The Lewin Group
Supporting Individuals with Intellectual and Developmental Disabilities (I/DD) as They Age
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Karen Davenport: Thank you. I'm Karen Davenport with the Lewin Group. Welcome to today's webinar on Supporting Individuals with Intellectual and Developmental Disabilities as They Age. Today's session will include a 45-minute presenter and panelist web discussion followed by 30 minutes for a Q&A session among the presenters, panelists, and participants.

This session will be recorded. A video replay and a copy of today's slides will be available at ResourcesforIntegratedCare.com. The audio portion of the presentation will automatically stream through your computer. Phone lines for this presentation are also available. To access the number, click the black phone widget at the bottom of your screen. Next slide, please.

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For today's webinar, the presenters and panelists have no relevant financial interests or affiliations. Next slide, please. This webinar is supported through the Medicare/Medicaid Coordination Office at the Centers for Medicare & Medicaid Services. MMCO is helping beneficiaries dully eligible for Medicare and Medicaid have access to seamless, high-quality healthcare that includes the full range of covered services in both programs. To learn more about current efforts and resources please visit the RIC website or follow us on Twitter for more details. Our Twitter handle is @integrate_care. Next slide, please.

At this time, it's my pleasure to introduce the faculty and panelists for today's webinar. Dr. Gerry Kerins is an associate clinical professor of medicine at the Yale School of Medicine, and associate chief of geriatrics for education at Yale New Haven Hospital. In

his clinical practice he focuses on caring for older adults with intellectual and developmental disabilities, with a particular emphasis on Down's Syndrome. Dr. Michelle Reynolds, or Sheli, is the associate director of training and technical assistance at the University of Missouri, Kansas City, Institute for Human Development, and a research associate professor with the UMKC School of Medicine. In these roles, she is committed to research, demonstration, and implementation of evidence-based practices that enhance person and family-centered organizational policy and systems change. Next slide, please.

Debbie Pfeifer is the intellectual/developmental disabilities administrator at Aetna Better Health Kansas. Debbie has been in the field of developmental disabilities for 30 years, starting as a direct care staff person, working in a group home while earning her undergraduate degree. She has a master's degree in public administration, and her career has spanned service in state government as a director of quality assurance and as a chief program officer for an organization providing residential support to adults.

Callie Simmons has worked for Aetna Better Health of Kansas since November of 2018 as a long-term services and support services coordinator. In this division she works with individuals receiving services on the intellectual and developmental disability waiver. Before joining Aetna, Ms. Simmons was employed by the Kansas Department of Aging and Disability Services, where she was responsible for managing the physical disability waiver. From 2011 to 2017, she worked as the program coordinator for an agency that provides employment support to individuals with intellectual and developmental disabilities.

Finally, Sharon Spurlock serves as director of family support at the St. Louis Arc. Before stepping into this position she led community engagement services at the Arc for 19 years. She oversees respite programs, family workshops, support groups, and self-determination and advocacy. Next slide, please.

Next, I want to share our learning objectives for today's webinar. Today we will learn about the physical, cognitive, and behavioral changes of the aging process, particularly how these changes may manifest for someone with intellectual and/or developmental disabilities, identify key support, family caregivers, health plan providers, and individuals with I/DD may need to manage these types of changes across the lifespan, and discuss an integrated approach health plans and providers can use to respond to the needs of individuals with I/DD as they age.

So in summary, we will be exploring both clinical considerations for people with I/DD as they age, and strategies for supporting these individuals and their families and caregivers. Next slide, please.

And here we have the agenda for today's webinar. We will start with a quick poll and then move to presentations from Dr. Kerins and Dr. Reynolds, and then a panel discussion. We will wrap up with questions and answers involving both participants and presenters. I also want to note that in the resource list on the left-hand side of your screen

you can download different files that you may find helpful at a few points during the webinar.

To start us off, we will begin with two poll questions so we can know the audience a little bit better. Let's go ahead to the poll. Here we go. So first, in what setting -- which of the following best describes your professional arena -- or area, excuse me. And the next, when we get a chance. Oh, looks like we have lots of case managers and care coordinators and social workers. Got a smattering of administrators and clinicians and advocates as well.

And then in what setting do you work. If we could see the results. All right, so we have a lot of health plans, some CBOs, and then others working in an ambulatory setting and in home care in particular. And there are a number of others. Great. Well, thank you, everybody, for sharing that.

I'm now going to pass the baton to Dr. Kerins, who will set the stage with a brief background on people with intellectual and developmental disabilities, and then discuss considerations for their clinical care as they age. Over to you, Dr. Kerins.

Gerard Kerins: Okay. Thank you very much. Good afternoon, everyone. Next slide, please. So it's an exciting time to care for people who are aging with intellectual and developmental disabilities, but inherent in that, obviously there are some challenges. And what I hope to do is outline some practical approaches to managing some of those challenges so that we can maximize function and quality of life for these special populations.

The number of older adults with these disabilities, intellectual and developmental, is obviously increasing, and as I mentioned, with that comes specific challenges to try to provide the best possible care. Dual eligibility is not uncommon, and the reason for the increase in life expectancy is multi-factorial. In addition to medical advances there were improvements in public policy, systems of care, and other factors, which have really enhanced the lifespan for persons with intellectual and developmental disabilities. Next slide, please.

So just to set the context, older adults with intellectual and developmental disabilities are at increased risk for developing comorbidities compared to younger or compared to cohorts at a younger age. And these may be biological factors, but I think there are other circumstances that also contributed to this increased risk -- things such as limited access, challenges physically in terms of getting appropriate care, and environment challenges such as sensory deficits or even practical ways in which they are examined, which can interfere with the healthcare appointments.

Older adults with such disabilities may have higher rates of obesity, may have poor nutritional status, less opportunity to be physically active compared to the general population. Other specific conditions might include increased rates of dental disease, mental health illness, and the like. And then certainly certain types of cancers might be

more common in a younger age, but as these populations get older, other comorbidities emerge such as dementia and similar such conditions, which do occur at an earlier age. Next slide, please.

Now, in addition, there are some behavioral challenges which may impact on the overall quality of care in applying that care -- things such as, as I mentioned, dementia, but also depression, seizures, anxiety. And I'd like to point out that the incidents of these conditions is not exclusively related to the underlying disability, in that they deserve the same evaluation and treatments for such conditions as younger populations, but we know that because of the disability, this may not always occur. And then there's some other medical conditions, such as, dental conditions, urinary tract infections, and constipation, which can also have an impact on medical care being applied. Next slide.

So why do we have health disparities with this special population? And I think there's a couple of key points that I'd like to point out. One may be the lack of formal training for clinicians, and I hear over and over again that there is many caring, concerned providers who just feel they need more information to provide the best possible care. And certainly we know that in, for instance, only three or four medical schools in the country, that there are formal curricula dealing with this special population.

Clinicians do report at times feeling a little uncomfortable with this population, and I think if we can train students of all different health disciplines at an early age, early in their training, we can overcome this barrier where they just feel uncomfortable. Preventive services and screenings may be limited, depending on the systems of care in which someone is cared for. And the other key piece is that we don't have good uniform standards of care.

What applies to one group in one setting in one system of care may be somewhat different to another group in another setting. So I think we have to come up with more uniform standards of care and increase overall access to care, as well as financial and related entitlements to help as well. And finally, things such as transportation -- not being able to get to an appointment should not be a reason that somebody doesn't get the best possible care, but we know that this does occur not uncommonly. Next slide.

So at the Adler Center, which is our outpatient geriatric assessment center at Yale School of Medicine and Yale New Haven Health, I follow a large cohort of older adults with Down's Syndrome, and I follow them over a two to three-year period, and I just try to gather some data, because then we have a better sense as to what conditions we're dealing with and the like. And most of the adults that I see with Down's Syndrome have some IDL, activity of daily living, need for assistance, and the majority need more instrumental activity of daily living help -- things such as shopping, cooking, cleaning, transportation, and the like.

We know that those with Down's Syndrome as they get older have much higher rates of thyroid disease, Alzheimer's disease, osteoporosis, osteopenia, and things such as sleep apnea. And we also know that the older population of Down's persons might be

subjected to or taking more medications than the age-controlled younger population, and the result is that they're at increased risk for adverse drug events, interactions of medications, and the like. So de-prescribing is something that we always strive to look for as well. Next slide, please.

And we know that these multiple medications may have common side effects, but they also may increase risk of falls, memory loss, delirium, and disrupt sleep, and certainly because the incidents of Alzheimer's is higher in older adults with Down's Syndrome, we must be very vigilant to make sure that the perception of cognitive loss is not the result of medications and not just attributed to oh, this is the unavoidable Alzheimer's dementia.

So we can have side effects which may be increased because they're multiple providers providing different medications, there's over-prescribing, and even over-the-counter medications which might affect or contribute to adverse drug events. And older adults with Down's Syndrome may have different pharmacological and physiological responses to medications such that even within the therapeutic range, a typical medication that is used may be or result in some toxicities. Next slide, please.

So when you're providing care with older adults with intellectual and developmental disabilities, you have to be aware of certain concrete principles. One is that you have multiple comorbidities, and this might include a dementia diagnosis which is gonna impact on one's ability to elicit appropriate history and complete the appropriate evaluation.

We know that older adults in certain settings with these disabilities are seeing multiple providers, and also we must rely on proxy sources of information, such as family and caregivers who may not at all times, at all medical encounters, have all the information that's available. So you must be aware of all this as we strive to take the best, most focused, appropriate history in the context of these medical encounters. Next slide, please.

So if you take an incomplete history, you may not get the full sense of what is someone's functional capacity, you may miss chronic conditions if you're just focusing on, quote, "the problem for which they're coming to see me now," and you must pay particular attention, as I mentioned, to atypical presentation of typical disease. So someone might have a urinary tract infection and be falling or be more confused, which is not uncommon in the general older population, but these presentations are somewhat atypical and you don't wanna miss an underlying, treatable condition simply to assume or simply because you're assuming that oh, well, they have cognitive decline independent of what might be going on more acutely.

And then also we know that, for instance, agitation is a very common sign of pain, where the patient themselves may not be able to completely express that they're having specific pain issues. We want to ensure that all exams are done in an adequate environment where there's appropriate lighting, where the examiner/examinee is being made

comfortable, the temperatures are adequate, and there is support staff, if applicable, who can help during the course of the history and physical taking. Next slide.

So you wanna make sure that you're preparing for doing an exam in this setting by getting as much background information. You wanna rely on those that know the patients best, and you wanna be flexible. You know, we teach medical students head-to-toe exam; many times, that's not possible in a setting. You may have to examine someone in a wheelchair, you may have to modify your approach. So just being flexible and being able to adapt to what you're dealing with is one way to ensure that you're gonna get the most valuable information.

And certainly we always recommend it, and we have the opportunity here at Yale to have increased time for these types of exams. And I understand in busy practices this may not be the case, but you wanna modify your timing that you allow to spend with patients with intellectual and developmental disabilities so that you can not give them the sense that you're rushing, and you can get all the information that you need. Next slide.

So you want to, as I mentioned, maximize their physical comfort. You want to ask the patient who they would like to be actually in the room with you. You may want to let them, you know, stay in their own clothes instead of forcing them to get into an exam gown, and as I mentioned, you wanna minimize wait times, not only in the exam room but in the waiting room so that that doesn't increase agitation and anxiety around the pending activities.

And you want to involve caregivers, and try to make sure that the caregivers have been given information before they present to you so that they know the types of questions you'll be asking and that you can get the most important information in the most efficient manner. Next slide.

And you wanna make sure you're maximizing sensory capability, so if someone has decreased vision, if someone needs a translator, if someone needs an interpreter because of hearing deficits, then you clearly want to make sure that you have all of those services in place and you would approach somebody with special sensory needs in this population the same way as you would approach any other patient who has such similar needs. Next slide.

Another very important component, I think, of caring for older adults with intellectual and developmental disabilities is having appropriate advanced care planning. And I think the point should be we should approach this as we do with any older population. So the more similar it is to the process with all of our patients, that's what we should strive for. But making sure that discussions are had before maybe more emergent situations arise, making sure you've engaged all the appropriate concerned parties, and also being aware of local, regional, and system approaches to advanced care planning as well. Next slide.

And finally, I think another crucial piece in caring for older adults with intellectual and developmental disabilities is caring for the caregivers, whether they be family members,

formal or informal caregivers, because we know that they are undergoing increased stress as they provide care to these populations. So you want to make sure that you're asking caregivers in whatever context they are providing care that they feel comfortable in the role, what can you do to assist them.

You wanna make sure they're aware of things such as respite, local support groups; even the Alzheimer's Association has some special capabilities with these populations. Getting people involved in other activities, such as Special Olympics -- all of this can go to allay some of the caregiver stress, which I think has to be addressed in the context of providing good care to older adults with intellectual and developmental disabilities.

Okay, I would now like to turn it over to Ms. Reynolds.

Michelle Reynolds: Thank you, Dr. Kerins. So next slide, please. That was a really great overview that really kind of ties together exactly why we started thinking about the Charting the LifeCourse framework that I'm gonna kind of provide you an overview with. I also wanna share some information about really kind of understanding the types of support people with developmental disabilities receive.

So typically, we know that using the prevalence rate and using the number of people that we know that are actually receiving some form of state developmental disability services, we know that about only one in four people actually receive those services. There's many reasons why or why not they might receive those services; they might also be receiving other services such as straight Medicaid, private insurance [inaudible] education, Social Security. They might also need services.

But the reason we really came around thinking about a framework was, is we recognized as we start thinking about policy changes, we can't just think about policy changes inside the disability community. We need to be thinking about policy and cultural changes, or about how we support a person with developmental disabilities in terms of the policies within medical care, within housing, within transportation, within employment, recognizing that not everybody is going to receive some sort of paid services such as a personal care attendant, group homes, residential support, employment support. Next slide, please.

We also know that when we start actually looking at the long-term service system that we call the developmental disability system for people with disabilities, there's a lot of different demands that's happening. We recognize there's a higher demand for services, there's a lot of people identified and in need. We also know there's a decrease in funding, whether it's federal, state, or local dollars.

But at the same time we're having staff crises. Our direct support professional crisis is really creating this need and gap and barrier for how we really think about supporting a person to have a good life. At the same time, we also know there are changing demographics in terms of people living longer, people with developmental disabilities aging much longer than we had in the years past.

At the same time that these are all occurring, we know expectations for people and by people with developmental disabilities are changing. When we think about our past, we didn't always think about people's rights to be a part of their community, their right to get married, their right to have jobs. And so this new expectation is really changing the landscape of the policies and the way we deliver our services. Next slide.

We utilize these three circles to really visually help us to kinda think through how are we going to establish best practices and policies to really support a person with developmental disability to really have the sort of access to all of their rights in this country. When we start thinking about ourselves without a disability, sometimes we probably take for granted the fact that we have family and friends and we have roles in our community.

If we look historically at the way that long-term services have been provided for people with disabilities, a lot of times unintentionally those services have become a barrier to relationships with families and friends, to roles in the community such as getting married and getting a job and having your own family and participating as a citizen.

So what we're looking at is the circles on the right-hand side -- how can we really look at each individual person, understand the context of their family, the people around them, the people they love and the people that love them, as well as the roles that they have and the community that they live in. Not only where they live, but the roles within their social community and their faith-based community, and how can we establish supports that don't become barriers to those relationships, but rather really integrate and support that person to continue those existing supports. All of this serves as the underlying foundation for the Charting the LifeCourse framework. Next slide.

The Charting the LifeCourse framework builds on, you know, 30, 40 years of the person-centered planning movement that evolved into really a person-centered thinking movement. And the idea is how do we move from more of a medical-focused model and really thinking about how do we fix this person to how are we thinking about what is the best support for that individual.

Moving away from sort of that larger, congregate types of settings to more, you know, how condition that person really achieve what they want in their life. So the Charting the LifeCourse framework kinda brings together and builds on that person-centered philosophy around how do we have this sort of guiding framework that really drives our understanding for problem-solving and thinking at many levels of transformation.

But we also have person-centered practices, so how do we engage with the person, how do we engage with their family or caregivers or the support team around them. How we interact with those and those that are providing those supports is a form of that person-centered philosophy. In addition to that are an accompanying set of tools that allow for person-centered planning to happen. And so those tools allow for education, they allow for brainstorming, exploring, and advocating. So it's the combined thought around the

cultural change, the practice change, as well as a set of visual tools that can really guide that practice. Next slide, please.

The Charting the LifeCourse framework started about six years ago, and what's happening across this country is we're starting to use it to really inform policy and practice change, working with legislators and policy change to really take that focus and take that lens and think differently about Medicaid, Medicaid waiver, how we deliver our services, how we're training professionals. But we're also utilizing it to really enhance the skills and knowledge of what I would call the end user or the target population.

So how are we helping a person with a disability understand how to problem-solve and navigate not only services, but their life. How are we supporting their family members or other staff to also assist with that? Next slide, please.

At the heart of the framework is our core belief that all people and their families have the right to live, love, work, and play and pursue their life aspirations in their community. What started out as an initiative around developmental disabilities has expanded beyond that. We've utilized this framework and really are calling it a human-centered framework that can be used with anybody, regardless of a diagnosis and regardless of their life stage, whether getting services or not.

The other thing that's important about our core belief is that we strongly believe that when we support a person with a developmental disability, whether it's in education, long-term services, whether it's in the medical setting, you're there really to help them really be able to have their full opportunity for the right to -- I always call it really a civil rights movement, and how are we helping people have the voice, the decisional support, to really achieve what they want in their life. Next slide, please.

So at the heart of the framework are some guiding principles. Our first principle really looks at how are we recognizing the person within the context of their family and their community. And what's important about that is not all people with developmental disabilities have been a part of their families or their communities. But we also recognize our second principle, is really recognizing that people need information and supports to do that.

They need social/emotional support as well as goods and services. As we start looking at the developmental disability field, historically we've really, really gotten better about connecting people to services. However, that's become our main focus without thinking about the other areas of need. Next slide, please.

The other principle that is really important in driving that is how do we push ourselves to think beyond health and safety as the only primary focus when we're thinking about people with developmental disabilities. How are we driving and thinking about all of the other sort of quality-of-life domains? Where they live, how they get around, what jobs they have, what are their social and spiritual needs, how are we supporting their advocacy and their right to be civically engaged in their community, as well as health and safety?

So we utilize these life domains to really help us dig in and problem-solve and plan and think differently about that. Next slide.

We also have one of our key principles is around the trajectory, and really thinking about how we're helping people to look for the future, understanding kind of where they were in the past and where they're heading, and where they wanna go. But more importantly, we need to understand what people don't want. A lot of times people make the assumption about people with disabilities and what they do want, but oftentimes we find more information by really digging in to help me understand what you don't want, because sometimes the vision for the future is really cloudy and unclear for people. Next slide.

We do this also by really not only looking at formal paid services but how are we helping people engage in life experiences. If we're wanting people to have a meaningful quality of life, then how are we engaging in the experiences that bring to that. And so thinking about the trajectory offers that. Next slide.

When we really start problem-solving now, we really want to help people start thinking beyond just paid services, so we utilize these five points of the star when we're talking to people about integrated support. So we want people to realize that paid disability services, down on that green part, around eligibility-specific, are really important to supporting a person's life, but they're not the only things that we should count on.

Or are they things that people always have access to? There are waiting lists across the country; people might not be eligible; people might not want paid disability services. So how are we building their strength and capacity? How are we accessing relationships? Support from the community, anybody can get, but how are we utilizing day-to-day technologies to get to the outcomes that we're looking for? Next slide.

The last principle is really reminding us that all of the work that we do in terms of any of our transformation needs to be driven by the target population. So what do people with disabilities want for their own lives, what do they want for the policies and practice changes? And so those principles really drive the work that we do. Next slide.

We have some basic sets of tools, and what this slide is pointing out to you is that we both have tools designed for working directly with the person, but more importantly -- or in addition to that we also have these slides working with families. And what's important about both -- or tools working with families. What's important about both of these is that we really value the voice of all of the people that are coming to the table. How do we value the voice of the person that may or may not have the ability to always advocate or communicate, but how do we also make sure that their voice is being heard in addition to the families' voice, and how are those being used collectively? Next slide, please.

This is a one-page profile, and these one-page profiles are being used internationally. These -- the Charting the LifeCourse framework utilizes what I always call some of the great work across the country, so the learning community, Helen Sanderson, Michael

Small, John O'Brien -- many of these are around person-centered planning, and the one-page profile has been used as a way to really help a person kind of explore and articulate what's important to them, whether they're getting ready to go to a doctor's appointment, whether they're planning for their next annual long-term -- you know, person-centered planning meeting.

Or maybe they're trying to articulate to their family or staff what they really want. This one-page document that's broken into two parts on the slide is a way for a person to collect that information and articulate that. It serves as a really quick passport for moving something on -- moving information on. Next slide.

We utilize the trajectory, taking that concept around that principle, and we really articulate it in terms of a tool. And so we really help a person start on the right-hand side, saying I can't really help you get connected to services, provide medical care to you, connect to their long-term supports unless I truly know what your vision for a good life is. And how do I know what that is? I know by asking that question of what you want, but also what you don't want.

And that, what I said, always becomes our sort of guiding star for supporting people. But what also is important is to understand, and this is our friend Ben, and understanding his life experiences, having a quick glimpse at what really made Ben who he is. What are those life experiences in the past that have both taken him where he wanted to go and kind of taken him away from where he wanted to go? But more importantly, the middle one is about what does he want to maintain right now, what does he wanna build right now, and what is important to him right now. Next slide, please.

This is just an example of how we took the life domains and we sat with the family caregiver and the family, and we tried to understand what's the vision you see for Ben's future, and what do you think are some of the most important things in his life. So using this tool we can really break down and hone in on that conversation, but more importantly it provides documentation for the larger team member who supports Ben on a day-to-day basis, or might support Ben in the future if something were to happen to his family. Next slide.

This slide is just a continuation of that same slide, so you see we break the life domains down. Next slide, please. But this is where we really start digging in and problem-solving with Ben. This is -- when we first started problem-solving with Ben, if you see here, what we did was we mapped what Ben's current resources are. Ben is somebody that requires 24-hour support for both his physical and his health and his cognitive support needs. And so if you see that star and you take that star and you put it over into what a typical week looks like, what you see here is that most of his supports came from a 40-hour a week capped Medicaid labor, as well as from mom and dad.

What we start recognizing here is one, this isn't a really full life for a 21-year-old. But two, what happens if we need more services and [inaudible] capped later, or what happens to mom and dad, or if something happens to mom and dad. Next slide, please.

As you can see here, we utilized the slide, working over a couple-year period to really start identifying what I always say adding more resources to each part of the star. When working with a self-advocate or a family, I'm always talking about we don't want to put any of our eggs in one basket, and there might be some baskets you don't have access to or we need to figure out how to get you access to.

So working with Ben and his family, we identified what are strengths that we could start building for him. Light blue -- what's technology that we can start utilizing, either in the home or having him start accessing. What are things in the community that he can go to without having paid staff? Who are other people in his life that we can start engaging in conversations with and start having them spend time with Ben and support Ben? But also, what are the paid services that we can leverage?

So it's not about any one part of the star, but about leveraging and accessing all parts of that star so we can think more holistically about providing integrated support. Next slide, please.

We take both the framework, the sets of tools, the way of thinking, and what we've been doing is working across the country, working with people within the developmental disability, eligibility-specific support [inaudible] special education, the long-term service system providers, and we've been saying this is how this framework can really help you enhance what you do.

But more importantly we recognize we also need to be working with the community -- employers, 911, EMTs, people in society, to recognize that people with disabilities have a right and a place in their communities. But we also know that our public/private partnerships are key to this. How are we working with managed care organizations, family organizations, aging -- area agencies on aging, and all these different sort of organizations to kind of utilize this framework to really create good lives for all people, with or without a disability.

So with that really quick, fast overview, I'm going to move on to the next slide and pass you on to our panel of presenters, who have been good partners in helping us think through, develop, and implement the LifeCourse framework. With that, I'm gonna pass it over, I believe, to Debbie.

Karen Davenport: Actually, this is Karen. I'm just going to jump in, since I'll be asking the questions for the panel. Thank you so much, Dr. Reynolds. So as Dr. Reynolds mentioned, to build on this introduction to Charting the LifeCourse, we're going to move into a panel discussion with Debbie Pfeifer and Callie Simmons of Aetna Better Health of Kansas, and Sharon Spurlock of the St. Louis Arc.

All three of them have been using this framework in their work with people with I/DD. Once again, I just want to remind folks about the resources in the resource list on the left-

hand side of your screen, particularly the two that are labeled trajectories might help you follow the conversation in a couple of different points.

So to kick things off, I'd like to pose the first question to Debbie and Callie. Specifically, what were your goals for implementing the Charting the LifeCourse framework for members living with I/DD, and were there specific challenges you hoped to address?

Debbie Pfeifer: Well, hi, Karen, thanks for having us. At Aetna, we have a national Medicaid advisory council, and the council looked at Charting the LifeCourse because it's complimentary to our integrated supports model. So we have that whole person approach, where we look at the body, mind, and spirit, so that bio-psycho-social approach. And the frameworks, principles, and tools help support and enhance what we are already doing, and of course it's helpful for our members with planning and developing what they want and developing their services and supports.

So Dr. Reynold's team I think has a really great analogy of a coat hook, and I think it's kind of helpful in describing how we use it and how it works with us here at Aetna. So we can take all the various practices and approaches that we use now, like motivational interviewing, trauma-informed care, and the framework acts as a coat hook to kind of hang all those practices and approaches that we use on, and then the framework kinda helps shape and guide us as we continue to use those person-centered practices while it's also helping build and kind of enhance our current approach.

Karen Davenport: Thanks, Debbie. Callie, is there anything you wanted to add?

Callie Simmons: Yes, thank you. As a service coordinator, my overall goal was to utilize the framework to ensure that my focus always remains on my members and their goals, specifically what they want for their life and what their vision for a good life is. By utilizing the framework, it's helped to create a common language between myself, my members, and their families, and it also helps provide continuity when individuals change providers or go through other life transitions. It helps ensure that what the member wants for their life is at the forefront, and doesn't get lost along the way, which helps avoid gaps in services as well as helps ensure quality of care.

Karen Davenport: Terrific, thanks, Callie. Let's move on to the next question, which we'll be asking to everybody. Let's discuss how a person-centered framework helps you support integrated and coordinated care for members with I/DD. Sharon, maybe you'd like to start us off?

Sharon Spurlock: Yes, thank you. For me, I think one of the biggest pieces is that opportunity to have that person's planning views included within the context of their family. This allows everybody to have a voice at the table. As Callie mentioned, the common vocabulary and individuals with disabilities and families often feel like their voice isn't necessarily welcome at the table. And the language is universal, so that they know that they're welcome. And then we're all participating in a plaintiff of broad-based planning and problem-solving that can occur across the lifespan.

Karen Davenport: Thanks, Sharon. Callie, could you add your perspective?

Callie Simmons: Yes, absolutely. Utilizing the framework really helps to facilitate conversations with members and their families. I have personally found that it can be extremely useful for individuals who have lived with their aging parents their entire lives. By mapping family roles and working through their vision for the future and what their good life is together it really helps to address all of the important aspects of that person's life, like where they want to live or who they want to live with, important aspects of their routine, or community engagement.

It really just applies to all aspects of life. I actually have a member whose morning routine is very, very important to him. He prefers to have his morning beverage, which his mother gives him every day before he takes his medication, and if his medication's given to him before he has that beverage, he'll refuse to take his medications. By having these conversations and knowing what's important to my member, you have the understanding that this isn't actually refusal; he just wants to follow his routine that he's always followed with his mother, which is vital as you look to transitioning to different support settings.

Karen Davenport: Thanks for that example, Callie. That brings things into a really great focus. Going to move to the next question, which I'm going to pose to Debbie, and ask her how Aetna has approached implementing the Charting the LifeCourse framework. I know that's something that you are in the midst of right now. What staff training and member education and other steps did you take, and where are you now in this process?

Debbie Pfeifer: Well, the first thing we did was we contracted with Dr. Reynolds and her team at the University of Missouri, Kansas City, for their expertise in developing the program. Then we did some introductory training for our service coordinators, and Callie and I did an in-depth ambassador training, and the ambassador training is moderated by the University of Missouri, Kansas City, and it's kind of an in-depth, six-week coaching and online class about the principles of the LifeCourse. It kind of allows a deep dive into the framework and allows people to become subject matter experts, to coach others and kind of be an internal resource.

So after that, in October, we trained almost 300 people along with the University of Missouri, Kansas City, we trained all of our service coordinators, and we also held community trainings. And in the community trainings we trained our members, their families, and providers as well. So it's very important to us, as Callie had mentioned -- we want a common language. So as we trained our service coordinators, we wanted our members to be trained with that same information, so we could start that common language.

So after that, our next step is in January we will have 15 of our service coordinators take that ambassador training, that in-depth training, so we'll have some more subject matter experts. So that's where we are right now.

Karen Davenport: Thanks, Debbie. Let's move on to the next question, which is what tools and strategies do you find most useful in your work supporting members with I/DD. Debbie, do you wanna kick us off?

Debbie Pfeifer: Sure. So we have a lot of the different tools. I think Callie, actually, you probably have some good examples of some of the tools that you've used. Do you wanna explain some of those?

Callie Simmons: Oh, absolutely. Thank you, Debbie. I think for me in my role, what I found most useful about Charting the LifeCourse is my ability to integrate the framework and the principles naturally into conversations that I'm already having with my members and their families. And that's not to say that when I sit down and I'm having these conversations that I'm immediately pulling out a piece of paper to go through these concepts with my member.

You have the ability to build the thinking of the framework and the questions into the conversations that you're already having with them, and in doing so it helps to have a more person-centered conversation that focuses on the individual and helping them identify their path to their vision of a good life. The trajectory of a good life, which Dr. Reynolds showed earlier, I find is especially helpful in discussing with individuals what their good life is.

Sometimes it is a lot easier for my members to immediately know what it is that they don't want, and what I like so much about the trajectory is that you aren't forced to begin at a specific place. It really just helps start the conversation, and by discussing what an individual doesn't want, you really can work towards figuring out what it is that they do want.

I also find that the life domain vision tool can be very, very helpful in drawing out what's most important to the individual that I'm working with. When you go through and work with an individual on ranking different aspects of their life and where it ranks in importance to them, spirituality could be number one, and it could be vital to them to attend certain religious events during the week, while their medical needs and services may be further down the list.

Debbie Pfeifer: Yeah, as Callie had mentioned, using the tools, you can use a combination of tools with people too. We had a service coordinator who shared how she used two tools with one of her members, using the trajectory and the integrated support star. And as Callie said, one of the benefits of the tools is you don't need to pull out a piece of paper when you're working with someone. It just kind of helps your thinking, and it helps guide conversations when you're working with someone.

So this service coordinator shared a story of how she was working with a member and they were trying to find out what the person wanted and didn't want in regard to her plan. So they used a trajectory to find out what she defined as her good life, and she defined that as being around family, participating in the community, and not being in a nursing home. And so that was where she wanted to go, and also where she didn't wanna go in her life.

So then they started working on what kind of supports she needed, so they used integrated support star, and that helped identify what she had and what else she needed. So using that star, they were able to look at what resources she had. For example, she had a smartphone, which is a technology support. It also can be helpful with maintaining relationships, and it's also a safety support. So they were able to help to identify areas where she needed more support, and encourage independence in areas where she was doing really well in. So I think those tools really help identify those existing supports and where more supports may be needed.

Karen Davenport: Terrific, thank you, Debbie. Sharon, I know you've had a lot of experience with these tools and strategies too. Could you share some of your experience?

Sharon Spurlock: Absolutely. I think this is such a hard question, because every tool is useful in many different ways, so I've used all the tools, with a variety of populations and for myself as well, which is if you haven't used them to think through, plan, and problem-solve in your own life, that's a great starting place.

So when you asked me this question, I really thought about the portfolios that are available through Charting the LifeCourse, and really a portfolio is a bundling of three of the tools that we've talked about already here. It includes the one-page profile, the trajectory, and the star in one handy, four-page document.

So it really gives somebody a complete picture of where they -- who they are, where they want to go, and the resources they need to get there. And it's a nice thing to be able to take with you to travel to different settings. One thing that individuals and families tell me is that they're tired of having to repeat their story over and over again. So this is a nice way to share their story, or parts of it, without having to redo that. So it's a one-page profile. It's such a nice way to build people's ability to express themselves, and also understand what it is about them that is important in their lives, what they're good at, what they know a lot about. So it's a great self-determination tool.

The trajectory, sometimes it's the first time people have been asked to share what it is they want in their lives and have the steps to be able to move forward with that. And then another aspect of the integrated star, in addition to being able to come up with strategies using a variety of techniques to problem-solve, it also creates a lot of buy-in. If I identify a strategy that I'm really invested in, in technology or something I wanna use in the community, I'm a lot more likely to follow through because I came up with that idea, and I said that it's something that makes sense to me.

So sometimes using these tools is helpful to get a conversation to a common ground. Working with somebody who's an adult who has their own ideas about their life, and their parents have their own ideas, it can be really helpful to kind of look through the trajectory and see where is there a common ground, and where is there a difference, and what does that look like.

I talked to a family where mom and son had different opinions about where he wanted to go down the road. But being able to look at that trajectory, we were able to see that there were common areas where they both wanted to have him keep working. It was important to him. He wanted to have friends and she wanted him to have friends too, but there were areas where they needed to have conversations, like future living environments.

And there were also opportunities to take advantage of some of the things he wanted, to look at concerns there were with his health. You know, if he had some issues with his health, he could play sports, which he was excited about, or do things with friends to have better health goals.

Karen Davenport: Thank you for those examples, Sharon. Let's move on to the next question. And I'd like to ask all three panelists, how has implementing this framework promoted culture change from a medical model to more person-centered care? Debbie, do you have some general thoughts or a specific example to share?

Debbie Pfeifer: Sure. I think one of the main things that helps remind us that services themselves are not the end goal, the end goal is people living their vision of a good life. So the services and supports are there to help them get where they wanna go. Like Dr. Reynolds said earlier, we have a mentality of how do we fix this person, not how do we best support this person. So I think the framework, it helps with that. It brings the focus to what members think is important, not what we think is important.

So we tend to sometimes think that medical services are top priorities to address; our members may not have that same priority. One of our service coordinators shared a story with us that I think kind of shows how the Charting the LifeCourse helped her readjust her thinking with that. She told us about one of her members who had a lot of challenges, so they used a trajectory to find out what the member's version of a good life was.

So they talked about what she wanted and the barriers that she had. So afterwards, the service coordinator shared that the member had a lot of pressing basic needs. Like she needed a phone and a washer and a dryer. So to our service coordinator, those were the most important issues to address immediately. But by using the trajectory tool, what they found was the member's vision of a good life was reconnecting with family members. So that's what her primary -- that's what she wanted, rather than addressing the other needs right away.

So it's not to say that those other things weren't important and not needed to be addressed, which they were. But her definition of a good life emphasized relationships. So this service coordinator said that she would have prioritized things differently, and she would

emphasize things that were not as important to the person. So by using the trajectory, the service coordinator was able to kind of readjust and see that what she thought was a high priority was not for her member.

So I think it's kind of -- it shows that the service is not the end goal, but keeping focus, for this person, on relationships was the primary goal. So it was very helpful in planning her supports. I think Callie has another example of that as well.

Callie Simmons: Yes, I do, thank you, Debbie. During a planning meeting, while discussing physical and medical needs with a member that had a physical disability, the service coordinator learned that he was really most interested in overcoming barriers to social interaction. He really wanted to be more active in his community, and the coordinator was able to help identify transportation and other resources to help make this happen.

By using the framework, the service coordinator was able to look beyond just physical health needs, and look also at social determinants of health and this member really wanting to be more active in his community. The service coordinator was able to provide education and resources that allowed this member to live his best life and continue doing the things that he enjoys most.

Karen Davenport: Terrific. Sharon, I think you have an example that listeners can also look at in the downloads, in the life trajectory hospice download.

Sharon Spurlock: Yes, thank you. So the trajectory, one of the things that Sheli challenged us with the last time we spoke is that the time frame for the trajectory is not dictated, so it can be a year or two years, but it can also be a day. And as Dr. Kerins referenced, we are supporting people through their whole lives now, and that includes aging and end-of-life support.

So we've really had to change a lot of the way we deliver services to support people through end-of-life, when they're getting hospice and palliative care. So the sample that I've given you is a vision for a good day for somebody that is in hospice, that still has a lot of kind of rules and restrictions around the way we deliver services that probably don't make sense for them.

So when we looked at Bob's good day, we realized that he didn't want to get up for 7:00 a.m. medications. He wanted to be able to sleep until he was ready to get up. He wanted to spend more time talking to his family. He just wanted to be comfortable, have comfy clothes and good music. And what he didn't want was to be in pain, he didn't want people to be poking and prodding him without understanding what was going on, and he was done with his low-fat, low-cholesterol diet.

And I think sometimes we forget that those are the priorities for that person in that moment, and we fall back into doing things the way our systems are set up to do. So with this trajectory we were able to go back and talk to the doctor about making his

medication orders more flexible, so that we could do something differently for him. We got rid of the diet off the doctor's orders, because who really cares at that point.

And we were able to have really good conversations with his family about how they could be more present in his home and in his life during this time. So all those things also created a really nice one-page document that the staff could look at every day to remember what their priorities were, so that every day of Bob's life was gonna be really great.

Karen Davenport: Thank you, Sharon. Let's move on to the next question. And that's basically what feedback on the framework have you received from your staff and your members with I/DD, and their families and caregivers? Debbie, would you like to start us off?

Debbie Pfeifer: Sure. The two things that I've heard the most from our staff are the framework has been very helpful in initiating difficult conversations, and guiding conversations with our members. So that's the two things we've heard the most. It's been a great reminder of why we do what we do, and it's a way to ensure that the whole person is being addressed, and not just the medical needs. And I think it's starting to help with that common language with our members.

As far as feedback from our families, we had a family who've used the Charting the LifeCourse already. They were concerned about the stress that their son experiences around team meetings, so he and his family completed a lot of the LifeCourse materials in advance, and they sent it to the service coordinator before his meeting. So it was a great way for the service coordinator to learn about him, and it created a less formal atmosphere and it kinda helped build that common language. So it was a great way to get up to speed, and it made his meetings much more useful for him, and he was able to discuss what he wanted, so it was great for that family.

Karen Davenport: Terrific. Callie, what have you heard?

Callie Simmons: Well, in my experience, it really helps to just put the member voice at the forefront of my interactions with my members and their families, and it really has also helped shape the way that I think about the conversations that I'm having with him, which has truly helped them to be more meaningful. For example, I was working with a son and his mother, and when we were discussing what his vision of a good life was and what was most important to him personally, the mother actually teared up during our conversation and commented that no one had ever asked anything really beyond his specific medical needs or saw him as a whole person in that manner before. So we really can provide better support by looking at the whole person and utilizing the framework is really helpful to do that.

Karen Davenport: Thanks Callie. Sharon, can we turn to you?

Sharon Spurlock: You bet. So, as I alluded to earlier, I think having that piece of paper, being able to do the planning in advance -- families have told me how much they appreciate the opportunity to organize their thoughts, and it gives them what they call "paper courage" to be able to walk into a room and really actively engage with professionals that sometimes have had other agendas in the past.

I think we forget that individuals with disabilities and their families have been sitting in these meetings sometimes for decades with people prescribing what needs to happen to them. So it's been, I think, exciting for many individuals and families to take ownership of that. I also mentioned earlier having those conversations between parents and their children with disabilities about where there's maybe a disagreement. As a professional, that can be a really uncomfortable kind of a conversation, but it's so important to be able to make sure that all voices are at the table, and we come to some common understanding as decisions are being made.

So as I mentioned earlier, Matt and his mom had some disagreements about future living arrangements, but what a great opportunity for us to then have a little bit more conversation about why he thought it would be better to have an apartment, why she thought it would be better for him to live with a sibling. And at that point, the opportunity comes up to really engage the adult sibling in the conversation. And we haven't really talked about siblings very much, but certainly for aging adults, those siblings are the ones that often are gonna be the people that are providing care for and about that person in the future.

And we wanna make sure that their voices are heard, and many adult siblings say I've never had this conversation. I've never had it with my brother or sister with a disability, and I've never had it with the parent. So everybody can be engaged in that conversation and that future planning.

Another example was to kind of talk about retirement between a mom and daughter, and we had somebody who was telling us I wanna retire, I want to retire, but what did that really mean? So being able to engage in the conversation really for that person, they wanted to be able to take a day off once in a while. And as somebody that is in my late fifties, I like to be able to take a break once in a while. Folks with disabilities don't realize that they have that permission all the time. So as we got into that conversation, what happened was we supported this person to advocate with the boss, can I take a day off periodically, a mental health day, and they were fine with that.

And so it wasn't really that they wanted to retire and give up their income and give up their friends. They just wanted to make a little bit of a change in their life. So again, I think the conversations that come out of the framework and the tools are the important piece.

Karen Davenport: Thank you, Sharon. We're going to -- I want to make sure we have time for questions and answers, so I think we're going to actually skip the next question. So if you can move two slides ahead, please? And just one final question for the panel,

then, to ask if you have any additional thoughts to share about supporting people with I/DD as they age. Debbie, maybe we can start with you?

Debbie Pfeifer: Sure. I believe that awareness and education is so important. So just making people aware of some of the specific challenges. And then planning for the future I think is difficult for all of us, but being armed with an education about some of the unique supports that may be needed, I think it can help make planning for the future a little bit easier.

Sharon Spurlock: This is Sharon. Would you like me to go?

Karen Davenport: Yes, please, thank you.

Sharon Spurlock: Great. I think for me, having a long-term relationship with people has really impacted my approach in working with people as they are aging. Those relationships really give you that tool to find out what people want, and then be really creative in problem-solving. And I think that is gonna be the key to success as we move forward with people, that we don't have all the resources within the developmental disability field.

We're going to have to be more creative and look more broadly for the resources that are out within our community. One example of that is that as we're looking at people's health, particularly related to behavioral medications, we're doing a holistic team review now where pharmacists, nutritionists, gerontologists have joined us to make sure that we're thinking through all those components to aging that might be impacting somebody's quality of life.

Karen Davenport: Thank you, Sharon. Callie, any last thoughts on this question for us?

Callie Simmons: Absolutely, thank you. For me, as someone that works with individuals of all ages, I really think that the most important thing is helping members transition through all stages of life successfully while also remaining focused on the things that are most important to them and their vision of a good life. Whether it's transitioning from school to the adult world or supporting individuals as they age, by building relationships with the individuals that we work with, we have the ability to provide consistent support that also acknowledges that people grow and change throughout the course of their life.

Additionally, these relationships really allow us to have those difficult conversations with people, and help them prepare for difficult transitions or challenges they may face as they age.

Karen Davenport: Fantastic, thank you, Callie. So that concludes our panel discussion, and I wanna give a big thank you to our presenters, Dr. Kerins, Dr. Reynolds, Debbie Pfeifer, Callie Simmons, and Sharon Spurlock. Thanks so much for joining us today. So now we have a few minutes for questions from the audience. Yes, thank you. So if you

have any questions for our speakers and haven't submitted them already, please submit them using the Q&A feature at the lower left-hand part of the presentation, and type your comment at the bottom of the Q&A box and press submit to send it.

We have some that have come in already, so I'm going to -- first, Dr. Kerins, I think I have one for you that asks what recommendations do you have for providers for supporting older adults with I/DD who also have anxiety or depression.

Gerard Kerins: Boy, that's really an interesting, important question. One of the issues is if they do have anxiety, which can be related to depression or not, or just depression, how do we approach that. And I like to say we should approach that in the same way as we do any older adult. There are some good, safe, effective treatments for depression. We wanna follow the principle of starting low and going slow, but certainly they should have every opportunity, through counseling, through medication and other supports, to have their depression treated.

Anxiety, we also have to be careful with the medications, but at times, they are indicated. One of the things I caution against, though, is many times on occasion patients, I will hear, are very anxious when they come to a healthcare provider, so they are, quote, unquote, "pre-medicated." I usually don't like that because I wanna see somebody in their most -- kind of how they are routinely, and I think that gives an artificial sense to it.

So in terms of anxiety and depression, I think we should use the same approaches as the general population -- it should be interdisciplinary, and we should also try to find, if we can modify the environment, to reduce what might be adding to their risk of anxiety and depression.

Karen Davenport: Terrific, thank you. I think I have a question for Sharon that I want to touch on. Sharon, how is the Arc working to extend Charting the LifeCourse training to additional staff, and why are you making that an organizational priority?

Sharon Spurlock: Thank you. Well, we have been engaged with Charting the LifeCourse for about five years, but it's been a bit haphazard. We have used it in different capacities across departments in our organization. We serve almost 4,000 people a year, so many, many different opportunities. When we did our strategic planning 18 months ago, we used the Charting the LifeCourse tools organizationally to create our own vision, and through that process determined that the framework would be really important.

And so we put it into our strategic plan that we were going to adopt that as our framework for planning and problem-solving. And in conjunction with that we are now doing an internal ambassador series, where 15 employees are going through the training so that they can be the experts and the cheerleaders across different service delivery areas to support everybody to engage in those activities. We also continue to provide training and support to individuals and families, both through traditional workshops but also by

embedding the tools and the activities into all of our family support groups and a lot of our workshops.

Karen Davenport: Thanks, Sharon. I have a question that I think potentially touches on both the supports that individuals might need, but may also stretch into the clinical considerations as well. So the question is can you elaborate on ways to work with individuals who are nonverbal to ensure their preferences and goals are addressed. And maybe Sheli or Sharon, start with you?

Michelle Reynolds: Yeah, so this is Sheli. So I've been kind of looking at a number of these things. So you know, what I always recommend to people is it has nothing to do with the tools. It has to do with really figuring out how the best way it is to get the information from the people that know that person the best. So whether it's a person's declining health or whether it's somebody who presents themselves as being nonverbal or utilizing behavior as a form of communication, so there are times where the tools become sort of the way to collect what the whole team knows about them.

Is it a direct support professional that knows something, is it a teacher, is it the mom that knows there's a special twinkle in their eye if they like something. And so they become more of a communication tool that allows people to capture the essence of that person, if they are not the person that is communicating.

Karen Davenport: Thanks. I think I'm gonna try to squeeze in two more questions. So first, one for Dr. Kerins. You mentioned older adults with I/DD have higher incidence of comorbidities such as thyroid disease and Alzheimer's. What strategies would you recommend to approach treatment for individuals with I/DD and comorbidities such as these?

Gerard Kerins: I think in those conditions where there was a higher incidence and prevalence, you wanna do routine screenings so you can pick up subtle changes that might indicate the development of these conditions before they become more problematic and affect function. So for instance, we recommend that thyroid function be checked every six months in our Down's patients, even though in the general older population it might be done once a year or once every two years, because subtle changes in thyroid function can present more dramatically in the Down's population than in the general population.

And certainly as well with cognitive screening, which we think everyone should undergo routinely. We recommend that for those common conditions that more proactive screening is done instead of just waiting until actual symptoms develop.

Karen Davenport: Thank you. Then as the last question, Debbie and Callie, why should health plans adopt strategies for supporting individuals with I/DD that extend beyond the medical model or traditional long-term services and support? What benefit does the plan see from your commitment to implementing Charting the LifeCourse?

Debbie Pfeifer: So, I'm sorry, the very beginning of that was why do plans do that --

Karen Davenport: Yes.

Debbie Pfeifer: -- for individuals with -- okay. Well for us, it's better for our members. I think it helps with their services and supports to make sure that they're getting what they really need for their services and supports. So again, not what we think their support should be, but trying to figure out what they think, and their family, what the services and supports are. So I think it's making sure they're getting the right supports at the right time, and the right supports.

Karen Davenport: All right. Thank you very much to our panel. If anybody in the audience has any additional questions or comments, you can email them to RIC@lewin.com. And I want to make sure everybody knows that the slides for today's presentation, a recording, and a transcript will be available on the Resources for Integrated Care website shortly.

As a reminder, additional guidance about obtaining credits and accessing the links to the post-test can be found within the continuing education credit guide in the resource section on the left-hand side of your screen, or at the Resources for Integrated Care website. In addition, resources related to this presentation follow at the end of the slide deck. And please visit the Resources for Integrated Care website for more information on this topic. Next slide, please.

Thank everybody very much for joining us today. Our panelists and the participants on the webinar. Please complete our brief evaluation so that we can continue to deliver high-quality presentations, and if you have any questions for us, please email us at RIC@lewin.com. Thank you again to all of the speakers. Please have a wonderful afternoon, and thank you so much for your participation.