AUCD Medicaid 101 for Trainees.

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>>: Welcome, everyone I am Cindy Smith and I'm the director at AUCD welcome to the series of webinars hosted by the collaboration team on various public-policy topics that we have heard that trainees would like to learn about this year and one of
the ones that we heard most the people are interested in learning about is Medicaid and Hume and community-based services. We have invited two experts that we work closely here in Washington DC today to giving overview of the Medicaid program and
community and home-based services pick a couple times in the webinar we will break for questions. You complete your questions in the chat or you can raise your hand and ask to put your name and questions. With that, I am not going to take up too
much time, but I will will turn it over to you Nicole and you David. The code you're wake is from caring across generations. Before that she served as the director of public policy and senior executive all officer of policy at the -- she has worked
for the member number of years up in Illinois and is the CEO president of the Institute of his disability pictures also trained as a special special education attorney, and will speak more and you come to this from working with your brother. Who
need support and care.

David Machledt is the senior policy analyst at National Health Law Program and he works on healthcare issues in a number of healthcare and Medicaid issues. He has a Ph.D. and is trained as a goal anthropologist. I will turn it over to you Nicole
and David to start.
DAVID MACHLEDT: Thank you. I will go ahead and hop on to the next slide pic I'm looking at the headshot and looking at my beard and the whiteness in it, it may be time to update.

Thank you all so much. I'm going to get us started for the chance to speak with you, and we will give a general overview and spend a lot more time of the questions part because I think the interactive part is always the most interesting part of a
good webinar. I work for the National Health Law Program, which is a nonprofit that provides legal

backup for that legal assistance in the 50 states. We also do advocacy at the federal level and we work with state partners including protection and
advocacy agencies on different state policies. I am going to start out in this overview just situating us. We can go to the next slide I will go back to the bad old days of we will be focusing on Medicaid today, but I wanted to put Medicaid into a
bigger context of the complicated picture of healthcare coverage in this country. Before the ACA. There were huge coverage gaps and this shows us with some of those gaps were. Medicaid, which is represented in blue covered low income children,
pregnant people caretakers and older adults and people with disabilities who had low incomes.

Older adults anyway.

If you look at youth who had higher income threshold and Medicaid they were covered by CHP, which is represented in green and then when you had older adults people over 65 and people with disabilities many people with disabilities under 65 they also
may qualify for Medicare coverage. That is the purple. At lower income levels they often had Medicaid and Medicare it which made them a duly eligible. There is a big white gap in the middle for adults and parents who had all but the lowest incomes
those people at the time got coverage through there employers or maybe they paid for it on a market if they could. Her they were subject, those policies were subject to coverage restrictions especially for people with pre-existing conditions that
made it prohibitively expensive to get coverage or they could not get it at all.

That affected many adults, people with disabilities and chronic conditions especially. Next slide.

The ACA changed a lot of that by trying to fill in some of these big gaps. First, you had Medicaid expansion, which created a new Medicaid eligibility category for adults who had incomes up to 130% of FPL which about this year is 34,000 $300 for a
family of three. That covered people with a lowest incomes. People who made slightly more money than that, adults and parents who made more money than that could purchase private coverage with no restrictions and no added costs for pre-existing
conditions through the marketplace, which is also known as Obama care or exchange coverage.

The government for people under 400% of FPL, the federal poverty limit, the government provides tax credits to pay for premiums and also helps with some of the cautionary expenses.

The Supreme Court made Medicaid expansion optional for some states. There are still states where this light greed medical Medicaid expansion category is still a white category. There were other people in this country like immigrants because of time

coverage bars. I put, "seamless" and coats, but you can get an idea of how these coverage programs fit in and how they fit in with the spirit next slide.

The other thing we're going to talk about today is LTSS or long-term supports and services. Who pays for that? LTSS and Nicole will go into the in more detail later. But this is things like if you are in a nursing facility or if you need to pay
someone to help out at home with a personal care or something like that. In private and employer marketplace insurance do not cover that.

Medicare, this is a common misconception because Medicare is centered on serving older adults and people with disabilities. That is exactly the people you would think need this extra assistance so they can maintain and live independently and thrive
in their community.

But Medicare does not cover that either. A cover short-term stays in nursing facilities and homecare benefits, but most of that is focused on rehab so if you had a fall and needed some extra time to rehab from surgery or something like that.

Those people on the decay Medicare have might have to turn to something else. You can look at long-term care insurance market, but that is super expensive and the last I checked it was 1 in 10 adults who were over 65 had that and even fewer for
people under 65 pick that does not cover it. Which leaves us with Medicaid. Ding ding, that is your answer. Medicaid based on a whole range of settings from institutional settings like I mentioned to home and community-based services. We going to
talk about that more later, but I wanted to make that distinction up.

Next slide. I'm going to do a quick distinction for people because it is very easy for people to get confused between Medicare and Medicaid. I will not go through a lot of details. We're going to focus on Medicaid, which is directed at lower
income people, there are many eligibility categories. It is a federal state program, which we will talk more about and has income and asset limits. For most categories. That means if you have a higher income, you probably won't qualify for
Medicare or I just did it.'S older notes and to seven there are no income or asset limit, but your work history does matter. Qualifying without a work history. It is a federal run program, which makes it different from Medicaid. We have already
covered the differences in LTSS. I will stop now and turn it to Nicole.
NICOLE JORWIC: Thank you so much Dave. Liz had asked me to define a couple terms and I will start with that and you can skip the two slides to the lingo because that is what I will start with.

I did this in the chat, but the ACA is also known as the affordable care act or Obama care so making sure that Dave and Liz and Sidney and I live in a world of alphabet soup. FPL is the federal poverty line and Liz wanted me the pre-existing
conditions, the Affordable Care Act allowed for people with pre-existing conditions to receive services. Those pre-existing conditions can include disabilities and something like a cancer diagnosis. Those of the folks that were covered that were
not covered before.

Dave already went through some of this, but just to reiterate because I might slip into it whether I'm saying LT SS that means long-term services and supports. HCBS's home and community-based services. You might hear things like homecare. That is
HCBS. You might hear things like employment services. Those are home and community-based services. But really think about home and community-based services as any support or service that can be provided in the home and community if I remove refer
to the Medicaid law what I'm referring to is the Social Security act because the Social Security act is what was amended to create Medicare and Medicaid.

That is a long. We are also going to go through and talk about regulations. We are going to talk about things like the HCBS access rule, no, the HCBS settings role and the access rule. Those are both regulations. There is also a bill or law that
mixes those together, which is why I just did it myself we will talk both about the laws that oversee it and some of the regulations, which are things that the agencies and the federal government it is the health and human service agency through the
Center for Medicare and Medicaid services that puts out those regulations to interpret the laws of Congress. I wanted to make that distinction.

Go to the next slide. Cindy referred her already talked a little bit about my employment background background. Always the most uncomfortable part of any presentation is you're listening to your own bio. But wide Medicaid matters to me personally
this is a photo of me and my brother Chris. I have permission to share his story. He is 33 and has autism and receives Medicaid Medicaid HCBS an Illinois. There is a large waiting list and his lucky. I will get to that. Medicaid is something
that I understand from a personal perspective and have been a direct care worker defended by Medicaid. It is something that matters to 70 people, but also something a lot of people that rely on the services do not understand or do not realize what
is being covered, which is why this presentations or something that Dave and I love to do.

We can go to the next slide.

Something that is important when they think about Medicaid if they think about Medicaid at all, they think of it as as a healthcare or health insurance program and it certainly does provide healthcare services, ER services, prescription drug
services, Dr. Points to a lot of people. Including disabled people. It also pointed out is the main funder in this country for LTSS including home and community-based services. It matters because it is such an important program, but why it is
important for the disability community for Medicaid is that while people with disabilities and older adults only make up 21% or so of and release in Medicaid, they account for about 48% of the cost.

That is because the services are long term the services are expensive and why all of us have a real responsibility to understand the program and advocate for they continued and expanded funding into the program. Next slide.

This slide lays out the fact again that Medicaid is the main funder for these services. It makes up a little over 52% of the funding and as Dave pointed out, there is some private long-term care insurance, but it is 11% of the market and shrinking
every year, which is why we need to focus on Medicaid.

Next slide.

Medicaid is a way for the state and federal government to share costs for long-term supports and services. Every state knows that if they are going to invest a dollar into the Medicaid program, that it is a prenegotiated, predetermined rate that the
federal government is going to pay back. On average the federal government pays states 63% of every dollar that they spend on Medicaid. That can vary in places like DC. It is around 70%. In New York and California it is 50 points 01%. It is
always a little bit more 50%, but it can be pretty close to split. Some services and groups do get a higher match and I will talk through some things recent that recently have include an enhanced percentage of federal funds.

That predetermined what we call Medicaid guarantee is that every state knows what they are going to get matched on there prenegotiated rate with the federal government. It is that state and federal partnership, which is important but it is also why
it can be confusing. We can go to the next slide.

When I say it is a state and federal partnership. It is not just because it is a share of state and federal funding although that is an important part. As advocates we can both advocate for more money from the state legislature because if the state
legislature puts more money and they will get more federal money and also more money flowing in

from the federal government to support states to expand services we want to expand.

Because it is a state and federal partnership with funding, it is actually not a state and federal partnership in terms of the law. The laws that SSA, the Medicaid law, and that federal law mandates what are mandatory services, what are required
services. When you think of mandatory it is required but the federal government is requiring states to fund it with Medicaid dollars and what are optional services. Mandatory services are traditional healthcare services, ER, drugs, some of the
things I talked about. In most instances mandatory services also include services in a nursing facility or intermediate care facility with people with IDD's or ICF DD's. That mandatory services again so states have to fund those services.

Where they do not have to fund are considered optional services although certainly for my brother and people who rely on them they are not optional. Under the federal all right now, we have a chance to change it, but I will get to that later, home
and community-based services are considered an optional service. How that plays out, without looks like is waiting lists. Estates can cap optional services. What that means is they can set week conserve this many folks in a certain category,
certain type of disability, some people have services specifically for folks with autism, physical disabilities et cetera, but they can cap that.

That is a big institutional bias of the Medicaid program. States have to fund those institutional settings where they can cap home and community-based services. I'm just noting that prescription drugs should be on the other category. I will fix
that before the next presentation. I will pass it back today to talk more about eligibility, how someone becomes eligible for those services even if it means they have to wait on a waiting list.

DAVID MACHLEDT: Just kidding. I have more and then I will turn it to Dave. Again, this is to drive home with these types of services are. I really went through this, but again it can be things like helping with cooking, medications, getting out
into the community. My brother direct support professional parts into the library, to volunteer so it can also include day programming job coaching a lot of the folks don't realize how many services are actually funded through home and
community-based services that also means our people people are waiting list as well these are the types of supports that are covered through Medicaid home and community-based services. Now I will turn it over to Dave to talk about eligibility.
DAVID MACHLEDT: Thanks, Nicole. I'm going to talk more about HCBS in Medicaid. We can jump into the next slide. To clarify, so when I talk about, I will talk about eligibility and just like Nicole was saying that states under the Medicaid act

they can say, they have to cover the mandatory services, but they can choose to cover some optional services, many of which every state covers. There also eligibility categories some of which are mandatory and some of which are optional optional.

I med mentioned Medicaid expansion before that the Supreme Court case made optional in the law, Affordable Care Act it was originally mandatory coverage so every state would have to do it but the Supreme Court said you cannot enforce that and then
states were able to choose.

I will say that with services and with eligibility categories, if estate says I want to cover this optional service, it does not necessarily mean that it can cover that optional service however it once. It is saying that I agree to cover the service
under the terms of the federal law, under what the Medicaid act says you have to do to cover that service and that goes for eligibility categories to, too. I can do the Medicaid expansion but only going to cover a few people and it. Anyone who
qualifies has to be covered and that is what makes Medicaid and entitlement. That is a weird word, but that is one of the things about Medicaid is that anyone who meets the eligibility criteria is supposed to be eligible. HCBS is unique in terms of
services and is some eligibility categories because those optional categories allow for caps and I will talk more about that in detail, but it makes a little different than the rest of the Medicaid programs so I wanted to make that clear. I'm going
to stop for a minute to just ask if anyone needs clarification or has a question related to that point. Okay I will try to come back to it and go over it again. If estate says I want to do this optional thing, it does not mean you can do whatever.

People with disabilities, there were many people with disabilities who are on Medicaid coverage or have both Medicaid and Medicare. The ways that that happens, supplemental security income if someone has supplemental security income, SSI, it is a
category for people with disabilities who have very low incomes and assets in a most every state they will get Medicaid or we'll have the opportunity to get Medicaid.

This is for coverage aging adults, but also people with disabilities. The disability category that criteria are pretty restrictive compared to some other definitions of disability. So that can be limiting.

It also is a very low, the maximum monthly benefit is $841 so it is a very low threshold.

There is also HCBS there is also state HCBS, which is another pathway weighed forgetting eligible for Medicaid I will talk in those more detail in a minute. A lot of people with disabilities become eligible through the Medicaid expansion. Like I

said before, it is available to any adult based just on income. However, there are lots of people who could not become eligible for Medicaid before. A lot of people with mental health disabilities who did not qualify for Medicaid categories before
who then became eligible for the Medicaid expansion. At their estimates about one quarter of the people on Medicaid expansion in the U.S. are actually people with disabilities.

There are a few other categories for people who are working with the disabilities like to get to work and Medicaid buy-in, which is confusing who have higher income levels and allows them to keep their access to Medicaid, and then there are other
less common eligibility categories, which we can talk about if you have specific questions in the Q&A. Things like medically needy. Next line.

I wanted to talk a little bit more about these waiver programs. You may have heard of it 19's 1915C or the waiver program. This is a specific eligibility pathway for people who need home and community-based services. I am singling it out because
it is one of the most common ways that people get access to HCBS. It is based on section 1915(c) of the SSA and every state has at least one waiver and most states have several or many of them. And all 1.8 million people were covered in one of
these waivers across the U.S. There are hundreds of them across the U.S..

What makes these waivers attractive to states is that they allow states to decide which HCBS they cover, so one part of the things and allows them to target each waiver to a specific population. It could be a waiver targeted to children with
developmental disabilities or a waiver targeted to people who have acquired brain injuries, or targeted to people with HIV aids. One of the criteria that brings these things together is that you need to me and institutional level of care in order to
qualify for these waivers. The income thresholds are a little higher than they are for a lot of the other Medicaid categories in most states, but the level of care criteria is pretty high.

The other thing states like about this aside from targeting is that they can limit enrollment and even spending per enrollee in these waivers. That is what allows them to have a waiting list. Normally in Medicaid there is no waiting list, no none
for service if you qualify you have to get it. In 1915(c) waivers that's not the case. States can R. and say I'm not going to serve more than 35,000 people or 300 people.

Those waivers have to be approved by the federal government. That is something when we talk about HCBS and optional services that states can cap this is what allows them to cap it.

Other HCBS programs there is a state plan HCBS that does not technically allow caps, but a states to

change the level of care criteria to adjust its enrollment for 1915 iMac to allows it to be targeted to different populations. And another area that
you might hear about his section 1115 and I will go out not go into detail, but I will cover in question and answer it is another way that states can cover HCBS and may waive some of the federal requirements that are normally applied to them. That
is a way that some states do this. It is not something that we need to go into detail in a 100101. Next slide.

State plan HCBS is another way people get access to HCBS this is the state plan is a written record that every state has. It can be really messy and confusing, but it is written somewhere and it talks about who this state has decided it can cover
and which services and has decided it will cover and also how the state is going to cover it. If the state uses managed care as a delivery system to cover its services, that would be detailed in its state plan.

Some states have decided through their standard benefit package available to anyone in Medicaid who needs it, they will cover some HCBS that way and that includes things like personal care, home health, some behavioral health services are covered
through the state plan and most states. Any of the services are optional but because they are state plan covered they are part of what the state has said I am covering this in my Medicaid program, they also do not have caps on them. If you are
eligible you would be able to access these state plan services per since they are optional, some states do not have them and other states, but a needs-based or level of care criteria that makes a hard to access. They also have the have fewer
reporting requirements so it is harder to tell how good is the service and how big is the network, how easy is it to provide a provider. That can be harder for state plan HCBS. Next line.

I have been going a little slower.

There is lots of challenges if you have worked with people with disabilities who need to use Medicaid, there could be lots of limitations and problems accessing HCBS. We will talk about these going forward. It can be hard to maintain community
housing, Medicaid to stop pay for your house. It does not pay for your apartment. It does pay your spot in a nursing facility if you qualify for that. That is another source of institutional bias that Nicole was talking about. Sometimes, people
could get into Medicaid but cannot pay for their housing or find it difficult with a low reimbursement they get from SSI for example. That can make a hard to get services in the community.

There is a huge staffing shortage for direct care workers. It can be hard even if you got approved to have hours, it can be hard to find someone to give you those hours. Often Medicaid programs lean on

family and friends even though they are not
supposed to to provide unpaid care in lieu of it paid care. That can be a big problem. It can really with the waiting list situation can be hard because people cannot move from state to state. If you are eligible and Medicaid in Virginia and move
to DC, let's say you move to Florida where there is a long waiting list, it may be years before he can get onto their Medicaid program. They may have different requirements anyway. That is a big issue with Medicaid going forward. Next slide.

Finally, I went to talk a little bit because I always like to bring this up on any presentation I do that when we are talking about Medicaid we cannot forget about issues of equity. Because it is a low income program and because more people in this
country who are low income are also black, indigenous, people of color, and people with disabilities, Medicaid test to have higher shares of those people. Anything happening with Medicaid also has equity implications. In other words, we have big
health disparities in this country and if it makes it harder to access care in Medicaid, you are probably making those disparities worse.

Those disparities can be really stark for people with disabilities who are also people of color, that can be a really complicated or make those disparities even worse. It can compound difficulties and barriers accessing care. We don't have a lot of
data on that. There are not a lot of odd lot of studies out there how bad this is, but we know that is the case. There is little evidence of that and COVID as well. This is something we need to pay a lot of attention to. I want to say efforts to
improve health equity should start with Medicaid. I will stop their and see what kind of questions there are on the things we have covered so far.

NICOLE JORWIC: We must be doing such a good job that no one has questions. I know if this is too much review for people and you want more detail both Nicole and I can go into more detail. I don't want to wish that on someone without some kind of
direction.
>>: I have a question you mentioned both certain things that people have services that that can be qualified under HCBS in the state does provide that but if what I need, what I need is not on the list of approved services, and I need that from my
PSP will it be covered under Medicaid?
DAVID MACHLEDT: That is a great question. I am going to, I will say, well, I'm going to make this more complicated. If you are a youth or adolescent and on Medicaid, there is a provision of Medicaid called early and periodic screening and
treatment. EPS DD. That is one of the most important provisions in the Medicaid act because for a person who is youth or adolescent if there is something that you need that Medicaid law recognizes

that people who are growing need that timely access
to care, that provision allows the individual to get the services that they need regardless of whether the state has said it wants to cover that service or not.

That is not applicable to everyone on the Medicaid program, but EPS TD is important for that reason. I don't want to go into too much detail about how they determined that it has a different threshold. If you are determined to need those services
whether it is the HCBS service, if it is something that is an optional service that could be covered by Medicaid if even if your state is not chosen that, then you would be able to access that service. However, that can be difficult to do to prove
and for adults who are not qualified or do not qualify for EPSTD if the state does not cover that service it can be hard to get that service Medicaid would not pay for it. What you think, in the coal quit would you add something to that.
NICOLE JORWIC: That was a much better answer.
>>: Thank you. Someone was asking, and heard, do school-based direct nursing careful under the umbra law of HCBS for students with Medicaid.
NICOLE JORWIC: If a student is Medicaid eligible it does vary by state, but some of their services are funded by Medicaid that is why when a different point and I will talk about this later Medicaid has been a real risk over $1 billion of Medicaid
money are spent in schools on those types of services for kids who are eligible.
>>: Does anyone else have questions? Feel free to put them in the chat or unmute yourself and ask Dave and Nicole.

DAVID MACHLEDT: >>: Parents are asked to approve, Leanne had a question and Jeanette had a question.
>>: Mine was a comment that in most states parens are asked to approve this before they can actually bill Medicaid for some of those services. And Colorado, parents are encouraged to not approve that.
DAVID MACHLEDT: This is another, this is a subject of recent rulemaking on efforts to change that consent law or regulation.

What I would say is a school-based care is complicated a little bit. As Nicole said it can some cases is covered by Medicaid, it also there are independent obligations that the school has to cover those services whether or not Medicaid is billed or
not.

That is one thing to say. The second thing what is often happening with those issues is there an issue for people who are getting services in the school and if the Medicaid is billed for those, if it is a managed care plan if that person tries to
get services outside of the school, which may be meeting a different need but related the managed

care plan may say you are getting those services in the school so we are not going to pay for them outside of school. That is not something, that is
not allowable. But it still happens. I would bracket the school-based care and Medicaid reimbursement questions essay higher level, as a really deep concern, but it is hard to cover all those details in a Medicaid 101.
NICOLE JORWIC: Yes. There was a question though from Leanne.
>>: I'm not sure if this is necessary I'm a mom of four boys and two of have autism at one level two and one Level three. I live in New York and we have OP W. DD. The system is a nightmare to get your foot in the door, but I was wondering how do
even begin, where do you go to get these long-term services and things of that nature because they do have Medicaid right now, but we have had no access to any of those services. I keep hearing a lot of forms of other parents, but I don't know
necessarily and how to start accessing them.
NICOLE JORWIC: I hear the frustration and I understand it having gone through it as a family member and now dealing with it on the other side with aging folks in my family. ICU see you pick pick -- [Overlapping speakers]
NICOLE JORWIC: Your fine. The fact that they are Medicaid eligible is a positive thing and in New York there should be some opportunity. I don't know if your kids are already connected to case management entity, they should be able to help with
that but also as a former member of the ARC staff I know that New York is a state where there is an architecture in every county. Somebody there should be able to help connect you to the services that your kids are, not the necessarily arc would
provide, but they can connect you to the right opportunities.
>>: I will provide Leanne with some links in a few moments directly to her. To keep us on track.
>>: Thank you. Sorry about that everybody.
>>: This is the real-life reality of what we are describing witches a complicated system and we have a lot of work to do that we need to make sure is more inclusive and easy to navigate for everyone. I see Rachel your question in the chat around
any, but any model states that he can point to that provided inclusive HCBS because my answer is no.

DAVID MACHLEDT: Yeah, usually when we talk about those states, there are good things happening in the state and other things not so good and good things happening in that state and other things also good picket at hard to find a single state doing
everything right. Washington State may be? Sometimes, but they have also been sued for things things.
NICOLE JORWIC: And they are working on building a giant nursing home.
DAVID MACHLEDT: It is very hit or miss. The fact is as Nicole talk about later,, there is a national structural question about how many resources are dedicated to HCBS which lead to the folks are doing a great job on it.

NICOLE JORWIC: There is a question on I am not familiar with a random moment in time to, are you Dave.
DAVID MACHLEDT: No.
NICOLE JORWIC: We will have to punt on that one. In regard to being a service provider.
DAVID MACHLEDT: There's a question about being a paid family caregiver I think a lot of states are working on changing, that is a state-by-state how it applies and whether the state has accepted that as an option in determining the rate is something
that is state specific question.

I know, thank you for asking it, I would be happy to follow up on that afterwards, but I would need to look into what is going on in Nevada to know how to give you an accurate answer on that question.
NICOLE JORWIC: The last question that I seeing right now is around is a great segue what we will be talking about later, which is if other states are seeing those shortages and staffing for direct care and I can certainly say that I see a lot of
conversation in the chat verifying what I have also heard witches, which is yes, it is a problem everywhere. I'm on the board of directions for the national alliance for direct support professionals and we were just in a strategic planning session
what is called is called the workforce crisis in 1994 and post COVID we are at a point of catastrophe I'm not being hyperbolic and I don't mean to be a Debbie downer but if we do not invest funding and we will talk about there are some things
happening on this front, but if we don't change it so that we are raising wages for direct care workers for services were talking about not only are people who are struggling to find workers it is just going to get worse. Or.

That is a big area of advocacy. It is very tied into Medicaid because Medicaid pays the wages of these workers and that is really complicated. We will get into some of it, but not all of it. We will talk more about workforce after Dave goes
through the settings rule, which also has workforce components as well. Before we do are there any last minute questions?
>>: We are good to go and I've asked folks to put their state specific questions in the chat and we will send resources after and it will go directly to their e-mails. I think that will be more helpful.
NICOLE JORWIC: Great.
DAVID MACHLEDT: I love to see everyone asking questions. There are no bad questions. If you have a question probably someone shares that question go ahead and ask it. I appreciate that.

Going to talk now a little bit, Nicole, we've been at the legal, low-level up until now, but I want to talk more at the regulation level. One of the big important regulations from the last decade this goes to a really important question. We've made
this distinction between LTSS and the smaller subset witches HCBS, home and community-based

services versus what LTSS includes also institutional LTSS, which are nursing facility care or intermediate care facility or for mental disease. Or hospital.
That is an institutional setting.

In the 2000s, the earlier 2000s, there was a big question when we had institutions there was a lot of pressure to move people out of institutions part of the homestead Olmstead decision, which followed up the ADA them ADA and said that people have to
be able to receive services in the most integrated setting. Appropriate to have people out so let people out in the community and not institutionalized anymore. It was a critical social movement. What was happening there was pressure on
institutional settings to close over states to move people back into more integrated settings. Some of these institutions would do things like put up a couple group homes on the campus and say we are in a community-based setting setting. Just keep
sending your people here.

That was a really concerning development. There was a push in the federal advocacy community to make a new regulation that would for the first time define what does it mean to mean a community-based setting? That went through a lot of comment
periods and back and a couple of years, more than a couple years, like six or seven. In 2014 there was finally a final rule, and approved regulation, that for the first time defined what a community-based setting would be.

Basically the set up basic rights and expectations for people receiving HCBS. It was these basic rights include things like what is listed here, autonomy and independence, the right to privacy dignity and respect sum freedom from coercion and
restraint some for access to the community sum control of personal resources sum, they get to choose the setting including where they want their services including a nondisability specific setting. Next slide.

For people in provider owned or controlled residential settings who are on Medicaid there were also additional roles. That a sort of an understanding that someone living in these kind of settings is in they may have a more difficult time, they are
in a slightly less independent situation because their provider is controlling where they live. There were some additional rules and protections around that like it has a lease or legally enforceable agreement that people living in the settings will
have access to food and visitors any time. They can decorate their own space and lock their doors. They can choose their roommates, that the place is physically accessible and if our modifications for an individual to any of these rules or rights
should say, those have to be documented. The alternatives that have been tried have to be document

or before the rules change. If you have someone who is a tendency to wander, they have to have that documented in their plan that you are going to
adjust the lockable door thing. There have to be other alternatives that have been explored.

That gives people protection. It is important. It is an important change in the holy escape of Medicaid HCBS. Next slide.

Realizing that this was a big deal, the role put out a five year transition period. States in that time had to look at all of their settings where they were paying for Medicaid HCBS and assess them. Then they had to look at their rules and state
regulations and licensing policies and update those to make sure they matched with the new federal regulation.

They had to get settings that were not compliant with some part of the world to get compliant so remediate and fix those settings.

They had to establish monitoring processes going forward so the settings stayed compliant and within the rules.

Any individual who had to move because the setting they were in was not able to come into compliance, they had to have a safe transition process.

That period started as five years would have ended in 2019 got extended during tromp and then COVID hit and I will want to say in hell in a handbasket handbasket. There there was huge disruptions in access to care with people disabilities. People
who had HCBS were at very high risk and had bad outcomes with the first phases of COVID. Many people died. What we have heard a lot of bout from nursing facilities and also in HCBS settings but not reported like it was for skilled nursing
facilities.'S estates adapted with emergency flexibilities including paid family caregivers, which was lower risk, doing more telehealth, more individualized services, and in many states offered extra support for direct care workers to try to keep
people in that field and able to provide services that everyone needed. It was not enough.

Next slide.

I was going to say, that settings rule has been part of the work that Nicole and I have been doing at the federal level for a long time. That transition period finally closed in March. We are not quite there yet because states have not gotten to
implement all parts of this rule. Forty-four states still have corrective action plans trying to get these

settings into compliance. CMS is still conducting site visits and checking states have implementing basic rules and in many cases they have
not.

That is an ongoing process. I wanted to let people know, let's see, when we look going forward forward, go to the next slide, as we implement this rule, this is a really good basis for making sure people have access to HCBS going forward. But we
have concerns about how this rule if we get past definitions and people are living in a more institution like setting that is approved for HCBS will how will that affect other parts of the law include the Olmstead decision and the ADA which requires
people to get approval and most integrated setting possible.

We have concerns about other things. We know that in no state is every HCBS participant able to ask for a nondisability specific setting. What is going on with that going forward? How are we going to do the ongoing monitoring? That is a question
that we have worked on a lot. And access roles in addressing that when people get Medicaid data to that they are getting quality services and a quality setting. We are trying to make a reality, but it is really something that is quite difficult. I
will pass back to you, Nicole.

NICOLE JORWIC: Thanks so much. It is good to see all the activity and sharing of resources and information in the chat. That is how the best connections happen. I'm glad to see that.

We're going to talk about a more recent as Dave said, I can't believe it has been almost 10 years since the HCBS rule came out. Now we have a more recent rule came out that came out just a couple months ago, the access rule that also came out along
with a managed-care rule. In this case we can move to the next slide. In this case the access rule has a lot to do with the workforce because so often access to home and community life is provided by those workers. There is a lot of complications
in the workforce and why the rates are so low nationally we are around $12 per hour obviously, is super problematic in terms of retaining and maintaining a strong workforce. It was 1996, not 1994 that it was first called a workforce crisis.

There is a lack of transparency in the rates. It is not like the federal government sets some sort of floor or ceiling for what direct care workers can be paid. Medicaid race rates are about the services being provided and the services been
provided. It is difficult to figure out, and find the rate methodology and states. Varies by state and type of services being provided. There is a real lack of transparency in that.

This rule would attempt to get at that. This rule would do two things that are important. It is right now a proposed rule is that the federal government is collecting comments on it, but what it would do is create a set based stakeholder group
disabled people and workers and unless we address from both the state and federal level a lot of these problems are going to get addressed in it for such the first standard of how much of a Medicaid rate should go to workforce wages. It is 8020 80%
to 20% cap frankly that is the part of the role that is most likely to be changed, but it does do a lot to address the fact to address the issues and you can go to the next slide that we don't have the ability to track these workers and also the fact
that this rule will also support the more data that we collect it also has a reporting requirement so that states are reporting back the rates of creating transparency in the rate methodologies that include the wages of the workers. This will allow
for greater efficacy around improving those rates. I will turn it to Dave to talk more about then my vague overview of the access rule.

DAVID MACHLEDT: We will cover another hot topic. We can come back to talking about access if you want and why the states are setting the rates, CMS is approving the rates and where that is falling short. If you have questions about that in the
Q&A. I wanted to cover, next slide, another thing you may have heard of but may not have, it is a really important thing that is happening this year as we speak. In Medicaid across the country. Just a show of hands if you can raise your hand if
you have ever heard of Medicaid unwinding? I guess I can't really see people.
NICOLE JORWIC: It sounds like from the chat that people are hearing this.
DAVID MACHLEDT: This is a weird catchphrase but I'm going to try to lay it out for you so we can help to understand what it is and why it is so important. During COVID there were major instant problems. People did not have access to PPE, there
were suddenly huge staff shortages, and that made it challenging for people to get the services they needed every day. The states and the federal administration and Congress responded by adding new flexibilities and resources to try and address this
problem in March and April 2020.

One of the first things CMS did is it aloud waivers that let states alter their Medicaid delivery systems. That included things like I mentioned before, expanding telehealth, expanding access to paid family caregivers, changing the rules about
assessments you can do them by telephone, increasing provider rates, and making it easier to recruit new staff by waving the need for background check or something like that.

Those flexibilities happened close to right away. Congress also responded by saying we're going to give the states more resources. We are going to provide an enhanced federal match of 6%. If your

state was paying 40% while the federal government
was paying 60% for Medicaid, now your state is going to be paying 34% at the federal government is going to be paying 66% in my math still works. (Laughs) it is a lot of extra money for states, for all of their Medicaid programs.

But the federal government put a string on that. Next slide. Any state that wanted to get that enhanced match also had to agree it was not going to reduce its services had what is called a maintenance of effort cause and that meant the state could
not change its eligibility thresholds or services or lower provider rates to save money. And there was a unique continuous coverage requirement that anyone who came into the Medicaid program during COVID stayed on the Medicaid program. Normally you
get get redetermined every year and if your not eligible anymore, you lose your access to coverage.

Enrollment increased from 71 million in 2020 up to 93 million by March of 2023 of 33% as it should as this chart shows. As of a law passed last December in 2022 they said we're going to start phasing out the continuous eligibility. We're going to
go back, "normal" and we are going to unwind our COVID protections. That is where the Medicaid unwinding comes from. It is how do we get back to doing gritty terminations again pick those reedy terminations phasing out started in March 2023. Estates, but this day started in March of 2023 that is what the unwinding was, but we have been now three years without doing real determinations great term turnover and people have moved lots lot of people have moved. People's incomes have changed there are all kinds of things that have happened that have made it complicated to now do these three determinations. So far when I did the slide on Tuesday it was set at 6.7 million have lost coverage since April. It is now nearly 7.2 million. Everybody in those 93 million people have to get redetermined in this 14 month Pilgrim period from March 2023 until May 2024. We may have some delays not because it has been going really badly.

Estimates are that up to 24 million people may lose coverage. Many of them are children. Most of these people three out of four have been terminated for procedural reasons. That means like we don't know if there not eligible for Medicaid, but they
did not return a form that they needed to return. We sent them the redeterminations packet but never got anything back because the address was no good. That is a procedural reason. Most of the people who've been unrolled have been they may still
be Medicaid eligible but being disenrolled from the program. We have very little information about how this is affecting people with disabilities who are more complicated to determine usually and they have verifications and level of care
determinations and all those things can make it more complicated to Garrett redetermined as a person with a disability.

What are some of the reasons for procedural errors? It could be a failure to contact like incorrect address. It could be that people are confused there are bad notices they get a notice from the state and it makes no sense to them. It is written
in a complicated legalese and they do not know what to do.

There was a study done by the Oregon Institute in June 2022 last year about Medicaid unwinding and the start of renewals. Only 5% of the respondents had said they had heard a lot about unwinding. 62% had heard nothing at all. A lot of people don't
know this is happening.

States may not be interested of a bad actor state may not want to hold people whole bunch people to know about this because they want the Medicaid programs to be slimmer and save money.

That is a problem. They can be a lack of assistance. If you require an accommodation in have trouble sitting and the call waiting overview have limited English proficiency and you want to get on the Spanish language call assistance call, that may
have, in Florida that had a much longer wait time, it was two and half hours. You might get dropped off immediately arrest people using the English line they only got they got a call and only had to wait for 40 minutes or something.

This can be really difficult when there is a lack of assistance. Not only are processes complicated but the staff who are helping you get through it, they may not be familiar with the processes because maybe they have never done redeterminations
before. Next slide.

Being loud is one way to do this but a lot of these things are affecting people with disabilities directly especially trying to get assistance from a call center are trying to get in person assistance to get through a redeterminations packet. So
what can you do equate disability advocates and call your state how do identify people who need accommodations? What training do call center workers received to respond to those requests? What is the accessibility of the website and the ways you
can do this online to update your address and things like that and doesn't meet the federal standards.

Is there an option for in person assistance for someone if they have trouble doing this kind of thing? The states may say no, but they have an obligation to provide these accommodations and that can be something that can be really important.

Next slide.

NICOLE JORWIC: Thanks, Dave. Any questions, actually I will go through this and then we will leave product questions for the end." Run through this quickly. Obviously, we have addressed some of this throughout the last plus, but there are some
real clear policy problems and gaps. At first is what I shared when we talked about mandatory and optional services around the institutional bias of Medicaid leaving almost 700,000 people on a waiting list for home and community-based services. We
have the rolling catastrophe of the low wages for direct care workers, leading to high turnover and other problems. Again, the waiting lists and the continued overreliance on unpaid family caregivers to fill the gaps in the system.

We know from data just in the agent community from AARP that unpaid family caregivers provided $65 billion of unpaid care and that means that those individuals who are being supported by people who are untrained often and also are not having the
opportunities to do with they want to do. It is not leading to a level of independence.

We have had some incremental wins. Go to the Next slide. We talked about that Medicaid matching rate, the fact that the state knows they are going to get a certain percentage back from the federal government in the American rescue plan act that
passed in March 2021. There was a 10% increase for one year just to strengthen and expand access to Medicaid home and community-based services. It was one year of funding so it was short term. Every state did take it up, which is positive however,
states are spending at a very slow rate, but is all is meant to be spent by March 2025. It was a a short term peer rehearsing things like states providing bonus payments or hazard pay to direct care workers. You are not going to see long-term bumps
in pay although 12 states have done that.

We've also had a five-year extension at the end of 2020 I think because we're going to have to start talking about it soon, I can't wait, the Money follows the person program for people who want to move out of the institutional services into the
community and also Pres. Biden's budget included the $150 billion that Congress originally passed that the house originally passed but did not ultimately pass as part of the build back better.

We also have a lot on the horizon."'S of the incremental ones and we need to get to those long-term solutions. We can move to the next slide and really in terms of the.

Get moved to the next slide in terms of what's next. Hopefully, everyone knows Cisco House rock. It is a public image so it is safe. The HCBS Access act is a bill introduced earlier this year and would address the long-standing issue of
institutional bias of Medicaid. This is is a bill that was introduced by Representative Dingell from

Michigan and Representative Bowman from New York and and senators Brown from Ohio, Hassan from New Hampshire, and Casey from Pennsylvanian that
would make home and community-based services go into the SSA to make home and community-based services a mandatory service under Medicaid. That is our long-term goal, our guiding light. It also includes a lot of funding for workforce in this bill. It also includes 100% of federal money, which will be negotiated down inside information. But to really support the building of infrastructure network that needs to be created. Obviously, the current system could not support 700,000 people off a waiting list. We also need to have the workforce in the system to support it. The HAA is an exciting bill to have out there. It is say long-term vision I would say. Already have a lot of gray hairs. I think it will be a lot grayer when we see it
passed, but it is something that we will see past. We can go to the next slide that illuminates more and already said some of this, but eliminate somebody moving from one state that if it is in that federal set of services they could rely on it
being a mandatory service in another state and it does not make it portable to, but it does create that consistency." It also fulfill the ADA does have an integration mandate that was spelled out in the Olmsted Supreme Court decision in 1999 and
this bill would make that a reality. That decision allows for states to rely on things like low state budgets to not fulfill people's rights to community living if they choose to live in the community.

That is our long-term vision and ankle as well as additional supports outside of the Medicaid program, but that is a different presentation for a different day. We happy to spend the next 13 minutes answering any questions that we can.

I forgot Dave you had that one.
DAVID MACHLEDT: That we will set it will get to it after questions. But we are getting older especially people who have white beards. Let's go back to the question slide. Out go back to that later.

I see Camillus mentioning that their state got a small pay increase. A lot of states got a small pay increase during COVID that has stuck around.
NICOLE JORWIC: Someone says as a question if they got dropped for Medicaid how do they reenroll?
DAVID MACHLEDT: It varies from state to state but there are some federal requirements. You have a constitutional right to notice and due process and ability to appeal a decision that is a wrong decision and also written into the federal predicate
Medicaid, it did kind of depends on how you are eligible so what category were eligible for but if you're disenrolled from Medicaid the state agency has to first check to make sure you are not eligible through some other category.

They are supposed to help you transition. For example, if you are now earning more money and no

longer income eligible but you might be eligible for marketplace coverage and they are supposed to help you enroll in marketplace coverage.

If you were wrongfully disenrolled, it gets complicated you can reapply. If you are eligible for the Medicaid expansion or a Magi category, which is a way of, if you're eligible for the Medicaid expansion or eligible as a child for example, and did
not fill in your form on time and got a notice that said you have been terminated, within 90 days, if you bring that, if you send the information that was requested of you that that they did not have to determine your eligibility, you will get back
on the Medicaid program and it will be backdated you will not have had a gap in coverage.

If you get disenrolled and you actually are not eligible then you might have to go to a different program or something like that. It depends on the situation and depends on the state. But the first thing to do is check and make sure they are
address is up today and you have gotten all those notices. If you do not understand a notice that you have received, you need to get contact a lawyer or contact at least an assistance line to try and understand what is at why it is they were not
eligible.
NICOLE JORWIC: Is really unfortunate that the states are doing and not doing.
DAVID MACHLEDT: I saw the ease and said that CMS took action during state coverage for 500,000 people and children and other individuals improperly disenrolled from CHIP.

That is really good news. That has to do with a long-standing problem where there is a lot of children who are able to be determined eligible through their own, as their own household and you have to determine the eligibility of everyone within a
household and it is by individual and not a household together. Many states were doing it as household together and not separately evaluating each individual to see if they were eligible and that is what led to that problem.

NICOLE JORWIC: I see your New York question. I don't know what those grant services are.

I could not be in front of our group of folks without talking about how important it is that these issues are understood because these issues have been really in the line of fire a lot. And 2017 the Medicaid program was at risk of a trillion dollars
cuts Dave and I spent a lot of time together on Capitol Hill and hundreds of home meetings. At that time because home and community-based services are optional they are at specific risk because states do not have any option about what to cut they
have to continue to fund the mandatory services.

Any time we're talking about major cuts to Medicaid again just recently earlier this year in the conversation or the debt ceiling that had been a proposal of a 100 billion-dollar cut to Medicaid Medicaid. Anything like that is going to be at real
risk. We do have bills like the HCBS access act to expand this program they will be expensive because of decades of lack of investment in this workforce and set of services.

At the same time, we need large investments and that is not some thing that Congress is really looking to do any time soon without a lot of pressure. At the same time, we're going to have to watch out for threats to the program overall.

Not to be Debbie downer or anything because I do think we have some real hope because we have so many disability advocates and other groups have really been raising the profile of the system and the huge level of need in the system which in a way I
think will be helpful but it does require people in Congress to understand the difference between Medicare and Medicaid, which is not always the case.

The more we can keep educating folks and I know Liz said in the chat that she is sick of telling her story. I know what she means is I've been lucky to hear it. I would keep listening to Liz for what it is worth. But I understand because it can
get really demoralizing, but we need people to talk about why the services matter to get those investments. Nobody needs to be an expert like any of us to be able to say that this is something that the government and that Medicaid because it is a
federal and state funding needs to be doing to support.

>>: I was just saying that because when you came into my life, I had to tell my story over and over again to her. I'm not tired of telling Liz because stories are the way we change, but when people come into my life I tell the story over and over
again.
NICOLE JORWIC: Teach somebody instead of paying folks so they can stay because they would rather stay because the wages are so low.
DAVID MACHLEDT: >>: We have four more minutes if we have anymore more questions.
DAVID MACHLEDT: I want to echo that without a doubt that advocacy from people with disabilities saved the Medicaid program in 2017. I could take a minute or two with the next slide just to reinforce the spirit I'm really glad that we got a chance
and I know that Medicaid, the structure is complicated and hard to enforce. I wanted people to know the reason we spent time on those settings rules is because those rights are there and regulations and those of the rights and people need to know
that. Has been a decade and a lot of people have forgotten what the original story was on the settings rule. I have been retelling that story now because it has to be told, again, the same thing goes for

deinstitutionalization. I think some of
those stories have been lost. If you go back and look at what is happening on the landscape, people favoring more congregate settings in some places are going to bigger group homes or something like that, it is really important that we recognize
that the same rhetoric was used long ago to justify institutions and it did not end up working out that way. List, you telling your story is very important. The reason I have the slight about we are getting older and here is because some people who
want to cut the Medicaid program refer to Medicaid they are typically characterizing it as a program of health insurance for, "poor people" students pregnant women and often a goes with stereotypes about poor people are poor because they don't want
to work and that's why we need a work requirement and Medicaid. That is not the case as Nicole pointed out, over half of our expenses for LTSS are being paid by Medicaid.

This is not just a program for people with disabilities. It also when you have an older adult who has worked all their life and need some help, they are paying for that out-of-pocket. That is going to deplete resources quickly. Often they end up
at Medicaid eligible. We look at the redline on the slide about what is happening with our population, doubling the number of 7070 -year-olds from 2008 to 202078 and over those people are going to need HCBS as they get older. We need to have a
conversation because this shortage is going to be exacerbated. It is going to be made worse by the fact that our population, we have more people getting to the ages where they need these services as well. We need to look at the agent community also
as a partner in pushing for conversation about what we do with long-term care in this country and whether it is the HCBS access act, which mandates HCBS coverage and Medicaid or some discussion about LTSS long term through some new kind of payroll
tax that covers like the class act from the ACA that pays for long-term care where we pay in as we work and so we can benefit when we are older. And it can benefit people with disabilities. That is a conversation we really need to have if we are
going to solve this problem in the workforce prices. Is a question of resources also.

>>: I think we could talk about this for hours and ours. And probably never solve anything, but I would like to thank Dave and Nicole for their time and Jeanette has within the chat the evaluation quiz. Fill that out. It helps our team and our
policy team. Thank you again Dave and Nicole for your time and Jeanette for all your support. And thank you all for your support as well. Thanks and have a nice night.
DAVID MACHLEDT: Thank you to our interpreters and to you, Liz.
>>: Take care, everyone.
(CONCLUDED AT

