

**Long Term Care Facility Access Policy Workgroup
May 30, 2023, Chat Transcript**

12:32:29 Caroline Servat, Manatt:

https://aging.ca.gov/Long-Term_Care_Facility_Access_Policy_Workgroup/

12:33:16 Caroline Servat, Manatt:

Workgroup members: Please click on the three dots in the top right of your picture to rename yourself in Zoom

12:36:38 Caroline Servat, Manatt:

https://aging.ca.gov/Long-Term_Care_Facility_Access_Policy_Workgroup/

12:37:14 Eric Dowdy, Alzheimer's Association:

Eric Dowdy, VP of Public Policy, Alzheimer's Association

12:37:17 Ellen Schmeding, CCoA:

Ellen Schmeding, CA Commission on Aging. Thank-you for this session today!

12:37:18 LTCFA Member:

Hi All, Claire Ramsey, Chief Deputy Director, CDSS

12:37:19 Melody Taylor Stark (she/her):

Melody Taylor Stark, Chosen Family

12:37:21 Eric Carlson, Justice in Aging:

Eric Carlson, Justice in Aging

12:37:29 Blanca Castro State LTC Ombudsman:

Good afternoon Blanca Castro State Long-Term Care Ombudsman

12:37:30 Kristin Rains, DDS Aging Specialist:

Hello! I'm Kristin Rains, Aging Inclusion Specialist at DDS

12:37:34 Heather Harrison:

Heather Harrison, CA Assisted Living Association

12:37:35 LTCFA Member:

DeAnn Walters, California Association of Health Facilities, Director of Clinical & Quality. Happy to be here.

12:37:36 Amber King, LeadingAge California:

Amber King, VP Legislative Affairs, LeadingAge California

12:37:41 Cassie Dunham:

Cassie Dunham, Deputy Director, CDPH Center for Health Care Quality

12:37:43 Amy Westling - Association of Regional Center Agencies:

Amy Westling, Association of Regional Center Agencies

12:37:47 Darrick Lam:

Darrick Lam, Vice Chair of the CA Alzheimer's Disease and Related Disorders Advisory Committee.

12:37:52 Nancy Stevens, Resident:

Nancy Stevens, Resident/advocate

12:37:56 Maitely Weismann, Essential Caregivers Coalition (she/her):

Hi all. Maitely Weismann, RCFE family caregiver, Essential Caregivers Coalition

12:38:01 Christine Gephart, DDS:

Christine Gephart, Deputy Director, Department of Developmental Services

12:38:18 George Kutnerian, 6Beds Inc.:

Hi, this is George Kutnerian. I serve as Senior VP of Public Policy & Legislation for 6Beds, Inc., which represents the smaller (i.e. 6-bed) residential care facilities for the elderly.

12:38:32 Leza Coleman CCoA:

Leza Coleman, California Commission on Aging

12:38:44 Todd Higgins Disability Rights California:

Hello Todd Higgins from Disability Rights California

12:38:48 Jack Light, Providence St. Jude Medical Ctr:

Jack Light, Director, Caregiver Resource Center OC | St. Jude Brain Injury Network, programs of Providence St. Jude Medical Center, serving Orange County.

12:39:05 Mandi Posner:

Mandi Posner, Chief, Field Operations South, CDPH

12:39:33 George Kutnerian, 6Beds Inc.:

6Beds, Inc. also represents Adults Residential Facilities (ARFs).

12:41:19 Talmadge House - Disability Organizer with (CFILC):

Talmadge House - Disability Organizing network - California Foundation for Independent Living Centers

12:46:03 Leza Coleman CCoA:

vis·it·a·tion

noun

1.

(in church use) an official visit of inspection, especially one by a bishop to a church in the bishop's diocese.

Similar:

official visit

visit

inspection

tour of inspection

survey

review

scrutiny

examination

2.

the appearance of a divine or supernatural being.

Similar:

apparition

"Visitation"- definition from Oxford language- 1. an official visit of inspection, especially one by a bishop to a church in the bishop's diocese. 2. the appearance of a divine or supernatural being. 3. describe a formal or official visit, often includes some kind of evaluation or inspection, or has some other formal aspect. Could we please call these "visiting policies"?

12:48:16 Juliette Mullin, Manatt:

Hi Leza, thanks for raising this. We will take that back and look at the language for these recommendations

12:55:04 Nancy Stevens, Resident:

I wish there was an I II III listed under advocacy

12:55:14 Ellen Schmeding, CCoA:

With this slide, we are talking about 'physical' access to the facility. We do need to improve digital access for those times when physical access is not advised.

12:56:26 Darrick Lam:

I agree with Ellen that we need to improve digital access.

12:57:52 Catherine Blakemore:

Agree about improving digital access and we also need to acknowledge that digital access doesn't work with everyone including those with advanced dementia and may cause more confusion.

12:58:11 Amy Westling, Association of Regional Center Agencies:

A) should be expanded to also include communication support, which is critical for those who may not communicate verbally.

12:58:16 Melody Taylor Stark (she/her):

All of the issues are essential to address

12:58:35 Ellen Schmeding, CCoA:

End of life - this was allowed throughout the pandemic and it seems paramount. All those who can should be surrounded by loved ones.

12:59:47 Maitely Weismann, Essential Caregivers Coalition (she/her):

C: Also, residents to be able to get outdoors for fresh air and sun (with their support person if the resident needs that).

12:59:52 Melody Taylor Stark (she/her):

@EllenSchmeding - it was "allowed" but not played out in reality - many many (Including me seeing my husband) were denied rights to see loved ones

01:00:26 Nancy Stevens, Resident:

FRESH AIR! Thank u Maitely!

01:00:52 Catherine Blakemore:

re @ ellen schmeding comment, I agree that end of life visits were the official policy. Sadly they were inconsistently administered across facilities.

01:02:22 Melody Taylor Stark (she/her):

Many times "essential caregiver" term gets conflated with paid staff - "resident designated support person" may be a term to use

01:03:34 Karen Jones, CLTCOA:

Requiring residents to designate one person to be the only person they can see during a public health emergency should be allowed for only a limited time (less than 30 days). Residents need access to many family members/friends who each provide a different type of support and should have access to everyone who is a benefit to them, not just one designated person.

01:03:36 Maitely Weismann, Essential Caregivers Coalition (she/her):

Re: Jayleen. Agreed and when staff can care with relative safety with PPE, there should be a right to a resident-designated support person with the same PPE as an essential element of those risk mitigation strategies.

01:03:58 Catherine Blakemore:

Options: 1) more than one family member is important; and 2) It seems reasonable for family member to follow say public health protection requirements as staff.

01:04:05 Blanca Castro, State LTC Ombudsman:

Agree with Karen's comments

01:04:49 Darrick Lam:

Agree with Catherine's comments.

01:04:55 George Kutnerian, 6Beds, Inc.:

6Beds, Inc. is generally supportive of an "essential caregiver" approach.

01:05:02 Melody Taylor Stark (she/her):

Agree with Karen's comment

01:05:09 Heather Harrison:

I agree that a broader term makes sense. And there should be consideration given the length of time the restrictions would be in place.

01:05:38 Maitely Weismann, Essential Caregivers Coalition (she/her):

Please note, some residents have one regular family caregiver so let's not limit anyone to 30 days. We give the decision to the resident and that sorts that issue.

01:06:53 Melody Taylor Stark (she/her):

Illinois SB2322 23.(5) notes that if a resident does not have a designated support person on file, the facility will work with the resident or resident's rep to identify support persons

01:07:31 Nancy Stevens, Resident:

Thanks Melody, for referring to the Illinois bill (clapping hands emoji)

01:08:58 Nancy Stevens, Resident:

FYI residents are STILL experiencing lockdowns

01:10:07 Leza Coleman CCoA:

Visits should be open with the requirement that they use PPE. ditto Karen!

01:10:36 Dan Okenfuss (CFILC):

Hi, this is Dan Okenfuss of CFILC. We need to ensure caregiver access for patients who are temporary residents of LTC facilities due to illness or surgery recovery. For example, my wife was admitted into a SNF after a surgery during the pandemic Her recovery there was for 5-7 days. During that time, me (her husband) and her children were not allowed to see here in person. We had to shout through a waiting room window.

01:10:41 Melody Taylor Stark (she/her):

Exactly Karen - PPE doesn't know if its staff or bio/chosen family - all the same to the PPE

01:11:29 Nancy Stevens, Resident:

Yes THANKS KAREN

01:11:38 Leza Coleman CCoA:

I have very strong feelings about “visiting policies” residents have not committed any crimes and should not be treated as if they have no rights to meet with friends and loved ones. Yes, safety must be considered, but just as a resident, even ones that are on oxygen, has the right to smoke cigarettes, or diabetics having the right to eat cake, just because you live in a licensed facility does not mean you should not be allowed to hug, share a meal, or be in the same room with loved ones.

01:12:26 Melody Taylor Stark (she/her):

There should be multiple support persons - perhaps they cannot all be there together but there may be a situation where one cannot come and there is still the essential psychosocial support by another designated support person

01:13:31 Leza Coleman CCoA:

Catherine Blakemore- yes!

01:13:57 Melody Taylor Stark (she/her):

Many staff work at multiple facilities out of necessity which increases risk

01:14:23 KJ Page (she):

I agree the number should not be limited. However, in shared rooms the number of visitors at any given time may be an issue. space is limited. others have visitors.. it could get out of hand rapidly.

01:15:03 Melody Taylor Stark (she/her):

We are hearing a lot from bio/chosen family, residents, etc - if someone from DPH is on the call, it may be helpful to hear from them too

01:15:46 Catherine Blakemore:

Thank you @Leza Coleman

01:15:47 Nancy Stevens, Resident:

I'm incredibly grateful for your voices!

01:16:32 Maitely Weismann, Essential Caregivers Coalition (she/her):

Thank you. Yes, Leza. Family caregivers were working hard to stay safe in case we could be called to help.

01:17:33 Melody Taylor Stark (she/her):

for the one and only 15 min compassionate care visit I was allowed to have with my husband, I wore the exact same PPE/safety measures as the staff - I had to stay 6' away while staff who were assisting with ADLs were very much close to him

01:18:43 Melody Taylor Stark (she/her):

Thanks Maitely - when my husband and other loved ones were in the SNF I made a point to make choices to stay safe (i.e. Instacart vs going into a grocery store, etc)

01:19:33 Catherine Blakemore:

Re number of visitors, I assume facilities have appropriate visitors at one time now--and no reason that should not continue

01:20:10 Nancy Stevens, Resident:

Yes!

01:20:49 Leza Coleman CCoA:

agreed no unlimited number of visitors- you can't currently host a party in your shared room, I don't see a reason that should be changed.

01:20:50 Melody Taylor Stark (she/her):

It may be helpful to use the language/content in the original AB 2546 Resident Designated Support Persons Act

01:21:24 Leza Coleman CCoA:

I don't agree with restriction to certain areas of the building. If PPE works for staff, it works for visitors.

01:21:44 Maitely Weismann, Essential Caregivers Coalition (she/her):

That is unfortunately so true. I was inside the majority of lockdowns and I consistently saw non-compliance with masks.

01:22:27 Maitely Weismann, Essential Caregivers Coalition (she/her):

The ongoing staff non-compliance with masks was shocking to see.

01:23:13 Nancy Stevens, Resident:

YES BLANCA (clapping hands emoji)

01:23:59 Nancy Stevens, Resident:

Great point Karen!

01:24:59 Maitely Weismann, Essential Caregivers Coalition (she/her):

Yes, Karen. It wouldn't work for my mom when she was sick with something other than Covid we wouldn't want other residents to catch, also. But she needed the support more than ever during that time.

01:26:14 Catherine Blakemore:

Agree with @ Todd Higgins that essential should not be included and we should also recognize support person (who may not provide direct care)

01:27:00 Maitely Weismann, Essential Caregivers Coalition (she/her):

We were suggestion Resident-Designated Support Person.

01:27:11 Maitely Weismann, Essential Caregivers Coalition (she/her):

suggesting*

01:27:57 Nancy Stevens, Resident:

I want to make important mention that most of the residents in my facility do not even have an essential caregiver at all.

01:28:12 DeAnn Walters:

If the choice is anyone could visit, but be required to follow staff PPE requirements, then there is no point having so-called designated support persons. All visitors would be allowed.

01:28:51 Heather Harrison:

Good point, DeAnn

01:28:55 George Kutnerian, 6Beds Inc.:

DeAnn Walters is correct.

01:29:12 KJ Page (she):

agree that if visitors follow the PPE and IP 'restrictions' staff are following - no need to name 'caregiver'

01:29:14 Catherine Blakemore:

Agree with designated support persons (plural) is great

01:29:54 George Kutnerian, 6Beds, Inc.:

You don't need a list of visitors if visitors are simply required to take the same precautions that staff are required to take.

01:29:59 Jack Light, Providence St. Jude Medical Ctr:

Suggestion that location of care be established as should be provided in an area where it would reasonably occur regardless of who is providing the needed care.

01:30:11 Ellen Schmeding, CCoA:

For compassionate care, it would be good to include clergy/religious representatives in addition to loved ones.

01:31:10 Melody Taylor Stark (she/her):

If visitation is allowed for Designated Support Persons - wouldn't that be inclusive of any status of the resident?

01:34:17 Maitely Weismann, Essential Caregivers Coalition (she/her):

Thank you Liz.

01:35:40 Nancy Stevens, Resident:

Ellen, you make a good point, but during moments of crisis, which was everyday during the pandemic; and for some, it's everyday in here period, spiritual advisors should ALWAYS be allowed in.

01:36:42 Jack Light, Providence St. Jude Medical Ctr:

Agreed that residents should be able to name caregivers. The durable POA, health care directives, should also include a person that can make those decisions should a resident lose capacity, if that is not already built into resident rights.

01:36:45 Leza Coleman CCoA:

- we should require that public health officers must be in communication with their local LTC Ombudsman program. Public health officials are not fully versed on licensed care, nor should we expect them to be, when less than 3% of their population reside in licensed care. Currently there are no requirements that local public health have to work with LTC Ombudsman programs.

01:38:20 KJ Page (she):

bare minimum: Visitors follow instructions/restrictions staff follow. reasonable accommodations or people in shared rooms. no restrictions.

01:39:36 Nancy Stevens, Resident:

We DO need a law to protect us from what just happened and continues to happen, please! If we have a law, who's to say a law won't get passed to allow individual facilities to make up their own rules.

01:40:24 Melody Taylor Stark (she/her):

(thumbs up emoji)

01:40:56 A Davis, CCLHO (she/her):

I agree that having relationships with many stakeholders is important. Depending on the emergency, Public health officials may need to make decisions to protect people and save lives in a time sensitive manner.

01:41:33 Nancy Stevens, Resident:

We residents NEED the protection from all those who are in belief of restricting our essential caregivers from coming in for us!

01:46:50 Nancy Stevens, Resident:

I can't choose for someone else to be by mom. Each essential caregiver has a role.

01:47:36 Catherine Blakemore:

The question about process is whether it will facilitate equity across all communities, types of facilities.

01:48:18 DeAnn Walters:

To change designated visitors whenever you want is an administrative concern for the facility to track, document and communicate in order to honor the resident's rights/wishes. Need to focus on parameters of visiting, not limiting visitors.

01:49:38 Darrick Lam:

This issue is particular important during the end of life of our loved ones.

01:49:50 Catherine Blakemore:

Compassionate care should not be limited to individuals who are eligible for hospice. The definition on the slide is broader, but I think important to be clear that hospice eligibility and compassionate care are not the same

01:50:39 Leza Coleman CCoA:

agree with DeAnn Walters- can't imagine the challenge of keeping track of an ever changing list of visitors.

01:50:59 Heather Harrison:

Why require residents to make a list (or update a list) if the same safeguards are in place? The goal should be a way to allow visitors.

01:51:48 Melody Taylor Stark (she/her):

If there are truly individualized planning for resident designated support persons without arbitrary limits, is there a need for a "compassionate care" designation?

01:54:03 Melody Taylor Stark (she/her):

Agreed, Maitely - I'm the one who discovered that my husband had pneumonia - and it was during a phone call on a bad landline - staff working directly with him did not pick up on the things I detected

01:55:10 Nancy Stevens, Resident:

Yes Maitely, I was victim of that. The admin, who already held grudges against me tried to say a compassionate care wasn't needed for me. I ultimately was able to fight back with the help of advocates and doctors. My nurses couldn't even speak up for me in fear of retribution and to protect their jobs.

01:55:16 KJ Page (she):

compassionate care may not only be at end of life. someone with dementia who does not understand suddenly being 'abandoned' by their daily visitor... very much in need of compassionate care

01:56:05 Melody Taylor Stark (she/her):

Thank, you, KJ

01:56:47 Melody Taylor Stark (she/her):

compassionate care - how can one truly know when it's "end of life"

01:56:59 Melody Taylor Stark (she/her):

Under what circumstances do you feel that essential caregiving and compassionate care can be DISABLED?

01:59:07 Leza Coleman CCoA:

agree with George

01:59:54 Leza Coleman CCoA:

Go for it Nancy!!!! You are the expert :)

02:01:21 Nancy Stevens, Resident:

Thank you for your encouragement Leza (heart emoji)

02:02:47 Nancy Stevens, Resident:

The need for this discussion explains the need for an essential caregiver law

02:03:10 Nancy Stevens, Resident:

We did NOT qualify for compassion

02:04:30 Ellen Schmeding, CCoA:

Compassionate care is a key category and likely need to remain called out as such as it would continue to be the top priority for residents in these situations.

02:06:32 Jack Light, Providence St. Jude Medical Ctr:

It would be helpful for me to understand jurisdictional issues between, Federal, State and Local public health offices and their ability to mandate behaviors.

02:07:27 Nancy Stevens, Resident:

Thank Tony

02:12:55 Nancy Stevens, Resident:

Same. I struggle with survivors guilt, as do many other residents, that comes up from not speaking up sooner, or from being allotted the time to give testimony.

02:13:51 Nancy Stevens, Resident:

This is not about taking away public health officials tool boxes.

02:15:41 Darrick Lam:

Thank you, Catherine, for the comments.

02:16:26 A Davis, CCLHO (she/her):

There could also be differences in masking. At the beginning of the pandemic there wasn't enough PPE and also you need to be fit tested for the N95s. So, sometimes there's extenuating variables you have to factor in.

02:17:33 Tony Chicotel:

Agree Nancy. I've said this before: designated support person protections are not taking away public health tools - it's treating support persons and staff similarly. In the case of vaccines being available to LTC facility staff first, the rules could be written to differentiate those who are vaccinated versus unvaccinated, not staff versus support persons.

02:18:56 Maitely Weismann, Essential Caregivers Coalition (she/her):

Yes, Tony.

02:21:48 Melody Taylor Stark (she/her):

The world was in shock what to do when COVID raised its awful head. The mental health agency I work for (largest in the State of CA) scrambled to get everyone functioning with telehealth - thinking it was "temporary" but thankfully management realized by the end of May that this was a long haul situation - a "plan B" (what if we are not back in the office by July?) a "plan C" (what if we are not back in the office by October?" then plan D, etc - it

02:21:59 Melody Taylor Stark (she/her):

...it's a good model to go by

02:28:32 Nancy Stevens, Resident:

Can anyone put in the chat the number of people who died from being isolated/failure to thrive?

02:29:07 Catherine Blakemore:

Perhaps there is a way to define safety--which shouldn't just include physical safety. And timelines by which policies such as visitation are reviewed

02:29:24 Maitely Weismann, Essential Caregivers Coalition (she/her):

Have we asked all the residents how they define protection and safety?

02:30:44 Nancy Stevens, Resident:

Again, we are kept from the public. No one asked us. I'm glad for this meeting to be "allowed" to talk about these things.

02:31:16 Melody Taylor Stark (she/her):

Excellent question, Maitely Weismann

02:34:21 Kristin Rains, DDS Aging Specialist:

Any policy recommendations should also consider volunteers.

02:34:30 Nancy Stevens, Resident:

No offense, because I understand that there was pressure and lack of staff, and thank you for ALL you do for us (heart emoji) But...I called numerous times to get help from public health officials because much of the staff refused to follow guidelines on PPE. No help arrived and my neighbors died. Let's prevent this by allowing for an essential caregivers law!

02:36:10 Maitely Weismann, Essential Caregivers Coalition (she/her):

To answer Nancy's question earlier about excess deaths from other causes in LTC: <https://apnews.com/article/nursing-homes-neglect-death-surge-3b74a2202140c5a6b5cf05cdf0ea4f32>

02:37:17 Nancy Stevens, Resident:

THANK YOU MAITELY! Soooo important

02:38:14 Maitely Weismann, Essential Caregivers Coalition (she/her):

"These extra deaths are roughly 15% more than you'd expect at nursing homes already facing tens of thousands of deaths each month in a normal year."
(Sedensky & Condon, 2020)

02:40:20 Nancy Stevens, Resident:

Exactly to that last comment by LTCFA MEMBER.

02:40:47 Nancy Stevens, Resident:

Thanks Maitely!

02:43:29 Caroline Servat I Manatt:

<https://aging.ca.gov/download.ashx?IE0rcNUV0zb8DkEU9hOspQ%3d%3d>

02:43:32 Melody Taylor Stark (she/her):

It may be helpful to look at and utilize language from the original version of AB2546 Resident Designated Support Persons Act

02:44:04 Karen Jones, CLTCOA:

I prefer A with requirement as the standard. Individual facilities should not be able to choose to limit visitor access.

02:44:49 Ellen Schmeding, CCoA:

Under "A" - agree with requiring adherence to PH guidelines and have this posted/available at all times.

02:44:58 Tony Chicotel:

I have very big misgivings about facilities having discretion to limit visitation.

02:45:35 Darrick Lam:

I prefer A.

02:45:53 Maitely Weismann, Essential Caregivers Coalition (she/her):

I second Tony's comment.

02:46:10 Melody Taylor Stark (she/her):

Another vote for Tony's comment

02:46:10 Nancy Stevens, Resident:

I third Tony's comment

02:46:48 Nancy Stevens, Resident:

Yes! Thanks Karen Jones! U rock

02:47:42 Ellen Schmeding, CCoA:

Some flexibility at facility level due to documented outbreak of communicable illness that could result in death of residents/visitors.

02:47:52 Cassie Dunham- CDPH:

Absence of a minimum standard is problematic for enforcement. Agree with Tony and Karen's comments, this must be carefully constructed.

02:48:27 KJ Page (she):

There are so-called core principles of infection control. core principles of visitation under emergency circumstances can be spelled out. facilities should not have the choice to set their own visitation rules.

02:48:31 Leza Coleman CCoA:

no limits for visitors- if PPE is available for staff, then it should be available for visitors. The control should not be in the hands of the facility.

02:52:02 Maitely Weismann, Essential Caregivers Coalition (she/her):

visitation should never be linked to staffing levels.

02:52:37 Melody Taylor Stark (she/her):

Maitely (check mark emoji) "visitation should never be linked to staffing levels."

02:53:59 Nancy Stevens, Resident:

Again, this is not to align against facilities or public health officials. This is about protecting the public's right to have support from another person whom we trust our care to. Residents should be recognized as the public and not separated.

02:55:46 Nancy Stevens, Resident:

That's an aha mention!

03:00:11 Melody Taylor Stark (she/her):

Thanks Team - excellent discussion. Everyone be well and be kind to you (sun emoji)

03:00:18 Hedy Lim, CDA:

https://aging.ca.gov/Long-Term_Care_Facility_Access_Policy_Workgroup/

03:00:28 George Kutnerian, 6Beds Inc.:

Thank you, everybody.

03:00:44 Blanca Castro State LTC Ombudsman:

Great job in facilitating this meeting Juliette!! Thank you all for your input and participation!!

03:00:57 Hedy Lim, CDA:

LTCFAPolicyWorkgroup@aging.ca.gov

03:01:05 Karen Jones, CLTCOA:

Thank you everyone. Looking forward to amazing results from this effort.

03:01:06 Maitely Weismann, Essential Caregivers Coalition (she/her):

Thank you for today.

03:01:08 Darrick Lam:

Thank you!

03:01:10 Nancy Stevens, Resident:

Thank you for your insightful work on this everyone!