[Nikkilyn Morrison] Thank you for joining. We are going to discuss today "Developing Questions to Identify Adults with Long-Term Services and Support Needs." Before I get started, just like to go over some technical instructions. So, all participants were muted on entry. You can access closed captioning and WebEx assistance on the lower left of the window. So, that little circle there is the WebEx Assistant and the CC in a chat bubble is the closed captioning. There will be a Question and Comment session at the end of the webinar. You can access that in the Q&A panel in the lower right. If you select the three dots next to your chat button, you can see the Q&A panel. I'll go over how to use that on the next slide. Please contact Derek Mitchell, who is the host, through the Q&A panel if you have any WebEx or webinar platform issues. There will also be a survey pop-up at the end of the webinar. This is really important for us to get your feedback on things that we are presenting today, get your opinions about what is important to you as a stakeholder. So, please complete that survey before we leave the meeting. And, finally, a recording of the meeting and slides will be available after the webinar and you will receive an email when those materials are posted as long as you registered for this webinar.

So, the Q&A panel, as I mentioned, is on the bottom right. You will select the three dots to see the Q&A pop-up. To submit a question to any of our presenters, click the Q&A panel, select All Panelists in the Ask field and then you can type your question in the text box and click Send. Only the presentation team will see your questions and comments, but we will read out your questions at the end and provide responses to those questions. Everyone is aware and can hear that discussion. For any WebEx platform issues, as I mentioned, you select the host and ask those questions. So, the goal of our meeting today is to let stakeholders know about the effort that we'll be talking about and to gather high-level feedback about our plan. So, we'll start off with some welcome and introductions, then get into a background on long-term services and supports and why this is important. We'll then provide an overview of the project at hand, which is a question development project on long-term supports and services. We will dive a little bit deeper into developing the question set and then talk about next steps and go into our Question and Comment portion. We'll start off with some introductions. Tisamarie Sherry is the deputy assistant secretary in ASPE's Office of Behavioral Health, Disability and Aging Policy. I will turn it over to her in a moment to give some opening remarks. I am Nikkilyn Morrison. I am a survey researcher at Mathematica leading the development of this -- the survey. And we also have our ASPE leads, Judy Dey, Bill Marton and Helen Lamont on the call. And you'll be hearing from them a little bit later in our Q&A portion. So, Tisa, I will turn it over to you.

[Tisamarie Sherry] Thank you, Nikkilyn. And hello, everybody. Good morning. As Nikkilyn mentioned, my name is Tisamarie Sherry. I'm the deputy assistant secretary for ASPE's Office of Behavioral Health, Disability and Aging Policy, or BHDAP as we call it for short. And I am also currently performing the delegable duties of the assistant secretary for Planning and Evaluation. I am a Caucasian female with brown hair wearing a gray blazer and a yellow shirt underneath. And my pronouns are she/her. We want to welcome you all today and thank you so much for taking the time to join this webinar to hear from us about some of the work that we're doing, but also very importantly to provide us with your feedback and your perspectives so that we can ensure that your expertise is represented in this work.

We are launching this effort because, as the primary source of insurance for long-term services and supports, HHS has an ongoing need to understand the need for services and supports for people with disabilities. There are no current national surveys that capture information on the full array of physical developmental, intellectual, cognitive, sensory and mental disabilities for the adult population under age 65. But, without this information, we at HHS can't easily assess the extent to or how well Americans' LTSS needs are being met, whether by family caregivers, paid caregivers or insurers. We also need this information to make sure that we have an adequate workforce to improve the quality of access to home and community-based services, or HCBS, for millions of Americans who are receiving or need these services. Having access to skilled professionals is essential to helping a person with a disability or older adult live independently and be fully integrated in the community rather than being in a nursing home or other institution.

And this is a particularly high priority for the Biden/Harris administration. In April of last year, President Biden signed Executive Order 14095 increasing access to high-quality care and supporting caregivers. That executive order laid out a number of key actions, including increasing support for the paid and unpaid workforces who provide care and assistance to people with disabilities and older adults. Now, because data is an essential input to guiding policy efforts related to the care economy and also evaluating the impact of policy changes, one charge of this executive order was for HHS and the Department of Labor to jointly identify opportunities to strengthen data on the HCBS workforce. So, in response, our departments teamed up to establish the Home and Community-Based Services Federal Opportunities Regarding Workforce and Research Data Workgroup, or HCBS FORWARD for short. One of the recommendations stemming from this effort was to establish and regularly field a nationally representative survey of adults with disabilities, in particular between the ages of 18 and 64 where we currently don't have any national data collection efforts to inform us about this topic about their need for and receipt of services and supports. The project that we're going to describe to you today, and on which we would welcome your partnership and your input, represents the first step towards satisfying this recommendation. We want to, again, thank you all for coming, thank you for your engagement. And, with that, I will turn it back over to Nikkilyn and our team at Mathematica to describe the project.

[Nikkilyn Morrison] Thanks so much, Tisa. All right. So, I'm going to go over some background, just building off of what Tisa just said about why this work is important. So, I'll start off with long-term services and supports and just talk about a little bit what they are. So, LTSS, or long-term services and supports, this includes a range of assistance to address people's health, personal needs or both over an extended period of time. Most LTSS, it's not medical care, but it's rather assistance with things like basic activities of daily living. This can be things like bathing, dressing, toileting, eating, similar activities. Medicaid and unpaid family care really form the core of the LTSS system in the United States and only a small portion of Americans are using private long-term care insurance. We all know as individuals age, LTSS needs may increase, but we do see among the Medicaid enrollees who use LTSS more than half of them are younger than age 65. And this becomes important when we think about what Tisa just mentioned that we are really lacking data on those individuals.

So, LTSS has been an important policy issue. There have been several federal initiatives over the past 14 years that have attempted to make LTSS financing more equitable and improve Medicaid coverage of home and community-based services. So, for example, the CLASS Act, which was later repealed, and the WISH Act bill, which did not pass, they both sought to cover LTSS through social insurance programs. And then the Build Better Act, which also failed to pass Congress, proposed to invest nearly $400 billion in Medicaid home and community-based services programs over eight years. What we're seeing is just a more complete understanding of the population of LTSS needs would help model potential costs of future reform efforts and really brings us to the work that we're doing now. So, data on LTSS -- or on need for LTSS is really crucial. Policymakers need the data on LTSS need to inform the demand for LTSS reform, to explore the feasibility of LTSS reform proposals and any changes to Medicaid, to understand the burden on unpaid caregivers, to make projections about the demand for workers and understand what happens when people do not get the LTSS they need. There is no consistent definition of LTSS need. So, this is one of our data challenges here. Even though this data is crucial, we don't have a proper definition on how to define LTSS need. So, the qualification for services under tax-qualified private long-term care insurance is defined in HIPAA to include the inability to perform without substantial human assistance at least two activities of daily living, or ADLs, for at least 90 days or having a severe cognitive impairment requiring substantial supervision. Even though HIPAA provides the closest we have to a clear definition of LTSS need, it still doesn't quite operationalize some key points, such as how do we define substantial and what is the threshold for needing substantial human assistance or supervision.

Now, Medicaid, as mentioned being the largest funders of LTSS services, they use various functional assessment instruments to determine eligibility for Medicaid LTSS. And this varies by state. Some states include assessments of instrumental ADLs, or IADLs. These are things like taking medications, managing money, food preparation or using transportation in addition to ADLs. Medicaid also varies in the level of functional impairment that qualifies an individual for LTSS. So, for example, one state might require dependency on four or more ADLs, whereas another might require dependency on only two. They also vary in collecting frequency and duration of LTSS need. So, there is quite a bit of variation across the states. Another data challenge that we face is the population coverage. So, the existing national population-based surveys that measure adults' functioning and need for LTSS, they largely focus on adults age 50 and older. They, also, do not align with Medicaid LTSS eligibility criteria. And, as Tisa mentioned, there is no comprehensive federal data collection among adults age 60 -- 18 to 64 to understand the need for and receipt of LTSS.

So, that brings us to the project at hand, which is developing questions to get at that LTSS need. We'll give a brief overview of this project. So, our goal is to have the ability to document the prevalence and types of long-term services and supports needs and the consequences of those unmet needs among adults to inform LTSS program design and policy changes. To do that, we are drafting a short set of survey questions to measure the domains of need for LTSS, use of paid and unpaid LTSS, what unmet needs there are and what the outcomes and consequences are if the needs are not adequately met. So, this set of survey questions we're developing, 15 minutes or shorter, this -- we are intending to field these questions within a national survey. So, this would not be a standalone survey. Our population of interest is non-institutionalized adults, those age 18 and up, and they have a need for LTSS.

So, we talked about how it was challenging to define what need for LTSS means. So, these are individuals that could qualify for Medicaid LTSS or private long-term care insurance based on their functional limitations. And the criteria that we are looking at would be based on their need for assistance to perform ADLs, severe cognitive impairment or need for assistance to perform IADLs. And you'll see we have "other" here with a question mark, we would like to be able to capture all non-institutionalized adults with LTSS needs. That includes those with intellectual or developmental disabilities, autism, dementia, a serious mental illness or other behavioral conditions or cognitive impairments that might lead someone to need LTSS. So, we'd like to hear from you if you think we need to add to our list of functioning in cognitive impairment criteria to capture these individuals. And I will put a plug in for our post-webinar survey, which will ask questions like this. And we would love to gather your thoughts in that survey.

Our timeline for the work. So, today, we are conducting this virtual stakeholder meeting and intending to solicit high-level feedback from you all on the plan, again, putting a plug in for that post-webinar survey. We will be developing our brief questions set and data collection strategy, so thinking about where we would host these questions over the course of this summer. We will be drawing on existing validated items wherever possible to include in this survey. Then we will be convening a technical expert panel, or TEP, to further refine the survey questions and potential data collection strategies over the summer, perhaps going into the fall of this year. And after the TEP and after we have that data collection strategy and survey questions refined, we will evaluate them for validity and reliability and some question testing. So, now I'm going to dig deeper into developing the question set. So, I mentioned the domains that we are focused on, so going a little bit deeper into each of these domains now.

So, starting off with our need for LTSS. So, we talked a bit about this. We're looking at the need for assistance with ADLs or IADLs or having these severe cognitive impairments requiring supervision. We'll also be asking about the length of time that the needs are expected to last. We are primarily interested in if needs are expected to last 90 days or longer, thinking about that definition that I mentioned from HIPAA. And then our next domain is the receipt of LTSS or how needs are met. So, in this domain, we intend to ask about who is providing assistance, so is this an unpaid family or friend, is it a paid worker. And then looking at the sources of payment, so how are these services paid for, is this out of pocket, is this covered by Medicaid, are their private long-term care insurance providing these services, are they unpaid or funded from another source. Our next domain is unmet needs. So, here, we are looking for whether there is more assistance needed than what is received. And we will be looking at what types of assistance is needed, additional assistance. So, these could be things like does the individual need more personal care, housekeeping or medication management assistance.

And then why are there unmet needs, so what are the barriers to assistance? This could be financial barriers, there could be a helper availability issue, whether that's a shortage of paid workers in the area or just not being able to find an unpaid worker, or not qualifying for public programs. And, finally, our last domain is looking at the consequences of unmet needs. And this could be things like missing work, missing meals, not bathing for more than three days or any -- experiencing any injury or bodily harm. We want to be mindful of the survey length. Because these questions are intended to be embedded within another survey, there are certain topics we have deprioritized or are unable to do within the bounds of this question set. So, what the questions will not cover is every state's unique Medicaid eligibility criteria.

So, we're not looking at -- as I mentioned, they all vary and the survey cannot evaluate every individual state's criteria. We will also not be collecting specific diagnoses or conditions as part of this item set, though this may be covered in other parts of the host survey, so that would be determined once we have a final host survey. Some of them do collect diagnoses. We are not collecting past LTSS needs or the timing of the onset of LTSS needs. So, as I mentioned, we are really looking perspectively, so how long are these needs expected to last, not necessarily retrospectively and when the onset happened. We are also not doing a detailed functional or cognitive assessment and not collecting data on the cost or affordability of LTSS. So, as I mentioned, we are looking at how the services may be paid for or unpaid, but not necessarily the cost because we have data on that already. And, finally, not intending to ask about satisfaction with LTSS. So, this is really looking at what needs a person has, whether those needs are met and the consequences of not having those needs met.

Okay. So, in terms of next steps, we are -- we will be drafting the survey questions, as I mentioned, then convening the TEP to get feedback on those, testing the questions and revising as needed, and exploring our data collection options, including host surveys and how those host surveys might influence our ability to field in different ways. So, now I'm going to open it up to questions and comments. As I mentioned, you can use the Question and Answer -- the Q&A option on your bottom right. So, if you hit those three dots, you should be able to see the Q&A panel. And Derek is submitting instructions in the chat as well, so you should see that come up. And I am going to turn it over to our colleagues at ASPE to answer the questions. So, I will reach out to my colleague, Hannah, to see if we have any questions that have come in yet.

[Hannah Bovia] Thanks, Nikki. We've had a couple questions come in. So, I will get started with those. Let's start with, "Does ASPE plan to seek public comment or input on the questions being asked?"

[Helen Lamont] So, I can take that one. Good morning, everyone. This is Helen Lamont from APE. We are not seeking public comment. We are not going to do a formal comment period. We're using this as an opportunity to spread the word about the work that we're doing. And then we'll have a technical expert panel in the late summer/early fall to weigh in on the questions themselves. In part, we're not doing a public comment period because we think that the discussions we need to have on this is a -- are a little bit more nuanced and detailed. And, so, instead, we're encouraging everyone to reach out to us directly and we'd be happy to set up a meeting or to communicate by email, but probably an email -- a meeting would be better, about your thoughts on the nuanced pieces of what we are trying to do. And, so, my email will be available at the end of the meeting. And we encourage you to reach out with any questions or comments that you have and we would love to speak to you in more depth about the work that we're doing.

[Hannah Bovia] Great. Thank you, Helen. Next, we will ask, "Can you provide a specific example of how you see the survey responses being used by the Department of Health and Human Services or maybe other policymakers?"

[Bill Marton] I'll talk a little bit about that. It's pretty critical in terms of thinking about various policy options to have these type of data. We briefly mentioned our work on the CLASS Act and thinking about how to implement that. And one of the things that we directly confronted is we just did not have very much information on the younger population with LTSS need. As a result, we had to use very old data from much earlier surveys and we also used other sources of information where we had to make assumptions about the prevalence to that translation. One of the implications of that is, given that we have to make assumptions then and we don't have the data, we tend to make fairly conservative assumptions. And those assumptions generally will drive the cost of various reforms up. And I think we do that to be prudent as we think about implementation. But, if we have better data, that certainly allows us to do a much better job at estimating the scope of the various proposals, who might participate and costs and impacts.

[Hannah Bovia] Great. Thank you, Bill. Next, let's go to, "Will the survey samples be large enough to produce state-level estimates for any states?"

[Judy Dey] I can go ahead and take that one second. Hi, everybody. I'm Judy Dey from ASPE. And I guess I'm happy to talk about sample sizes and the ability to create state-level estimates. I think that some of this is obviously going to depend on which survey this is fielded on. But some of the candidates, like the National Health Interview Survey, already have limitations in terms of state estimates. And since this is likely because the prevalence isn't as great as maybe some other characteristics of the population, we expect that even with pooling years and things like that it might not be possible to create state estimates, although we are very, very interested in being able to do that. So, welcome any suggestions or feedback for making that a reality. Thank you.

[Hannah Bovia] Thanks, Judy. We, also, have quite a few people wondering, "What national surveys we are considering as host surveys for this effort?"

[Helen Lamont] This is Helen. I will take that question. So, we are trying to think of host surveys that are very large in size because we know, thankfully, the prevalence of LTSS needs in the younger adult population is relatively low, so we need sufficient sample size to have the power to ask the questions that we want to ask policy-wise. So, we are looking at surveys like the National Health Interview Survey, the Survey of Income and Program Participants from Census and then we're also looking at internet panel surveys, such as the NORC AmeriSpeak Panel and a few others. We think there are some efficiencies when it comes to the internet panels that might allow us to get a little bit more information than we would get an in in-person or a telephone survey. And we're also thinking very deeply about the best methodology for capturing both people with disabilities who may or may not be included in some surveys for the proxy modality that's offered in our surveys.

We know that if proxies are not available that we might lose many of the representation of many of the people that we're looking for in this LTSS need survey. And then also thinking about opportunities, again, to maximize our response rate. So, if there's an opportunity to ask about all of the people in the households and whether they have LTSS needs, that might increase the likelihood that we find the population that we're looking for and can answer these questions. So, we haven't narrowed it down beyond sort of those broad large national surveys, but those are the considerations that we have in place. And then one other question, you know, is whether this will be generalizable at a state level. And, again, probably not with those large national surveys, but we know that other partners have tried to do this with the Behavioral Risk Factor Surveillance Survey and there are other ways that you could get this data at a state level. So, that would be a next step, something that we're open to, but, at this point, thinking about large nationally representative surveys.

[Hannah Bovia] Thanks, Helen. It looks like we have a couple more questions, "Would you consider asking a question about assistive technology that's used and needed?"

[Bill Marton] I'll go ahead and take that question. Yes, it's an area that we're very interested in. Although I would say in the priority of questions, it's a little bit further down, mostly because the definition of need in HIPAA and largely Medicaid is tied to personal assistance for and with ADLs and IADLs. But we are obviously very interested because it's an important piece of understanding the need for LTSS and how people have their needs addressed. But I think it's going to come down to, given the scope of the survey and some of our constraints, whether we'll be able to tackle that or not.

[Hannah Bovia] Thanks, Bill. We also have a question, "Will persons with dementia or other cognitive or functional impairment that limit their participation in the survey still be included, such as by proxy or maybe oversampled to ensure representation of those most in need?"

[Helen Lamont] I can take that one. Yes, we very much want to make sure that we are capturing those populations, people that would need a proxy, and are being very intentional in looking at the proxy methodology for the surveys that we are working with. So, for example, if an interviewer goes to a home where there are two adults and they're -- both of them have some cognitive impairment, we would want to make sure that, to the extent possible, there's follow-up and that there's a proxy sought out for them. These very minute methodological considerations are really important when it comes to capturing the population that we're interested in. And, so, we are really thinking through these things and very committed to sort of optimizing what we can in the methodological realm to capture these populations.

[Bill Marton] I'll add one other quick thing. And it's not only having a mechanism for capturing proxies, but also ensuring that you get adequate representation of the populations in the sampling frame. One of the things that we've struggled with over time is the lower response rates in surveys in general. So, one of the things that we're going to think about is to make sure that we have the population captured so that we do get a representative group of people and also high-quality data.

[Hannah Bovia] Okay, thank you. So, we also have, "Are we gathering data on solely the needs of the individual requiring LTSS or is it inclusive of the needs of their immediate unpaid caregivers?"

[Judy Dey] So, this is Judy Dey again from ASPE. And I want to answer this by saying we really, really actually are quite interested in capturing the experience of unpaid caregivers and actually paid caregivers. So, I don't think it's going to be -- this first step I think will identify that there are caregivers in this first step, but we would love to do something like what's done in the NHATS, which is to kind of follow up with the identified caregivers after, both to learn more about the HCBS workforce and also to learn more about family caregivers and their needs. Thanks for the question.

[Hannah Bovia] Thanks, Judy. We, also, have, "How are you thinking about capturing individuals with intellectual and developmental disabilities within the sample?"

[Helen Lamont] This is Helen Lamont again. I'll take that one. This is an area where we would love more input from the public because we don't exactly know how, for example, states -- what data states need to understand the population of people with IDD living in the community who are not currently, excuse me, on Medicaid. And, so, we would love to know more about what the states take into consideration when they think about eligibility for this population. Obviously, it goes beyond just a diagnosis, severity of needs, for example, multiple conditions. And then wondering whether the states see ADLs and IADLs right now as sufficient to capture that population. So, that is certainly a population where we need a little bit more input in thinking about how to capture them. And then, as we mentioned, we are also going to be fielding this on a large national survey where we expect to have a number of health questions. And, so, we are hoping that we would also have, "Has a doctor ever told you that you have" list the health questions and be able to crosswalk that to a developmental disability or an intellectual development -- intellectual disability diagnosis. So, more on the function and needs, of course, and then we'll be able to, hopefully, crosswalk that to a diagnosis. But please reach out if you have thoughts on how to do that well.

[Nikkilyn Morrison] Thanks, Helen. And that's a really good segue into we are collecting feedback in this post-webinar survey. So, I just want to mention there are some things specifically that we are interested in getting your input on and we have some targeted questions in this post-webinar survey. But we are interested in how to capture -- just as Helen was saying, how to capture the individuals with LTSS needs. And, when we're thinking about especially this cognitive impairments -- those with cognitive impairments, do we need to ask specific questions and what are those questions outside of ADLs and IADL functioning. So, how should that be structured, what is important to you with respect to a host survey or a sampling strategy? I put in the chat if you have recommendations outside of those that we are looking at either for host surveys or source surveys, you think a particular survey asked questions really well, please let us know that in this post-webinar survey as well, and then any feedback that you have on the domains that we are looking at, as I mentioned before, so the need for LTSS, receipt of LTSS unmet needs and consequences of unmet needs in the past month. If you have additional questions that we didn't get a chance to answer today, you can reach out to Helen at helen.lamont@hhs.gov. And, as I've mentioned multiple times now, please respond to that post-webinar survey. So, thank you all for joining today and look forward to hearing your feedback.