

Pacific ADA

Achieving Equity in a Time of

Scarcity: Lessons from the

COVID19 Experience

Thursday July 1, 2021

2:10-4:00 p.m.

>> Welcome to the healthcare and ADA webinar series. I'm Lewis Kraus. It is brought to you on behalf of the ADA national network.

Let me pause for a moment. The ADA national network is made up of 10 regional centers federally funded to provide training and information as needed.

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Sorry. 9128. Or 646-558-8656 and use webinar ID 86488542838.

I want to remind you that this webinar is being recorded and can be accessed at the ADA presentations website in the archives section of healthcare next week.

This series is intended to share issues and practices in healthcare for being with disabilities.

Physical accessibility, effective communication and reasonable modification of policy issues under the Americans with disabilities act of 1990, the ADA.

Upcoming sessions are available at ADApresentations.ORG under the schedule tab and follow to healthcare.

These occur the fourth Thursday of the month at 2:30 eastern.

You'll notice today is not the

fourth Thursday. We had to have a reschedule.

By being here, you're on the list to receive notices for future webinars in this series.

The notices go out two weeks before the next webinar and open that webinar to registration.

You can follow along on the webinar platform with the slides. If you are not using the webinar platform, you can download a copy of the power point presentation at the healthcare schedule page.

At the conclusion of today's presentation, there will be an opportunity for everyone to ask questions. You may submit your questions using the chat area within the webinar platform.

The speakers and I will address them at the end of the session, so feel free to submit them as they come to your mind during the presentation.

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Today's ADA national network
learning session is titled
Achieving Equity in a Time of
Scarcity: Lessons from the
COVID19 Experience.

This presentation will review
the experiences of Medicaid and
people with disabilities in
California and nationally
related to vaccine

prioritization and deployment.

And reflex on policy and
practice supporting greater
equity moving forward.

Today's speakers are Andy
Imparato. Andy is the executive
director of Disability Rights
California.

It's a legal services
organization that serves people
with all types of disabilities
across California.

He serves on California's
community vaccine advisory
committee and in February of
2021, appointed by president
Biden to serve as one of 12
public members of the
Biden-Harris COVID-19 health
equity task force.

Priya Chidambaram is a Senior
Policy Analyst with the Kaiser
Family Foundation program on
Medicaid and the uninsured.

Her research focuses on Medicaid
for seniors and people with
disabilities and those eligible
for Medicare and Medicaid and
long-term supports and services.

Andy and Priya, I will turn it over to you.

PRIYA: Thank you Lewis. Hi everyone, my name is Priya Chidambaram. I'm be starting off the presentation today.

I'm here from the Kaiser Family Foundation, also known as KFF to talk about our research on COVID-19's impact on people with disabilities as well as Medicaid's role more broadly for people with disabilities.

My presentation will be joined heavily on KFF's research from over the past year and prior to COVID.

I'm happy to share the links to reports and issue briefs I referenced to anyone interested.

Next slide.

I'll start today by discussing COVID-19's impact on non elderly adults with disabilities.

I'll go through the data gaps and research findings in this area and discuss how all of that manifested itself into state vaccine prioritization plans and

then touch on new vaccine reporting and education rules and how they apply or more accurately don't apply to many community based congregate care settings.

I'll talk about Medicaid's role in reducing institutional bias and other areas where Medicaid overlaps with the ADA.

I'll discuss some of the recent policy proposals around Medicaid HCBS.

Next slide.

So since the start of COVID, KFF has been tracking cases and deaths in long-term care facilities fairly closely.

We have found that nearly all states report some amount of data on cases and deaths in nursing homes and assisted living facilities.

However, those are settings that tend to serve older adults. We want to know what data is publicly available for non elderly adults with disabilities.

Primarily to see if states were working with the same amount of information for both older adults and non elderly adults with disabilities as they were beginning to design their vaccine prioritization plans this year.

The data on this slide was collected in February 2021 and at that point, only 31 states were reporting data on cases and deaths in settings that primarily served non elderly adults with disabilities.

We're talking about group homes, personal care homes, adult day programs and psychiatric institutions.

Settings that span from the home community based side of things to the institutional side of things.

I just want to note here that not all states report all of these types of settings I just mentioned. In most cases, states only report a few or one of these types of settings.

This data collection process, we tried to exclude settings that primarily served elderly adults such as nursing facilities and assisted living facilities.

There were two major findings from the data hunt. The first, there's a lot of missing data.

The second, there's enormous state variation in reporting which makes it very difficult to compare between states or have any sort of complete understanding of how people with disabilities have been impacted by the pandemic.

Just among states reporting this data, again, as of

February 2021, we found over 111,000 cases and over 6500 deaths due to COVID-19 across these settings.

We assume they are primarily non elderly adults with disabilities.

We found eight states reported data for an institutional setting.

Eight states reported data for a

home or community base setting.

And 15 states reported for some type of setting in both categories.

There was huge state variation with regards to whether states were reporting cases or deaths.

Data on residents and staff.

Active outbreaks versus cumulative.

And we found that states were using different definitions for the same type of facilities making it extra challenging.

Another challenging aspect of the data collection was actually the numbers that states were reporting.

I'll give you an example of this. If a state reported that there had been for example 300 cases of COVID-19 in group homes in the state,

We were given little additional context of how many group homes the cases were spread out between.

And what share of group home residents that 300 cases

represents.

This is in contrast to the data on cases and deaths available in nursing homes.

We have clear numbers to see the impact on nursing homes.

But we don't have this level of data available to us to contextualize the impact of COVID-19 on non elderly adults with disabilities.

We also identified other research on the impacts of COVID-19 for people with disabilities and flagged a few running themes throughout our findings.

First, we found that people who were receiving long-term care in settings other than nursing homes actually faced very similar individual risk factors as their nursing home counterparts.

People with disabilities often rely on close physical proximity to caregivers for communication and daily needs.

This limits their ability to socially distance. Very similar

to residents in nursing homes.

There's a strong body of research indicating that those with IDD specifically are at greater risk of contracting and dying from COVID-19 compared to those without IDD.

A study of private insurance claims found that people with developmental disorders across the spectrum had the highest odds of dying from COVID-19.

Those with intellectual disabilities such as down syndrome had the third highest risk of death from COVID-19.

And research suggests that people with disabilities who are members of racial or ethnic minority groups are disproportionately affected by COVID-19.

Counties with higher rates of COVID-19 were home to disproportionately higher shares of black, Asian, Hispanic or native American people with IDD.

The ways and means committee put out a report finding black

working people with disabilities were more likely than other racial and ethnic groups to have lost their jobs during the pandemic.

People with disabilities have an increased risk of adverse health outcomes because of work force shortages, interruptions in care and lack of care during the pandemic.

We found for this population, in home services were often suspended and some workers declined to enter client homes because of health and safety concerns.

People with disabilities have faced discriminatory care.

Direct care workers who provide to people with disabilities outside of nursing homes were found to have faced increased risk from COVID-19.

For example, a house oversight committee report found that behavioral health treatment facility staff were more likely than the general population to

contract COVID-19.

Next slide. As far as state vaccine plans go, while everyone now 12 and older can get a vaccine, that was not the case earlier this year.

When we first looked at state priority plans in February, only a few states specifically mentioned people with disabilities in priority groups.

First, we can back up and talk about how exactly state plans were put together.

In December of 2020, ASIP, the group putting together the federal recommendations for vaccine priority plans, recommended that long-term care facility residents be placed in the Phase 1A for vaccine distribution.

All state plans that came out soon after that abided by the guidelines and included people in nursing homes in first 1A and most included those in assisted living facilities.

Additional ASIP guidance came

out at this point for congregate living facilities such as group homes.

States could place them in the same group as front line facility staff.

They were given discretion on plans so state plans were wide in transparency and some offered far more details on which populations were being prioritized.

Some examples of states that included people with disabilities early on include Tennessee and Oregon.

Tennessee prioritized people ages 18-74 unable to live independently.

Oregon prioritized people with disabilities who received services in their home.

Both states prioritized the population in Phase 1A, the same as people in nursing homes.

Maryland and Ohio included developmental disabilities in Phase 1B.

Illinois included people with

disabilities in Phase 1B and Nevada and Washington included people with disabilities in 1C. Although Washington it was limited.

California was also a state that received a huge amount of attention early on for not prioritizing people with disabilities. I'm sure Andy will touch on that.

One policy that California adopted was allowing healthcare providers to make -- to use their clinical judgment to prioritize people with disabilities if they thought that particular individual were likely to develop severe illness or die due to lack of access to COVID-19 vaccine.

All in all, few state vaccination plans mentioned people with disabilities early on.

Some did mention people with high risk medical conditions, although we know certain high risk medical conditions may

include some but not all people with disabilities.

Since then, vaccine plans have changed drastically.

Looking back on where people with disabilities ended up in the priority lists, we found that over half of states included people with disabilities or high risk medical conditions in group 1B.

By group 1C nearly all states included at least some people with disabilities in their priority lists.

Although many states prioritized subsets of people with disabilities.

Such as older people with disabilities or those with IDD.

Plans that mentioned other long-term care settings did not typically place them at the same priority level as nursing homes.

It was pretty rare to have other long-term care settings mentioned at all.

In addition, few plans mentioned direct care workers who provided

long-term care in settings other than nursing homes.

CMS issued a rule that established new vaccine reporting and education requirements for nursing homes and intermediate care facilities as of May 21st 2021.

The main takeaway is that CMS is not enforcing all rules on all types of facilities.

Only nursing homes would be required to report data on vaccines and COVID-19 therapeutics and educating of residents and staff about the vaccine and offer the vaccine.

CMS excluded from the rules although they included some language explaining why.

CMS noted that inpatient behavioral health facilities were excluded because individuals in these type of facilities may only be inpatient for a short period of time.

They can't guarantee the availability of single dose vaccine.

CMS encourages collaboration between settings which include group homes and personal care homes.

To partner with state Medicaid agencies and state and local health departments to learn about vaccine distribution options and facilitate vaccination for folks who live and work at community base settings.

Next slide. So shifting over to Medicaid more specifically.

I'll start by laying the ground work on Olmsted and the ADA and implications for Medicaid.

I won't go into too much detail here. I believe previous webinars have touched on this topic.

But just to lay some ground work. The unjustified segregation of people with disabilities constitutes violation of the ADA.

They ruled that the states have a community integration obligation when serving people

with disabilities.

One thing to note about this particular ruling, it does not specifically change or interpret federal Medicaid law.

This particular case was not about the structure of state Medicaid long-term care budgets, but rather about how states when budgeting public programs need to avoid institutional bias against people with disabilities.

All of that said, this decision does have major implications for the Medicaid program.

Medicaid as I will note on the next slide is the main payer for long-term supports and services.

This includes the home and community base services that many people with disabilities rely on.

I'll spend the next few slides going over examples of how the Medicaid program has reduced institutional bias over time in part due to the June 1999 Olmsted decision.

So a bit of historical context
about the Medicaid program.

Medicaid was created with what
is called an institutional bias.
Meaning that state Medicaid
programs have always been
required to cover nursing home
care while most home and
community based care is
optional.

Because of this, Medicaid
long-term care spending used to
be heavily concentrated on
institutional spending.

Over the last several decades,
there's been a shift in spending
from institutional care to home
and community based care.

In 2013, spending on home and
community based care surpassed
institutional care for the first
time ever.

And in 2018, home and community
based care comprised 56% of
total Medicaid long-term care
spending.

We have seen the shift overtime
for a few reasons

First, they tend to receive care

in their homes or communities.

States are offering that option, they are more likely to take part in that option.

The second, states like it because it is typically cheaper to provide than institutional care.

And finally what we talked about earlier, states have a community integration obligation under the ADA and Olmsted decision.

There are a few major federal grant programs that have played a key role in reducing Medicaid's institutional bias.

The first is money follows the person. Also known as MFP.

MFP is a demonstration program that helps seniors and people with disabilities move from institutions to the community by providing enhanced federal matching funds to states since 2007.

The program operates in 42 states and transitioned over 100,000 people as of

December 2019.

It is often credited with helping states establish formal institution to transitional programs.

States have used the funds to offer housing related services and hire housing specialists to locate affordable housing.

Which is routinely cited as a major barrier to transition folks from institutions to communities.

The other federal grant program is the Medicaid balancing incentive program.

It was established by the ACA. Developing and expanding community based alternatives to institutional care has been a priority for many state Medicaid agencies.

States have made significant progress in increasing the percentage of long-term care dollars that go towards providing HCBS.

The ACA established this program as an option available to states

to support that rebalancing effort.

If states rebalance the spending to spend more in HCBS and implement required structural changes to the programs, they were eligible to receive enhanced federal funding.

Many of the participating states met the infrastructure and rebalancing requirements.

There was some state variation in how successful the program was.

Next slide. Another way has been to align eligibility criteria for receiving HCBS and institutional care.

One of the ways that state Medicaid programs provide HCBS to beneficiaries is through a waiver.

This slide here shows that for nearly all waivers, functional and financial eligibility criteria is less stringent or the same for institutional care.

For only a few waivers is eligibility criteria more

stringent than institutional care.

Next slide. The last area I'll touch on here has to do with pathways to expanding financial eligibility for Medicaid long-term care and aligning the rules across different long-term care settings.

So many states have taken steps to allow for slightly higher income beneficiaries to qualify for Medicaid long-term care.

Historically, they have been adopted for institutional care.

However, states have taken steps to adopt the pathways for HCBS as well.

This is important towards the overall goal of eliminating program bias towards institutional care.

If people can qualify for institutional services at higher incomes then would be required to qualify for community base services, they may choose to unnecessarily enter a nursing facility because they qualify

for it.

Rather than spending down their income to qualify for home and community based care.

One thing I'll note as I talk about the different pathways, I'll refer to individuals with higher incomes a few times.

By this, I mean individuals with up to 300% of SSI.

The first thing I'll touch on, the special income rule.

The special income rule allows people with slightly higher incomes to qualify for Medicaid LTSS as long as functional needs requires institutional level of care.

Historically it has more often been applied to institutional care but states have recently been applying the special income rule to home and community based care as well.

There's also a rule that allows an individual with higher income to qualify for Medicaid long-term care as long as excess income is administered through a

trust.

It's called a qualified income
or miller trust.

Nearly all states that allow
miller trusts for institutional
care, allow individuals to use
miller trusts to qualify for
Medicaid HCBS.

Again, using the same financial
eligibility rules for
institutional care and HCBS
helps to alleviate the bias
towards institutional care.

And finally, spousal rules.

If one person lives in an
institution and the spouse lives
in the community, the spouse
rule allows the spouse who lives
in the community to retain some
of their funds for living
expenses.

As of 2018, 50 states were
applying the spousal protections
to HCBS waivers as well.

Meaning if someone is receiving
care through a waiver, their
spouse can still retain some
funds for their living expenses
without needing to spend it all

down to ensure their spouse can qualify for the waiver.

Next slide. The last area I'll talk about falls into utilization limits.

The way that Medicaid HCBS waivers are designed allows states to choose and limit how many people are served under them.

Capping HCBS waiver enrollment can result in waiting lists.

When the number of people seeking services exceeds the number of waiver spots available.

For example, in 2018, we found that nearly 820,000 people were on an HCBS waiver list nationally.

One thing I'll note about the data point, not all individuals on waiting lists may be eligible for waiver services.

For example, of the 41 states that reported the data on waiver lists, 31 states screened for waiver eligibility before putting them on a waiting list.

The other eight states did not screen for waiver eligibility.

Other types of controls that exist in HCBS waivers are hour limits, cost limits and geographic limits.

All of those states can implement to control utilization in the HCBS waivers. The utilization controls have sometimes been cited as institutional bias in the Medicaid program since they don't exist for institutional services.

Next slide. A few policies out there that would increase Medicaid. The American rescue plan.

It included a provision to increase the F-map rate by 10 points.

It would be about an additional 11 billion federal dollars in the one year time period that the additional federal increase would be in effect.

Given the fact this is a time-limited proposal, we think

that states will be more likely to use the funds to adopt policies for the pandemic.

This includes such as increasing pay for direct care workers or offering targeted services.

The more recent proposal I'll touch on, the better care better jobs act.

When I say recent, I mean within the last week.

This was sort of the -- this was the bill that came out of the original infrastructure bill.

It is the democrat's proposal for the \$400 billion towards HCBS.

The proposal has three provisions to expand and strengthen Medicaid HCBS and direct care work force.

It includes a major provision around infrastructure improvement.

This offers a couple of ways for states to receive enhanced match for Medicaid.

It includes incentives for

states to adopt self-direction programs, expand eligibility up to the federal maximum and update HCBS payment rates and ensuring the rate increases are passed directly on to direct care workers.

The other two provisions in the bill would provide funds to make money follows the person permanent.

And make HCBS spousal protections permanent.

So with that, I'll pass it on to Andy who will talk more specifically about California.

ANDY: Thank you Priya. Great to be here with everybody.

I'm going to try to be brief.

As Lewis mentioned at the beginning, I'm the executive director at Disability Rights California.

I started this job in February of last year. Right before the pandemic.

And I got appointed by the state of California to their community vaccine advisory committee

during the holiday period,
towards the end of last year.

This was a multi stakeholder
committee that California wanted
to work with to make decisions
related to vaccine
prioritization.

It was chaired by the California
department of public health and
the surgeon general of
California.

Our state has its own surgeon
general.

So she co-chaired the community
vaccine advisory committee with
folks from the California
department of public health.

Erica pond was the lead
physician but the head of the
California department of health
who started in that role during
the pandemic was also very
active.

And they had about I would say
90 different organizations
represented on the stakeholder
advisory committee.

There were five of us coming at
it from a disability perspective

and we worked closely together to make our voices heard during the process.

That included in addition to Disability Rights California, it included the education and defense fund, the California foundation of independent living centers and our state council on developmental disabilities.

And then the representative from justice and aging ended up supporting all of our recommendations.

He was wearing a hat bigger than disability but definitely saw the importance of prioritizing high risk people with disabilities.

The story from California as Priya referenced was kind of a series of ups and downs that were very frustrating at times and got better overtime.

In December, the state following the approach that was recommended by the ASIP group that Priya referenced, they had a tiered structure similar to

what Priya described.

And in that tiered structure, the plan was to basically get the vaccine to people as a priority who were at highest risk of negative consequences from COVID.

So a reason to start with front line healthcare workers is because by nature of their jobs they would have more exposure.

They prioritized people in nursing homes as Priya described, in part because we had data showing there were disproportionate deaths happening in nursing homes.

And we had a back and forth with the state on how to identify high risk people with disabilities under 65 and over 65.

In January, the state decided that the tiered system was going to be too complicated to administer and they decided a better system would be to do everybody over 65 in California.

And then they would go down

based on age cohorts. Everybody over 65 and then 55-64 and on down.

They estimated at the time they announced that to our committee that it could take as long as three months to get to anybody under 65.

So we were very concerned when they made that announcement that people with disabilities who were at high risk of dying from COVID, who were under 65 were going to die unnecessarily because it was going to take so long to prioritize them for vaccines.

And we had a lot of back and forth with the state.

In February, they announced they would start to prioritize people at high risk because of the nature of their disabilities.

Starting on March 15th, they honored the commitment and they did start to prioritize people under 65 with disabilities.

Including everybody who received in home supportive services

through our home and community based long-term services support system in California.

And everybody who received services from a regional center in California, our intellectual and developmental disability population.

We recommended that to create categories for those groups because they are large populations at higher risk of getting and dying from COVID.

We made the case to the state it wasn't worth doing individualized assessment of each person's risk, it would create barriers to people getting access and it would boil down to the quality of the medical evidence that people could present.

It was not easy to get during the pandemic and we didn't want to divert resources away from treating patients to make this kind of showing on individual basis for people to get the vaccine.

We also convinced the state to let people self attest they were high risk.

They could self attest that because of the nature of their disability they were at high risk of getting COVID and having negative consequences.

The state went along with that.

We were very grateful for that.

Starting march 15th, a broad group of folks who were high risk with disabilities under 65 were eligible for vaccines.

Since march 15th, the state has been doing a lot of things to try to bring people with disabilities to vaccines or bring vaccines to people with disabilities, including paying for transportation, mobile clinics, working with partner organizations on the ground.

There's been a lot of creative approaches to getting the vaccine to the community.

But we don't have great data.

We have data around race and ethnicity. We know that African

Americans and Latinx population in California disproportionately still many of them have not been vaccinated.

We don't have great data on how many people with disabilities are in that category.

I think I just wanted to reflect on some lessons from the California experience.

And then I really look forward to the Q&A.

One lesson you heard from Priya, we need better data.

The data problem is an interesting one in the sense that it feels like the fact that we didn't have great data about what was happening to people with disabilities during the pandemic was an equity issue.

We basically underinvested and felt the impact during the pandemic. And then we used that equity problem in a way that made it worse when we were making decisions on priorities for vaccines.

Through no fault of their own,

the disability community in California, we didn't have great data on what was happen together us during the pandemic.

Then that lack of data was used against us on prioritization at least initially.

Second, the public health system in California did not have deep knowledge of the disability community.

They were slow to leverage the knowledge of the disability community that existed in other parts of state government.

Eventually we had a task force really focused on getting the vaccine to people with disabilities, including the state department of developmental services and rehabilitation.

The office of emergency services, all of the agencies had much deeper understanding of where the disability community was, how to get the vaccines to them and how to make the case for vaccine prioritization and

how to make it accessible for people with disabilities.

One of the problems in California, we had a number of local public health websites not accessible for people with disabilities because the local public health officials didn't have that expertise.

So, you know, I think there's two pieces to this.

One is for the department of public health to develop more disability competence.

I think they can look to Cal-OES as an example. They have invested in building in house so they can respond to the unique needs of people with disabilities during a disaster.

We need the department, all state departments of public health to develop more expertise.

Similar to what has happened around FEMA at the federal level and emergency services at the state level.

Interestingly, budgets for

public health have been going down overtime.

Budgets for emergency response have been going up overtime.

That's another factor.

There's a lot more capacity in the emergency preparedness and response system in our country than the public health system.

I think leveraging the capacity to make better decisions in a pandemic moving forward is going to be important.

I would also say the media ended up being a huge ally for us in California.

One of the things I found particularly interesting -- I have been doing this about 30 years.

This was the first time, first issue I worked on, the vaccine priority issue, about a third of journalists who reached out told me their personal stories.

They had a personal stake in the issue and wanted access to the vaccines and they understood how important it was and made that

case.

The L.A. times did in one week, we had six stories on this issue, pretty much every day it was in the paper.

There was a lot of media attention to the issue which I think helped get the state of California to change their position on the issue.

We also at a key moment in the discussions with the state, we had a group of physicians in California join us in making the case to our secretary of health and human services.

I think it was helpful for him to hear the medical case of prioritizing under 65 from a group of physicians we had worked with to convince the state to change their position on crisis standards of care.

So, sometimes it's frustrating that you need the medical voice as ally to be heard but it was helpful for us making the case for vaccine priority.

The last thing as a lesson

learned, when the vaccines first became available, we asked for the state -- .

Part of the purpose of the advisory committee was to make the case to various constituencies we were connected to that it was a good idea to get vaccinated.

We asked the state to give us the best data they had about the efficacy of the vaccine for people with a wide range of disabilities.

Like what do we know about how the vaccine was going to interact with disabilities, had it been tested on people with disabilities.

Overtime there were questions about teens and children.

We didn't have great information we could share with the disability community. We do now. So many have been vaccinated.

But when they first started deploying the vaccine, we didn't have great data. The disability

community wasn't really identified as a group that needed to be tested when the vaccine was being tested for safety and efficacy.

I think that slowed us down in terms of the demand for the vaccine within the disability community and still affecting us.

There are still folks in the disability community and parents of teenagers with disabilities afraid to get the vaccine because they're not sure it is safe for somebody with their condition.

We don't have great data across a lot of conditions to help them understand why it's safe.

So I'm going to stop there.

Look forward to the Q&A and appreciate the opportunity to be with you today.

>> All right. Thank you Andy and Priya. All right.

This is your chance to submit questions in the chat area and we'll get to those as you post

them.

Let me start off with the first couple of questions that came in.

So, one person -- I'm going to summarize, we had a discussion back and forth.

So, Andy, you kind of covered like the non institutional, non personal care in California, but maybe you or Priya, do you have a sense of how that went for elsewhere in the country?

Priya, you did a great job of covering what happened for institutional and HCBS populations. What about the disability community not part of that?

ANDY: Priya, do you want to go first on that?

PRIYA: Sure. I can talk about -- my answer will almost be a non answer.

One of the struggles we had with sort of understanding what was happening on the ground for folks who might not be reflected in state records because they

either are not receiving care at an institution or not enrolled in a Medicaid HCBS program.

There's just not really data available. And a lot of antidotes do come from journalism and local news that chooses to highlight the individual experiences.

There's not a systematic way that states are collecting and sharing that information.

From a research perspective, it's not a population we were able to really get a grasp on.

In terms of how many cases and deaths there were in that population.

What their unique needs and challenges were.

Certainly that's something that that population has been speaking up.

I think it's much more anecdotal than we would like.

But unfortunately because there's not good data there, we haven't been able to get a good grasp of the unique needs and

what is going on with the population of that level of disability.

ANDY: I would just add from the work I have been doing on the federal health equity task force, we have kind of under invested in disability data collection for a long time.

I remember, I came to DC in 93 to work for senator Harkin during the Clinton administration.

In 1994 and 1995, there was a disability supplement to the national health survey.

It gave us a lot more data on what was happening with people with disabilities and where they were in interaction with the current government programs and services.

That supplement has never been repeated. That deep information we got in the 90s, part of that was a determination by the leadership of the Clinton administration that it was important to have better

disability data.

If there ever was evidence of the importance of having good disability data, it was on the issue of vaccines and lack of clear data and comprehensive data was being held against us in multiple states.

On if we were a priority population for vaccines.

Priya, you mentioned the ASIP kind of process that CDC convened.

Interestingly, the ASIP developed a list of conditions that they considered to be high risk.

Related to COVID, and one of the conditions on the list was down syndrome.

But they did not mean intellectual more broadly.

I think they had the criteria for down syndrome but not other types of disabilities.

ASIP specifically said they didn't think their list should be used because it wasn't comprehensive and developed for

that purpose but many states used it for that purpose.

I feel like this issue of not having enough investment in collection of disability data is a huge equity issue that can be a life and death issue for people with disabilities during the pandemic.

Priya, I don't know if you want to say more on that. I appreciate the research Kaiser Family Foundation has been able to do on this.

PRIYA: We have been doing work with the national health and aging trends data, which has some information on unmet need and functional limitations for folks who live at home.

That data is restricted to those 65 and older. That is one of the struggles with the data set.

It doesn't reflect non elderly adults under 65 who live at home.

I would echo the need for additional data and we have been doing research with the

available data but absolutely additional investments is needed.

>> All right. Andy, this connects to my history.

I'm happy to hear your call for more data.

One person asked do you think more disability information should be collected in electronic health records and would it help to get information out to public health.

ANDY: Yeah, I think if we're going to collect disability data in a way that is robust and meaningful, we have to do it in a way that is doable for our healthcare system and our various population-based data collection efforts.

Electronic health records is one way to do it. Kind of figuring out how to do it in electronic health record where the data is meaningful and you have a way of identifying disabilities without asking hundreds of questions. That's something we need to

figure out. I don't know if anybody has figured out a way to capture all people with disabilities on electronic health record.

I don't know if you have looked at this, but my sense is -- .

The census asks six questions and there are a lot of disabilities that won't show up on the six questions.

This is one of the challenges we try to get through the data and make it easier to collect the data.

How do we do that without asking too many questions.

PRIYA: The one thing I'll add to that.

We work with Medicaid claims data at KFF. This is not indicative of the population as a whole in the U.S.

But the newer years of Medicaid data 2016 and onward has disability status of Medicaid beneficiaries, which is very new.

It should give us more

information on service
utilization and enrollment
pathways and things like that
related to people on Medicaid
with disabilities. But not
indicative of the U.S.
population as a whole.

>> Yeah, I don't want to make
this too much of a discussion
about the disability data.

There's a difference between
population data and beneficiary
data. It's not the same overall
population.

As Andy's referring to, the six
questions on the -- which are
the ones used on the census and
have been used in other places
as well.

They are trying to use that --
with all of its warts, it's the
one that everybody uses
hopefully to try to make a
consistent population recorded.

So that was the answer to the
person who asked the question
about encouraging people with
disabilities to report
information on themselves to the

census.

There are six questions on the census for that. It's not just the census. It's the every year sample the census department does.

Next question. The Massachusetts department of public health had disability questions in the COVID-19 impact survey and got really meaningful results.

They're working on ways to pull disability data from electronic health records and would welcome any input on that.

Also let me just sort of step back to a couple of things that Andy brought up earlier.

Let people know there are other webinars that we have hosted that cover a couple of these topics.

The crisis standards of care, we had a presentation on that.

That was a couple months ago, you can find it in the healthcare archive on the website.

Looking at the crisis standards of care around the country and what they were doing or not doing for people with disabilities.

Just last month or a couple weeks ago really, on the emergency preparedness, emergency management webinar series in the same ADA presentation platform.

If you go in that archive, there's a discussion from FEMA and California about setting up the vaccine distribution sites.

And making them accessible to people with disabilities.

So just wanted to add those for people to know.

I have another question here.

In California, there was a county level implementation of the vaccine distribution.

So we saw at our center, we saw reports of some -- quite a few delays for people who were homebound about getting their vaccine depending on if their county and system was set up

well enough.

Even had one instance where a person received finally received their vaccine a couple -- maybe even in June I think.

It required a team that came from another county like far away, like maybe 60 miles away.

Andy, I don't know if you saw that or had discussion about that at the state level.

How the counties were an element of this?

ANDY: That's a great point.

The county variation worked in both directions. There were counties that were prioritizing people with disabilities under 65 before march 15th. They made the vaccine available.

So what the state was doing in California was making recommendations but the counties, at least some of them, felt it was up to them how they were going to make their own lists.

I think over time, the state tried to get more consistency

and hired a third party administrator at blue shield to help them do that.

It felt like the wild west at different times, different counties coming up with different rules and sometimes it was based on the quality of the relationship the local public health authorities had with the local community.

To the extent that the independent living center were part of county level advisory groups.

They were making decisions and getting the vaccines to people with disabilities faster.

You're absolutely right. 58 counties in California and a lot of variation, especially in the first quarter of the year.

>> And Priya, I know your data is state based. But did you have anything you saw or were aware of that went below state level?

PRIYA: I don't think so. I think a lot of our data was more

high level.

>> Okay. Go ahead and get your questions into the chat room everyone if you have questions.

So --

ANDY: Can I ask a question of Priya?

>> Absolutely.

ANDY: I know Kaiser is big and I don't know if you know the answer to this.

My sense is the Kaiser Family Foundation was doing its own polling during the pandemic to kind of find out whether people were ready to get a vaccine or understand vaccine hesitancy or readiness in different populations.

My sense is you all were asking a question to help identify if as people were responding to those questions, if they had a person with a disability in their household.

PRIYA: That's a great question.

I wish I could recall that off the top of my head. We did do some polling around vaccine

hesitancy.

We started tracking that back in January. Tracking it over time.

I do think there was a question asked about that.

I think it was asked two different times.

One earlier in the vaccination process and one more recently.

I don't recall what the responses were.

That is a different team at KFF that puts out the polls and analyzes the responses.

Unfortunately, I can't remember that off the top of my head.

ANDY: I'm just grateful you all thought it was important to identify it as a demographic factor.

That's one of our fundamental opportunities coming out of the pandemic.

When we talk about disparities and equity, making sure that disability is not just an outcome but a demographic factor that we're capturing information about.

As we both know, that doesn't always happen.

PRIYA: Sure.

>> All right. So coming back to another lesson for either of you and maybe antidotal concept here.

Did anything you saw or learned feel like it rose to a level of being a problem or barrier to ADA implementation by the states or local governments?

Or anything specific related to the three main things about facility, accessibility or effective communication or reasonable modification of policies, practices and procedures.

ANDY: I'm happy to start from a California standpoint.

It wasn't unique to California with websites not being functional for people with disabilities.

One of the problems in California, the website when you went to sign up for a vaccine, the website would time out if it

took too long to enter your information.

For some people with disabilities, they need more time to enter their information.

There were problems with screen reader especially for the local public websites.

If you look at the mass vaccination sites, their level of knowledge to create a process that was going to work for people with a lot of different disabilities varied dramatically.

Again, this is where the sites supported by FEMA and able to tap into the expertise of the California office of emergency services, they started out with a lot more knowledge about how to do these kind of sites in a way that were going to be accessible for folks with disabilities.

Yeah, I think there's an opportunity to educate the public health system in California and around the

country with how to respond to a pandemic in a way that is accessible and compliant with the ADA.

A lot of these public health budgets have been strained. They have laid off staff. They don't have a lot of in house expertise around the issues.

PRIYA: Yeah. The one thing I'll add to that.

The new CMS rule around vaccine reporting and education requirements does have some language encouraging intermediate care facilities to make sure vaccine education information is accessible.

Whether that is making it available in braille, providing it to folks in large text format.

They do actually have the rules preamble has quite a bit of information on making sure the information is provided in an accessible way.

My best assumption is that happened five or six months

after the vaccine process started. I assume the language was taken from feedback and that feedback hopefully will be implemented as residents and client facilities are educated about the vaccine.

>> Okay. We have somebody.

There's a few questions coming in here. For those who have disabilities and suffered vaccine side effects for several weeks, there seems to be no support for paid time off.

Rather the focus was vaccination compliance. I felt abandoned during this time.

What are recommendations for the future?

ANDY: In the employment context, California issued guidance to employers telling them they should give employees time off to get a vaccine.

I think you're right. They didn't really get into giving people time off to deal with the side effects of a vaccine.

Especially if they went on for

several weeks.

And your comment reminds me there are a lot of people who have long COVID -- .

Who got COVID and has had long-term consequences from it.

That population in my mind no question has protections under the Americans with disabilities act.

Think of an opportunity for the ADA network educating folks with long COVID about their rights in employment, healthcare, educational settings. I think that's a real opportunity.

These are all folks, a lot of them are folks with new disabilities who haven't necessarily learned about the ADA and don't know the definition of disability in the ADA.

How to get an accommodation and put in the request.

In the context of someone just having long-term side effects from the vaccine and doesn't have an underlining condition.

That's an interesting question
if that would be a reasonable
accommodation of the ADA to
have more flexibility around --
it would be good management.

But if that's required by the
ADA, I don't know.

>> I think this kind of a
question is a very good one.
Probably is not the best one for
our speakers today.

This is exactly the kind of
question that you could call the
national network at 800-949-4232
and they can answer the question
for you.

All right. One person mentioned
there are a lot of physical
locations made aisles and spaces
narrower or put in one way
arrows they expected people to
follow.

Or added tables before registers
so people with some mobility
issues couldn't reach counters
or did things that made them
less accessible.

Including but not limited to
drug stores.

I think that might just be a comment but if you want to add to it, you can.

ANDY: The only thing I would add, a lot of restaurants here in Sacramento and around the country, because they couldn't use indoor space, they created outdoor spaces that would block access.

For people in wheelchairs and other disabilities.

Some restaurants are trying to continue to use that outdoor space as a way to make up for lost revenue.

I think this is kind of an ADA mission still playing out.

Making sure whatever the work-arounds are and as restaurants expand outside, they'll have safe accessible pedestrian access.

>> Yes, that is true. And we are getting -- we've had many calls from jurisdictions about what to do about these situations and how can they deal with the restaurants themselves.

Sometimes the restaurants just build these things themselves. So next question. In terms of future pandemic planning, which I think we should start developing a comprehensive plan for as soon as possible.

What are the biggest lessons of handling in the future.

I'm going to add a bit to that.

I was going to ask that question, too.

Right now there's long-term future and then there's the short term future. Andy, you mentioned the vaccines are going toward children now.

There's a similar question about if we're prepared and have this correct for children with disabilities.

And also what happens if we all have to get a booster shot in the future.

What do you think the lessons are that might be learned from here or are we prepared I guess.

PRIYA: I can give a quick response to this. I think

leveraging local community leaders and people that are trusted in communities we have sort of struggled to disseminate the vaccine to.

That's communities of color, disabilities. Where there are local trusted leaders.

Giving them more power and have them lead the efforts.

If we're talking specifically about the booster shots we may have to get, leveraging the power and network the communities already have.

Giving them the resources they need to be able to reach people that they know the best I think is where I would start.

ANDY: Yeah. And just kind of reiterating what I touched on in my remarks.

To the extent that we have made an investment as a country in disaster preparedness and response that is going up over time.

Through global warming and other reasons we are having more and

more disasters. We have kind of made a decision to lower our investment in public health.

I think we have to ask the question, does it make sense to put public health in charge of responding to a pandemic or to put the emergency preparedness and response infrastructure in charge.

And then have public health as an advisor to them.

I feel like in California and although of states, we gave public health a huge pass.

I think maybe the answer is we need an all government response and figure out different roles.

I feel public health was asked to do too much in this pandemic.

I don't know it's fair to expect them to play the same leadership role in the next pandemic.

>> Okay. Related to that, this comment that came in.

I think this is awesome that the disability community has a voice within the new administration.

I thank you for your work and

dedication. I am seeing cities sued around the country for failing to address title 2 and 3 accommodation.

How can we get them to be more proactive. ADA at times seems to be an after thought.

Before you guys take a crack at that. Let me just say, that's the purpose of the ADA national network and we are trying to reach out to people.

It's hard to get to everybody.

We're doing what we can to educate people publicly, but people have to know that they have an issue to approach us many times.

There is that. Anybody want to add anything?

ANDY: One thing I'll add.

I'm seeing a phenomenon that more and more people with disabilities are running for political office.

Many are starting at the local level. We're seeing it at every level of government.

My hope is that is going to help

whether they are on city councils or mayor or county executives who have lived experience with disabilities and prioritize accessibility.

Looking at local jurisdictions around the country, the city of Chicago really stands out for me as a city that has invested in a cabinet level position, the mayor's office for people with disabilities.

Compared to other cities, it is a well-resourced office with competent leadership to make the whole city make good decisions around accessibilities.

I feel we need more entities like that across the country so there are people sitting at the table with the mayor with real expertise and lived experience.

PRIYA: I would just echo what Andy said. Things like this, culture often starts at the top.

If elected officials at local, state and federal level, if they are talking about it, it's more likely it will be reflected in

the responses to pandemics that we see in the future.

>> Yeah. I think sort of part to emphasize about what everybody is saying here.

If you're asking this question, there's a role for all of us, everyone to talk to your elected representatives.

Talk to people in your jurisdictions to get them to pay attention and look at the issues about their jurisdiction, their title 2 or 3 entities.

ANDY: One other thing on that comment. Lewis, I think your network has been part of this.

There's a whole smart city movement happening globally.

Where cities are trying to use technology to inform decision making and to be responsive to the needs of their population.

Both their residents and also visitors.

I think that smart city movement is another opportunity to bake in ADA requirements and accessibility requirements as we

develop platforms for transportation system or other systems.

I'm guessing your network has been connected to some of folks working on that. That's an exciting development.

>> Yeah, and different ones of our regional centers have been involved in different ways. So, yes.

All right. Andy and Priya, maybe you can put your contact information in the chat box for everyone to see.

Send it to all panelists and attendees so everyone can see it.

I want to just tell people if you still have questions for Andy or Priya and you didn't get a chance to ask that question, they're going to put their information there.

You can then ask that question.

I'm going to ask this one last question here before we close it up.

How did California deal with the

inability of individuals
differently abled to comply with
the three CDC protocols as
protection from COVID-19. Andy?

ANDY: So -- I just want to
clarify the three CDC protocols,
I'm assuming social distancing,
wearing masks and hand washing?
I'm going to assume that's what
they are referencing. I think
what we tried to do, at
Disability Rights California, we
worked with the education and
defense fund.

We tried to come out with
thoughtful guidance about how
mask requirements were going to
play out so folks with
disabilities and kind of ways to
honor the fact that there are
people with disabilities who
can't wear masks.

There are people with
disabilities who can't go
anywhere if people don't wear
masks.

Kind of getting that right was
nuanced and we ended up doing
some joint guidance.

I think as we were talking about earlier, how that played out across the state of California varied dramatically.

We had a pretty strong movement in California that was the anti mask movement that tried to use the AD A to say people didn't have to wear masks even if they didn't have underlining disability related reason for not wearing masks.

It was complicated. The answer to the question is yes, it is available on the Disability Rights California website. I can see if I can find it right now.

>> Okay. While you're looking at that -- let me just reiterate to everyone.

If you have a question for Andy or Priya, they have their information there in the chat for you.

If you have a question that relates to the ADA, you can call your regional ADA center at 1-800-949-3232.

Andy has put the link for the guidance there in the chat. So you all will receive an e-mail with a link to an online session evaluation.

Please complete that evaluation for the program. We really value your input and want to demonstrate the value to our funder.

We want to thank Andy and Priya today for sharing their time and knowledge with us.

A reminder to everybody that the session was recorded and will be available for viewing next week at ADApresentations.ORG in the archived section of healthcare.

July 22nd we'll be joined by adult and child consortium for health out come science for working with diverse healthcare organizations.

We hope you can join us for that. Watch your e-mail two weeks ahead of time for the announcement of the opening of registration for that.

All right. Thank you for

hanging in there and attending
today's session. Have a good
rest of your afternoon. And
thank you again Priya and Andy.
Have a good day everybody. Bye
bye.