and I have savings, I was able to supplement the hospice visit with the hospice, with help at home, and she did live for 10 weeks. During that period, we had to reassure her over and over again that she had a right to be with us, that we had not abandoned her, that we were gonna continue to care for her. It was heartbreaking, and those 10 weeks cost me \$30,000 in the help that I needed because of my physical disabilities, which not everyone can afford. And so, even though we made it through COVID, we missed a whole year of a decent quality of life, and she died having to be reassured that we had not abandoned her. I hope we can learn from our mistakes, prioritize face-to-face visits, prioritize resident designated, essential caregivers to be treated the same as staff, and honor the rights, and, not, honor the rights of a long-term care residence and not discriminate against a whole class of people, and treat them like cockroaches, because they happen to be dependent on long-term care. Thank you.

14:09:20

[SLIDE 30]

JULIETTE MULLIN: Teresa, thank you for your comments and for sharing your story and your experience of long-term care. I'm not seeing any additional hands raised, so I think we'll go ahead and move into the next section. We will take additional public comment at the end of our meeting today. I am seeing some additional notes in the chat as well, invite folks to look at that. Thank you again for the many people who have shared their story today. It's so important for us to have the lived experience in mind and to be building policies that account for the lived experience. With that I am gonna transition us into our third and final section of our meeting today. In this third and final section, we're going to look at an overview of long-term care visitation policies in the US, so this is where we're going to start looking at what are some of the policy options and practices that have been leveraged? By states across the country, to establish visitation guidelines and policies for long-term care facilities in their state. We've taken the time to talk through what is available in the research to understand about long-term care. We have had an opportunity to hear the really impactful stories from our workgroup and members of the public around their experience with it, and now we'll transition into this section. So, we could go to the next slide.

[SLIDE 31]

So I wanna begin this section by reminding us of our core principles that we've established in our kickoff meeting, iterated on after our kickoff meeting, and Mark shared again at the top of our call today. As Mark noted at the top of our call, these principles are going to be important for us as we start to map out what are some of the policy options for the state of California, and as we ultimately, at the workgroup come to recommendations built on learning from the experiences we just discussed. As I will note, and as Mark emphasized at the top of this call, these recommendations are for future public health emergencies broadly defined. So, these are not necessarily policies for COVID-19. They are policies for public health emergencies that could include pandemics. You know, Mark went through the slide of the types of public health emergencies, we might consider. The 4 core principles, that we've looked at, and we, we're grounding this whole section to are balance, parity, regionalism, and equity. To help us understand how we might develop policies focused on balance, parity, regionalism, and equity. We've looked at how over a dozen states have approached these 4 principals. Before I dive into the summary that

we'll present in these slides, and you'll see it, it's quite high level to promote conversation in the meeting today. We have posted summaries of these state laws and links to the bills on the CDA website, or we've even just dropped links to those in the chat for folks, again. As a reminder that document you can read through, read brief summary of each bill and then click through and read the whole bill. And what we'll do today is just provide higher level, summary and themes across the different states. So, we're not gonna dive into what each individual state did, but rather pull up and present what are different approaches the states have used.

We're gonna cover that in these 4 categories. We'll begin with balance. At where we'll really talk about how most of the state laws approach balance by identifying some baseline rights to visitation. And we'll talk about how they do that. And then identifying permissible limits to those rights to protect public health. During a state of emergency, and so that's the concept of balancing the personal mental wellbeing and autonomy of individual residents with the public health need to protect in a in a state of emergency. We'll look at how states have approached parity, and specifically here, we'll look at how some states laws specify that visitors cannot be subject to more stringent safety protocols than those required of staff in the facilities. We'll look at regionalism specifically some laws have provisions that acknowledge localized. That acknowledge localized emergencies, and also that acknowledge variations and resources between different areas. And then we'll finally we'll close by looking at equity and specifically highlight How some states have specified accessibility requirements, and processes to ensure equitable application of rights. We will ground all of this to what other states have done, but we will invite throughout folks to recommend additional solutions that we might consider, but definitely will take moments to pause for conversation, and but we also invite people to comment in the chat throughout next slide, please.

14:15:08

[SLIDE 32] Alright before we look at what all the other states in the country have done, we do want to remind people about some work that's already been done in the state of California around establishing some policies and guidelines for long-term care visitations. specifically representative Nazarian introduced AB 2546, called the Resident Designated Support Persons Act in March of 2022. This law, I'm gonna walk through in a moment what it would do if enacted, but prior to passing legislation on this issue the state legislature tasked this workgroup with developing consensus recommendations on the long-term care facility access and visitation. So, this proposal has not been passed into law, but we wanted to

take a moment to review what that proposal would have entailed, and specifically how it approached the 4 principles that we're looking at in this section. So, the first, the first piece is around balance, and there are 2 core pieces that will highlight for AB 2547. The first is the law would allow residents to designate 2 support persons who can visit them in person at any time during a public health emergency, and it would require long-term care facilities to allow at least one support person, one of those 2 support people, to be present at any given time. Looking at the balance side of it so, looking at the public health protection side of it, it would allow facilities to implement infection control protocols for visitors and limit access within the facility to the space in which the resident lives or receives care. The second core piece it established, or would have established, is a resident's right to leave the facilities for an outing. Oh, that should say without a blanket requirement to quarantine upon return. The law would require residents to follow, quote reasonable infection, control precautions unquote and allow quarantine, but only in specific circumstances, such as if they do not fall, such as in a case where it's known exposure, and a case where they did not follow the same infection control protocols as staff, or if they showed symptoms of a contagious disease related to the public health emergency. On parity, this, this bill specifically noted that the facility may require designated support persons to adhere to infection control protocols, not greater than those require of facility staff. On regionalism, it noted that it would require the facility to provide PPE and testing resources, but only to the extent that they had been made available readily for the facility's use by local or state entities. And on equity, it would include requirements to communicate changes in infection control protocols in accessible formats, and in a resident primary, and preferred, or preferred language. So, this is a deeper dive on what the California bill put forward last year proposed doing in this space and how it approached those 4 principles. We're gonna take a look more broadly at how other states have done this as well. So, let's go to the next slide, and we're gonna pause after each principle for discussion.

14:18:43

[SLIDE 33] So we're gonna begin with balance. And again, I'll just refresh for folks that the balance is really the principle of balancing individual, physical, mental health, and advocacy needs, rights and autonomy with the public health protection. The way that most states have done this, as I noted before, is by establishing baseline visitation rights and then permissible limits in a state of emergency. The approach for permissible limit has varies significantly, so we'll look at some of the ways states have

done that. But let's start by looking at the baseline visitation we go to the next slide.

14:19:21

[SLIDE 34] There are 2 common approaches used across states that establish a baseline right to visitation. Several states have passed laws that allow for an essential caregiver or support person, or a similar type of designation, the language can vary, and this is an individual designated by a resident or their representative, and it allows them to conduct in-person visits during visitation. Some laws specifically note that this person is not required to provide care in order to receive this designation, and the designation is at the decision of the resident, or their representative. Generally, these laws allow residents to designate one or multiple essential caregivers, the number can vary based on the law, and it establishes a level of guaranteed visitation or access for those caregivers, and the level of guaranteed that and can vary by law, and again, all of these laws are listed in the document that we've linked to in the chat, and note when they use the essential caregiver or support person visitation. Several states have established a right to compassionate care visitation regardless of any state of emergency. and just to note at a high level, as defined by CMS guidance, compassionate care visits are visits for individuals within long-term care facilities, whose health had sharply declined, or who are experiencing a significant change in circumstances. So, a number of the laws actually provide specific definitions of compassionate care that build upon that. And many laws established that long-term care facilities must, at a minimum, allow compassionate care visitation, even during a state of emergency.

Seeing a question from Catherine Blakemore in the chat about whether these some states have both provisions. Yes, some states do both, but these are 2 very common approaches some states do one or the other, smaller subset, have done both. If we look at the next slide and we go to the next slide.

14:21:44

[SLIDE 35] So on the other side of the balance piece, as I noted, there are a number of states that outline allowable, but limitations to visitation within a long-term care facility to ensure public health and safety. So what these laws are doing is essentially establishing there's a fundamental right and then these are some permissible limits that can be established on that right in order to protect public health. Some state approaches for this include,

requiring that visitors follow guidelines and safety protocols established by an entity that put forth inspection control protocol, so that may be the commissioner of public health for a state, and maybe CMS it maybe CDC, it varies, based on the state. some states require long-term care facilities to establish reasonable or least restrictive limitations to long-term care, facility visitations. For example, there's a state that indicates that the reason for any restrictions needs to be directly related to the state of emergency, and that that link has to be in place for restrictions. Some states require long-term care facilities to publish updated information about limitations, and the legal evidence-based reasons for limitation. There are approaches where states identify specific elements of limitation that can be visited, such as the number of simultaneous visitors, the hours of visitation, or the locations of visits, and then some states will set a minimum requirement. So just to provide an example, a state might say you have to allow, you can limit the number of hours of visitation in a state of emergency, but you have to allow at least X number of hours. And then finally, some states allow facilities to implement a limited period of visitation lockdown due to an emergency with some laws actually establishing a maximum number of days in the law. and as you'll see if you are currently also scanning the state law document we put in the chat, we sort of highlight for each state law which of these strategies they're implementing and provide some high-level information about how they do that there. Go to the next slide.

[SLIDE 36] So we've taken a moment to talk about the concept of balance. And I'm gonna acknowledge right now that we probably, we may not get through all 4 of our principals today, and that's okay, we can kind of wrap up our principles at the beginning of our next meeting as needed. What we'd like to do here is pause and hear from the workgroup what you consider to be some promising approaches that California could consider for ensuring balance in long-term care visitation. And as you think about your response to this question, it may include some of the strategies we just lifted up, that other states have implemented, it may include something different that comes to mind for you. But focus specifically on this idea of balancing the physical, emotional, and cognitive and behavioral health of residents and their autonomy and their right to autonomy, with the public health need to protect in a state of emergency. What are some approaches that the state of California should consider to ensure in that balance? I'll open it up for comment. Please Jayleen, yeah.

14:25:43

JAYLEEN RICHARDS: Thank you. Jayleen Richards for Solano Public Health, and also representing the County Health Executives Association of California. I mentioned earlier that in Solano Public Health we had really great relationships with our long-term care facilities here locally. We had a weekly check-in meeting with them on telephone, we noticed that was extremely helpful. We also noticed that going to the facilities and providing that technical assistance on site, so that we could observe how the long-term care facility was working was extremely helpful as well. We also, I mentioned earlier, not only training the staff at the facilities, but also the visitors, and how to put on a personal protective equipment, how to prevent the spread of disease was very helpful in the facilities. But just one thing, I wanna make sure is that, I say, is that long-term, and it, that local health jurisdictions need to maintain the tools in their toolbox to respond to, not only public health emergencies but also outbreaks that happen in facilities, prior to this pandemic and post this pandemic, and they have those 2 tools and flexibility to respond to the situation. So, there you go!

14:27:21

JULIETTE MULLIN: thank you, Jayleen, appreciate that. Any additional comments around approaches for balance. I see that the Ann Walters has her hand raised.

14:27:49

DEANN WALTERS: Yes, thank you this is DeAnn. I just wanted to comment that when reading what the other states had put in there, just that the definition around compassionate care visits, it is very broad, and I think that maybe having the designated caregivers may be a better option, only because then, you know, a facility has to, then, basically define what that compassionate care situation is, and that would be up to interpretation. And so then we would not see that equity across the facilities, across the state, whereas if someone had designated essential caregiver, then that would apply for all residents, whatever, in generally whatever their condition, and so it wouldn't be limited just a persons that are, fall under that definition or what the facility tries to interpret is that definition. Thank you.

14:28:49

JULIETTE MULLIN: Thank you appreciate that comment. Melody I see you have your hand raised as well.

14:28:57

MELODY TAYLOR STARK: Yeah, I, know, we've gotten a lot of feedback certainly today, from families, from groups on the ground. We're not the only groups on the ground, sorry, I shouldn't let that out, everybody was, but there were a lot of, there are a lot of different components involved. There were the residents, and the families, and then the facilities and DPSS, CDPH, and so forth, just trying to, you know, figure this all out, and certainly there were challenges on their part, and I'm just wondering if there might be able to be someone on, or if there's someone on the call from DPSS or DPH, or so forth, that can you know, help to give their side of, sorry we're working together as a group, forgive my language on that, but to be able to give perspective from their part on, you know, on how this could have been balanced; because I think there was some, you know, kind of pulling their hair out, you know, as well of saying, you know, what do we do, we're trying to keep people safe, and a lot of us are looking at it from there with, there was the protecting, but the protecting them to death, and so where do we come together? So, it would be really good if, just wanted to ask if someone's on the call from any of those the departments, we did here from one, but where we can kind of balance out those challenges or help out, maybe it's communication. Maybe, whatever it might be to put that out there.

14:30:33

JULIETTE MULLIN: Thank you Melody, definitely appreciate that request for perspective. I will just take a moment to see if, in the chat, any one would like to weigh in on that particular piece before I move to the next. I'm gonna keep going in the line, and I think we may have to.

14:31:09

[UNKNOWN MALE] I think Liz Fuller want to respond to that.

JULIETTE MULLIN: Great Liz, would you like to take yourself off mute and comment?

LIZ FULLER: I, just, this has been a fantastic day, and I've spoken with someone earlier today, and how hopeful I am for this working group. And I hope that after each working group it's not gonna be perfect, but that everyone can feel somewhat positive about the direction we're going. I'm very familiar with the bill that was put up just a few minutes ago, talking about the legislation in California. While I couldn't be more supportive of the bill language that you referenced, that was not actually the way that it made

its way through, it's second policy committee, and I wanna just be honest and frank about that, because if that had been, if the amendments that came out of Assembly Health had come through Assembly Aging, and they were kind of not really referenced in the way that the bill was presented, I wanna give some deference to my colleague and health, who certainly took strong recommendations from public health. And I did hear public health say, you know, there are a lot of please don't take away the tools that they have, and that they need. That being said, I think that what we can take away, not just from today, but from having worked that bill through policy committee, and also I wrote the analysis through Assembly Aging, on that bill is, I think, that one thing that I would say was common was, everyone felt that there were constant communications that were contrary to one another, or that not everyone felt that they were getting information. And so, as we're building out something that ideally, I love the fact that we're looking at this regionally, I thought everything that had been put up today, I couldn't agree with more, that we're trying to figure out how we do these things regionally, not just as a state. But that maybe one of the things that we can acknowledge or express moving forward is what people should expect in what they would receive in communication, and where they would find the best information. That we all would look to be kind of the end, all be all, and I would say that you know, similar to how did we use the CDC guidelines, and then how that got shut down. So, I just, I wanted to say something particularly around the legislation, because I, while I am fully supported of a lot of the language into 2546, ultimately the recommendation as it came out, was that we should study and it kind of end up where we are right now, which is, look at it with lots of different people.

14:34:14

JULIETTE MULLIN: Thank you, Liz, appreciate you sharing the evolution of the California bill and the context as well around its development, thank you. I see George is next in line with his hand raised.

14:34:29

GEORGE KUTNERIAN: Hi, can everyone hear me fine? Can everyone hear me?

14:34:38

JULIETTE MULLIN: Yes, we can hear you.

GEORGE KUTNERIAN: Okay, thank you, thank you so, I'm George Kutnerian, I'm here with 6beds. We represent the small residential care facilities for the elderly, and adult residential facilities. So, I wanted to just comment on the question of the balance. And wanted to say just, very appreciative of the family testimonials that we heard. You know as from a facility perspective, I wanna highlight that as facilities I don't think we provide care in isolation. The family members are extremely important participants in that care, and providing care in our facilities is a collaborative effort. I think that's when you have the best experiences, and so definitely, when visitation was curtailed, that collaboration was kind of thrown out of equilibrium, and certainly, I think, for facilities made a particularly challenging as well, and the direct care staff. And, you know, participation from families, you know, like is on a total you know, on a spectrum, but I mean just as an example, you know, facilities might have residents with progressed dementia, they may be scared of water, and taking a shower, so often times, you know, family members stop by help talk to their loved one, help them to take a shower, so they're clean, and their hygiene is intact. You know, that's just one example, several other types of examples, too, on how families participate and how facilities work with families. And so when that visitation got curtailed, it kinda created it, you know, kind of a black box, and disrupted the collaboration. So long story short, what I'm getting at, is that, I think part of the balance is to acknowledge that, you know, not all visitors are the same, and there are, you know, maybe certain visitors that are more essential i.e. family members. And so, I think part of striking a balance is acknowledging the importance of certain visitors, and how that, you know, contributes to not just quality of care, but quality of life. So, thank you.

14:37:08

JULIETTE MULLIN: Thank you, George. I see we have Claire Ramsey next.

14:37:17

CLAIRE RAMSEY: Thanks, Juliette, so I'm Claire Ramsey, from the Department of Social Services, and wanna speak a little bit to, sort of the question that was raised about, sort of, a response from the state. So first, I just really wanna appreciate hearing from all of you today who've had lived experiences with these policies. You know, what they meant for people living in care. The Department Social Services takes that very seriously, you know, we really, to George, what he just said right at the end, I just wanna lift that up, that you know, it isn't simply a matter of physical health, that quality of life is really important, that people's mental and emotional health is also

considered. I also, just wanna be really clear that the departments, all that departments here are really in listening mode. To Liz's earlier point, this is a very complex issue that requires a lot of thoughtful analysis and careful balancing. I know we've used that word balance a lot, but that balancing of policies, and I just wanna lift up a couple of things, both how do we balance, you know, individuals' rights to see family members, essential caregivers also, we've been talking a lot about public health, but I also wanna lift up the fact that, we also wanna think about the balance for other people living in those facilities, and their safety, and their peers potentially around catching a communicable infectious disease. So being careful, they are thinking about, you know what protections and what tools we do have in place to keep people safe beyond locking down facilities. And also realizing that a lot of times with these situations they are dynamic so COVID was a very long extended amount of time, it was one particular type of challenge, multi-faceted challenge but there are other things that might cause a facility to need to prioritize public health. And so just making sure we're being really cautious and thoughtful about how we think through all these scenarios and these different things that arise, and kind of, the many needs we're trying to balance as we think about all our resident safety, so you know. I know that may not, like be exactly what people wanted to hear in terms of like, let me tell you the 3 things you know the department is thinking of, but I really do want to be clear that we're using this time in this workgroup to really inform ourselves to have a better understanding of what's possible, what other states did successfully. I'd really be interested if we could lift up, also how those policies worked, whether that, like, you know, they had the results that they intended, in terms of people were able to see, or if they created other unintended consequences. Also to see how their COVID rates were in the states, and kind of that balancing act, as well. So, if there's additional sort of information there on how other states responded, but also how, what that meant right, for resident safety and health that would be really helpful to know as well so, thank you all. Appreciate hearing from you all continue to listen and be an active participant here.

14:40:38

JULIETTE MULLIN: Thank you, Claire, appreciate your comments. Anissa, so you have your hand raised, we'll go to you next, and then I think we will open up for public comment right after that.

14:40:51

ANISSA DAVIS: Hi, thank you. So, Anissa Davis, I'm the City Health Officer for the City of Long Beach, and I just wanted to say that that during the

pandemic, that we did have a very extensive and constant communication with our long-term care facilities, and I think the aim for everyone was acknowledging the mental and physical health of all of the residents that were at the long-term care facility, in a very chaotic and overwhelming time that was unfortunately very long lasting, which I think is really unusual for emergencies, and there were a lot of really, you know, awful impacts of that, both from COVID and then from the policy that will put into place in order to protect people from getting COVID. I do think it's important for local health officers to maintain their authority and their nimbleness in order to be able to respond quickly to all sorts of types of emergency that really can happen on a local level, whether it could be something like a chemical leak, in our jurisdiction we had a fire that decimated a senior living facility, and we had to shelter, we had to move everyone, all of the residents to a shelter for some period of time, and so those are just kind of like an example of local things that can happen that we have to be able to respond to quickly still within the understanding as local public health, that really autonomy is very important and mental and physical health in all of the, you know; the totality of the person is really important. But I just wanted to say that I do think it is important that we're able to maintain the, being able to quickly make decisions, and respond to local public health conditions. Thank you.

14:43:12

JULIETTE MULLIN: Thank you for those comments. I'm gonna take a moment before we do public comment because we are running a little bit behind, to acknowledge that we have a few more principles we didn't quite cover today. What we'll do is we'll be sharing this deck on the CDA website, and can share it with workgroup members as well, and invite everyone to review the additional principles, and how states have approached those. And we can come back in our next meeting and really talk through those pieces. I think some pieces I'm taking away from the workgroup today is wanting to really, maybe dive into what permissible limitations look like and what it's like to make sure that we can have that balance with the public health protection in place. And so that may be an area where we focus on next. But we'll first turn to our public comment before we wrap up our meeting today. I do see we have a couple people with their hands raised in the public comment. We'll start with R A A S, sorry RAAHS, Inc., and I know you've had your hand raised for a little while now, thank you for your patience. And I'm seeing in the Q & A your name is Denise Logan. So, I'm gonna go to you next for public, first for public comments.

14:44:33

[SLIDE 45]

DENISE BOGAN (RAAHS, INC.): Yes, thank you so much for taking my comment. This is Denise Bogan, I am a member of Essential Caregivers Group. My story is unique to my situation with my mom, who is a resident in long-term care. But I want to point out that telling her story, her story is very common to what happened to so many people during the pandemic. So I'm gonna make it brief, she was thriving in a long-term care facility, mostly because her 3 daughters, that she was very close to and loved her forever, we would come, we would take turns being her essential caregiver. So, the staff there knew all 3 of my mom's daughters well, and they always took a sigh of relief when we were there. My mom had dementia, they knew that my mom would be well cared for while her daughters were there, and we were there at least 6 days a week, so each daughter took to 2 days, and usually 7 days a week. My mom was very happy, regardless of her dementia. She was very spirited and loving, kind, smiling all the time, and loved life even in the state that she was in. Once the pandemic, once the lockdown occurred, the only way that we were able to communicate with my mom was through a Facebook portal that, thank god, my techie sister put that Facebook portal in her room just minutes before we were shooed out the room because of the lockdown. We then were able to communicate in a way that was so much bigger than most residents, but that Facebook portal also became a window into my mom's suffering. And it was heartbreaking to see what was occurring. There were times where she was, she had to use the restroom, and nobody would come and nobody would come, and nobody would come, and we would watch her try to get up out of her wheelchair. We would call one of the sisters would get off the Facebook portal and call the nurses station, only to just hear it ring and ring and ring, nobody answering. Finally, one time where this was occurring, I did get through to somebody, and the nurse basically said, I can't talk to you right now, I know you're calling about your mom, but she's fine, she is asleep. This is the kind of stuff that went on time and time again, and this was a very good long-term care facility. My mom, like so many others, was protected to death, and I understand, you know, the Public Health Department needs to have the authority to make really important decisions about public health. But nobody is trying to take that authority away, we are just trying to be able to be seen as, not just visitors, but essential caregivers who can wear all the same PPE and take all the same precautions as any other paid staff. And the truth is, we care more than many of the paid staff, not all, but many. We care more to protect our loved ones. We don't go from room to room to room

as paid staff does, we would go to one room where our loved one was and take care of that loved one. My mom did things like, we're on the Facebook portal and she would hear somebody walking by in the hallway, and she'd say, help, I'm in here, please come and see me, please, crying out to anybody out there in the hall because she needed physical touch. She needed physical contact. That is part of what human beings need, they don't just need to be protected from a virus. Yes, we have to protect them, but we also need to give them their total being, we have to meet their needs, not just their medical needs. So I, I'm so grateful and so thankful that this workgroup is coming together and hashing out all these layers. This is a very complex issue, but the truth of it is, every human being has the right to be with their loved ones, regardless of what's going on in the world. Every human being has the need to be with those who bring them the most pleasure in life. And, by the way, when you're in your nineties or you're in, you're in a long-term care facility, regardless of your age, the thing that brings you the most joy is the people who love you, and who you love, and we don't have the right to take that away for long extended periods of time. So, I beg you for my mom's sake, who, by the way, was protected all the way for 10 months without seeing her loved ones, and then was given COVID by a caretaker, who would spend the day there at the facility, but evenings, were spent going wherever she wanted, doing whatever she wanted, and then she brought COVID in. So please let's not protect our loved ones to death, let's give them quality of life, let's protect their life. So, I thank you, thank you for this chance to speak on behalf of my mom and be a voice to the millions of other people in long-term care, that need you all to make these important decisions on their behalf.

14:52:06

JULIETTE MULLIN: Thank you, Denise, for your comments. I'm going to go to the next person in line. We have Mark Alipio.

14:52:28

MARK ALIPIO: Hi, Mark Alipio from California Care Association, as well as a board member of the Long Beach Homeless Coalition. While we recognize that the pandemic definitely brought some extra challenges, there definitely is some room for improvement. I'm a, I'm a provider myself, and I can acknowledge that the pandemic brought on a lot of the flaws in, in the, in the system, and so in which you know, even where loneliness really was a big part, or a big part of the impact in which families suffered, right. And I myself, my dad passed away from non-covid, related, during 2020, in the beginning of the year. And so, there was a lot of adjustments from pre-pandemic to

where we're at now. And even now we're still really understanding how we can work together. One of the things that we can recognize is that technology has definitely abridge some of the challenges in getting connected with individuals, and so where we can, we can really work towards this technology component is that there needs to be more training, not only to the seniors, but also to the providers and caregivers as to how we can better support, and also impact the aspects of loneliness in long-term care facilities. Secondary to that I think that this is great, that the workgroup is coming together to really identify the challenges moving forward as we embark in this unknown territory, where we're really having challenges of increased, baby boomers or individuals that are in retirement stage. So, that's all that ends my comment for today thank you.

14:54:32

JULIETTE MULLIN: And I'm not seeing any additional hands raised from the public, and so I think at this time we can transition into our next steps. As I know, just wanna acknowledge we did not completely finish the section on existing policy approaches of states, but do encourage people to review that between now and our next meeting. And I will hand it off to Brandie to share a little bit about that next meeting.

14:55:06

[SLIDE 46 & 47]

BRANDIE DEVALL: Thanks, Juliette. So, in preparing for the next meeting, the second meeting of the workgroup is scheduled for May thirtieth. The time will be 12 30 to 3 pm. CDA will circulate the agenda for this workgroup meeting to the public at least 10 days prior to May thirtieth. CDA will send meeting materials to workgroup members in advance of the meeting, and we will post all of the material to the website. Workgroup members are encouraged to review material prior to the meeting and consult with other individuals within your organizations as needed. Materials will be listed on the Long-Term Care Facility Access Policy Workgroup webpage which the team will drop into the chat. Next slide, please.

14:56:10

[SLIDE 48] So thank you again for participating in this important work and thank you so much for sharing your stories and lived experiences. We look forward to continued collaboration with everyone who is part of the workgroup, and we look forward to working together over the next few months. Next slide.

14:56:33

[SLIDE 49] If you have questions or comments, please reach out to us at the email address that you see listed here, and we'll also drop that in the chat. And just a big thanks, everybody for joining. I hope you all have a wonderful rest of your day.

14:56:55

MARK BECKLEY: Thanks everyone.