

The Lewin Group
Building a Person-Centered Culture of Care: Shared and Supported Decision-Making and Goal-Driven Care
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Karen Cheung: Hello everyone. My name is Karen. I am with the Lewin Group, and we are supporting the Medicare and Medicaid Coordination Office at the Centers for the Medicare and Medicaid Services to ensure that dually eligible beneficiaries have access to seamless high quality healthcare.

This is the second webinar in our 2017 Meaningful Member Engagement series. Today's session will include a 60 minute presentation from experts, including a beneficiary, followed by a Q&A discussion between you and the presenters. This session is being recorded and a video replay of the slide presentation, as well as the question and answer will be available on our website at www.resourcesforintegratedcare.com.

This webinar is presented by the Lewin Group and Community Catalyst and supported through MMCO. MMCO is developing technical assistance and actionable tools based on successful innovations and care models such as this webinar. To learn more about our efforts and resources, please visit our website or follow us on Twitter for more details. Our Twitter handle is @Integrate_Care.

We have a packed agenda, and I think you will all take away some key learnings from each of our presenters including strategies for supported decision making so members can make life decisions for themselves without overboard guardianship and shared decision making and goal setting, goal driven planning, and goal containment.

At this time, we would like to introduce our speakers. We have Jonathan Martinis from the Burton Blatt Institute, Sandra Fournier from Neighborhood Health Plan of Rhode Island, Laura Sankey from Centene, and Robert Schreiber and Janet Donnoe. I am going to go ahead and turn it over to Jonathan.

Jonathan Martinis: My name is Jonathan, and I am with the Burton Blatt Institute. I am very happy to talk to you today about supported decision making. If you have heard of supported decision making, you have no doubt heard about it as an added alternative to guardianship. I hope you will see that the use of supported decision making can also improve people's life outcomes and be the keystone part of the service provided to people and what people receive from you.

Let's talk about John Paul Sartre. Look at the quote on your screen. It makes perfect sense. We are all our choices. Each and every person listening to this webinar is here because of the choices they've made all their lives. The important ones, silly ones, significant ones, bad ones; our choices tell us who we want to be, who we don't want to be, and how we want to live our lives. In fact, if you think about it every important right that you have comes down to the right to make choices, the right to free speech, to choose what to say; the right to vote is the right to choose our elected officials. Life, liberty, the pursuit of happiness is the right to choose the kind of life we live, the people we're with and what we do.

So this right to make choices is what makes us who we are. Clinically, that is called self-determination. Self-determination is a fancy word used by professionals. It just means being in charge of your life. People who have self-determination are the captains of their ship. They do things rather than having things done to them. They are causal actors.

What we know from 40 years of studies is that older adults and people with disabilities have more self-determination when they exercise their right to make choices; they have better lives. This is undeniable four decades of research. People with disabilities and older adults who have more self-determination are more independent, healthier, more likely to be employed, and according to at least one survey, safer.

What we have been doing for 2,000 years is taking away the right for people to make choices by assuming that people cannot be in charge of their lives. Going back to ancient Rome 2,000 years ago, if you were what they called feeble minded, you would have a curator put over you to make decisions. In the middle ages of Britain, if you were an idiot or a lunatic in their words, you would have a committee put over you to make decisions for you.

We've continued this historical pattern through guardianship. Every state has their own laws, but the laws essentially come down to one thing. If a judge decides that Person A cannot make some or all decisions in their lives, they give that power to Person B. Person B becomes Person A for all intents and purposes because as studies have shown the vast guardianships are full or plenary and take away the rights all of the rights. One law professor I know called that type of guardianship a civil death because the person on the guardianship ceases to exist in the legal sense. That person cannot interact with society except through someone else. I refer to guardianships that are too broad or ones that people do not need as overbroad or undue because they take away rights from people when people can exercise them.

We know that self-determination leads to a good life and taking away people's rights to make choices leads to a worse life. Study after study has shown when people lose their right to make choices they feel helpless or hopeless, and they are self-critical. Their ability to function decreases, and in some cases, they are less healthy.

A recent study, as of last year, shows that when people have the right to make choices and they are in charge of their lives, their lives are better. On your screen right now is a summary of the National Core Indicators (NCI) study The NCI was an apples to apples study done in every state. I call it apples to apples because it reviewed the quality of life of people of intellectual and developmental disabilities viewing people in similar situations as others. In other words, they used the old standards including mild, moderate, and severe disabilities, and they compared people with mild disabilities to others with mild disabilities, and moderate to moderate, etc. They looked at the quality of life of these people across a number of variables.

One of the variables they reviewed was whether or not a person had a guardian. Looking at just that one variable, they found that people who did not have guardians were more likely to be employed, independent, have friends, dates, and practice the religion of their choice than people who had guardians. So, potentially the only thing standing in between having that kind of life and not having that kind of life is having a guardian. Doesn't that mean that we need to be very careful about whether or not we put people under guardianship? We should not do it reflexively.

I am not here to say people should never be under guardianship. That is not my intent, but what I am here to say is we need to be careful and find ways to maximize people's self-determination because that has been found, time after time, to be the key to a good life. So what we need to do, I propose, is find a way to keep people in control of their lives to the maximum of their abilities while at the same time recognizing that some people need more help than others. Those of you who deal directly with people with disabilities and older adults, you know that as we age we need more help or that some people need more intensive types of help. That is why I say we need to find ways to provide that help while finding ways to keep

people in control of their lives. That is at the heart of supported decision making, what I'm here to talk to you about.

There's a big long definition on your screen about supported decision making. I wrote it, and I don't like it. We can talk all day about the importance of working with friends and family members and professionals to help people understand their situations and choices they face so they can make their own decisions, but I would much prefer to define it this way: How do you make decisions? What do you do when you go to the doctor and the doctor speaks jargon to you? Those of you who are doctors, I apologize, but it does happen from time to time. The doctor will say you've got a subluxation in your cervical brachial area that can be treated conservatively with a course of anti-inflammatories or aggressively with a surgical intervention, and I'll say something intelligent like "what, can you explain that to me like a five-year-old," and the doctor will say you've got a crick in your neck, and we can give you Motrin or we can give you surgery. Then I understand because I have been told in words I understand what my options are.

When you go to the auto mechanic, and they talk about things that you can't possibly understand, at least I don't because I don't know about cars, and I call a friend and ask for advice. When I go to an accountant to help with my taxes or when I talk to a buddy for relationship advice, in all of those I am practicing supported decision making. I am getting the help I need to understand the situations and choices I face, so I can make a good informed decision. It is about making decisions just like you and I do. The only difference is if you are a person without disabilities, if you are me, temporarily able-bodied as one person called it, doing that, using supported decision making, saying I don't understand is smart. You're considered to be wise and judicious, but for 2,000 years, if you're an older adult or person with disabilities saying I don't understand, what we've done is taken away rights. So across the country, as we see on your screen, we've had a change in position, a paradigm shift, moving away from reflexively taking away rights and more towards supporting people. We have laws in Texas that recognize supported decision making as a way to make decisions. The U.S. Administration on Community Living in the Department of Health and Human Services has funded a national resource center for supported decision making that I am honored to be the Project Director of. States like Virginia and Missouri and others are taking positions that it is better to support people than take away rights. The American Bar Association and National Guardianship Association, NGA, an organization made up of guardians by guardians for guardians has taken the position we should seek to support before we seek guardianship.

Across the country, we are seeing active programs designed to do just that. In the Carolinas, in Nevada, Maine, New York, Florida, Idaho, we are seeing courts and people and agencies and entities coming together to use supported decision making to help people become independent and stay independent rather than lose their rights.

That is important because we're not just talking about guardianship here. Think about the definition of supported decision making, working with people to help them understand their options so they can make their own decisions. Those of you who do person centered planning, doesn't that sound just like supported decision making? In person centered planning, you're required to work with a person to understand his or her preferences, so the person can choose the best possible programs and services to help live their best possible life in the community. How can you do that except through supported decision making? How can we have a student led IEP in special education, which is best practices where the student sits at the head of the table surrounded by educational professionals, parents and advocates with the goal that the student leads the meeting and the student defines his or her goals? Doesn't that sound like supported decision making? How can we do informed choice in healthcare or vocational rehabilitation which is predicated on the professional providing information to the person so the person can make the best possible choice

unless we are using supported decision making? As I said at the beginning, supported decision making permeates throughout the system. It is not only best practice; it is already required by our laws and regulations as you see on your screen. I pulled that directly from CMS's website on what people should do to do person centered planning. I submit to you it is a perfect definition of supported decision making.

What we can do next, knowing that supported decision making permeates through the system, is use it as the common tongue to connect the supports and services that help older people and adults with disabilities. Something my partner and I call the culture of supported model is the idea that agencies that use supported decision making should work together to implement supports and services. We should not have an employment provider, a Medicaid provider, and a school without them speaking with each other and connecting. Think about the definition of person centered planning. It is supposed to address education, employment, healthcare, finances, and future planning. In the culture of coordinated support model, that provider is already collaborating and coordinating with other entities that do or could do the same thing. In that way, you each can share burdens and build on strengths, so that you're not overloaded. To any of you who do person centered planning, I've been around the country and I've heard the complaints. I know that it is impossible to do all of the things that you're required to do by the settings rule and all of the things you're required to do under the person centered planning rules without short shifting the person and without asking a series of checklist questions. Well, by working with others and bringing other entities into the mix, you can now better meet your requirements. If you were working, for example, with a vocational rehabilitation agency to take the lead in employment areas using supported decision making to ascertain the person's preferences and goals, that is one less thing you have to do. You can simply say that you are aware that employment goals are being met and that you are regularly keeping track on how they're being met, which now allows you to focus more clearly on things like community integration.

I am honored to be the chair in the first statewide taskforce that is designed to create a culture of coordinated support model in Vermont. We have pilot projects where people who had never before worked together are collaborating and building on their strengths to help people live better lives; that is just one example. The service provider, a Medicaid service provider, is collaborating with the public guardian. Two entities, who never worked together before, are working to identify people who are currently under guardianship and identify what is missing from their lives. What services and supports could help them better organize their lives and better run their lives so they can be in charge of their lives? Then, they work with a self-advocacy group to help the person choose what services he or she wants, and bring in attorneys so that when this process is in place to create power of attorney forms or to help the person ask the court to let him out of guardianship because they have addressed the very things that put them in.

In Vermont, we are working with Medicaid providers, schools, and rehab administration in order to identify students who are at risk of guardianship and help them get the wrap around services from those three entities in a coordinated way that builds on the things each of them do well to help the student live the best possible life and get the services he or she needs to be independent and avoid guardianship. We have a task force that meets regularly to discuss ideas and discuss new ways to collaborate so that no one entity feels like it has to do it alone. I've heard people across the country say social workers feel like they are on an island. They are supposed to be bringing people in, but no one brings us in. This model puts people at the center, truly at the center of person centered planning, and empowers you, each agency, and provider to better serve that person. It also allows you to coordinate services so that the person is better served and so that you can spend more time doing that which it is that you got into this field in the first place, not to fill out forms, check boxes, but to truly plan services and supports and create networks so the people you work with live their best lives.

That is where I want to end. This quote on your screen is from an article that I co-wrote with my partner published in *Apostrophe* magazine. What we propose is world change because too long the system has been siloed. You have been on an island. People have been running to different places to seek different types of support even though those supports are consistent with supports that can be provided in other places. The result has been, what one expert calls, a fragmented system of services that leads to the failure of people with disabilities to become productive members of society, not because they lack in ability but because we, as a society, fail to provide good supports and services because we are so busy sending people off in different directions that they spend so much time trying to figure out who can provide services that they never actually have the time to access good services. By creating coordinated collaborative networks that have supported decision making at their gut, which they're supposed to have under law right now, we create an ability to give people with disabilities the same options that people without disabilities have. We then provide them with the same opportunities to reap the same benefits of self-determination that people without disabilities have, and if we do that, if we change 2,000 years of culture that say people with disabilities cannot live independently to a new culture that says they can and we will work together to make it happen, then we'll change the world.

Thank you very much for having me today. I would like to turn it over to Sandra Fournier. It's been my honor.

Sandra Fournier: Thank you, Jonathan. I would like to take a second to thank you all for joining us in this very important discussion. I hope you find this information helpful in your approaches to work with all individuals.

As Jonathan said, we all make decision and we all have goals. Goals are composed of a lot of different things. Although many of us have identified something as a goal for ourselves, we do not always identify the objectives and the methodology that is incorporated into making our own goals or our attempts to reach that goal. Each of you think of a goal that you have made. Some of them were achieved more easily than others.

Patient engagement is an increasingly important component in healthcare. The contribution of the patient highlights the skills and confidence that patient needs to make informed decisions and be actively engaged in their health and well-being. There is a growing body of evidence showing patients who are more advocated have better health outcomes and care experiences. Evidence indicates that interventions that tailor support to the person's level of activation and that builds skills and confidence are effective in increasing the patient activation. An activated patient is more fully engaged in achieving their goals. Some evidence indicates that patients who started at the lowest activation levels tend to increase the most.

It all comes down to meaningful engagement. The process of meaningful engagement results in the engagement of the person. It allows them to express their goals, their expectations for care and their level of involvement and help the person to reach the established goals.

A person centered approach is always necessary. A person centered approach help us to move from the need to protect and confine to a place in which we honor the person's concept of life. Our new role in this day and age is to help a person experience and explore in growth and development.

Person centered thinking is where we need to be. Person centered thinking serves to empower the person. It results in a service system that supports rather than controls individuals, and we enter into a partnership with the person. It promotes self-determination and interdependence and provides opportunities for people to make choices in their own lives including where they live, who they have relationships with, the

way they spend their time, the pursuit of their personal future and program planning and implementation which results in a choice of lifestyle options with the least possible control by others.

It is a process. Person centered planning assists persons to build their capacities and capabilities. This planning effort is not a single event but a series of discussions or interactions among the person, the family, service coordinator, and the team. It is a real partnership. Whatever your system is in your state, it involves everybody. The team would be comprised of different people according to who the individual trusts and who the person is involved with.

This process is not something, as I said earlier, that happens in one meeting. It is a series of steps. So now we need to look at how we are going to measure progress towards a goal that somebody meets. First, we need to make sure that we are on the same page with the person. The goals that are set are the goals of the person. They are not the goals of the team member or the members. Too often in the past, what the team thinks the person needs, likes, or wants become what the person believes they need, like, or want, yet in reality the person may not have been given the independent exploration, independent thought, or even a say in the question of what happens to them or what matters to them.

It is a series of steps. After we identified things, we need to identify steps to get to the goal and the resources. We need to identify barriers and approaches, and we want to identify those early on because that is going help us mitigate them ahead of time. We want to empower the person to implement the plan that will achieve the goal.

How do we discover what's important to the person? We help the person to explore their interest. What are they good at? What is their skill or talent? The challenge for the future is to establish the person's goals as the norm. How do we help us to understand that although their goals for the person are important, the individual's goals for themselves is primary? The person is choosing their life based on his or her own life experiences, experiences which we may not have lived. Speaking from my experience as a nurse, too often as healthcare professionals we impose our goals for the person, and we do not recognize the person's goals may be different. We tend to seek hundred percent of goals, and that just isn't always achievable or interesting to the person.

When we talk about the future, setting goals often involves a team of people. Those on the team should understand the person's history, their abilities, their preferences, the barriers they've encountered in the past and barriers foreseeable in the person's attempt to achieve the life they want. The team members should understand the concerns of the person in meeting the goals and the problem that perhaps the goals will then produce. As an example, let's take employment for a person with a disability. This is a common goal nationwide for many. The state that I lived in is under a Department of Justice decree to get people employed. It is well achieved by many, but for some, an increase in income can result in a loss of benefits if the planning is not done correctly. People are unwilling to work or unwilling to achieve success at work. The realization is you need to examine the person's past and life circumstances to determine the future. Give the person credit to what they accomplished despite values and what those barriers have prevented in the past. It is a real challenge because every person has different led experiences, and often we have little to no real experience with many of the challenges to the individual.

The planning process helps us identify potential barriers to the goals and helps identify strategies to address the barriers before they inhibit progress. We can't move forward if we're restricted by the barriers and the different hurdles that need to be jumped over. Sometimes we need to find a way around or between those barriers.

So as we move on to measuring those goals, achieving a goal can often be a daunting experience. Depending on our own unique life circumstances, we each define success differently. Goal attainment doesn't have to be an all or nothing measurement. It's not always 100%. Gaining success towards reaching a goal allows a person to move forward in increments.

By measuring increments to achieving the goal, an individual can move forward in a steady pace. A setback can occur in achieving the next step though it is still a success to be privileged in achieving the previous efforts. It becomes easier to recognize success versus realizing defeat.

First, incentive planning and goal planning is a realistic way to improve patient engagement and activation. By recognizing what is important to the person, we can help individuals succeed to improve their health, their independence, and overall quality of life.

I will give you an example of a person centered goals approach that we used. We always start with an assessment of the person. Often, it also involves team members if an individual has some difficulty communicating or isn't comfortable with discussing goals with a stranger. A care plan is developed and the goal setting is done with the person, not done just with the team. Care plans with goals are sent to the interdisciplinary team, which results in one care plan and a person has the major influence on developing that goal. We conduct repeat assessments from three to twelve months depending on the classification of the service level the person needs as well as hospitalizations. We maintain telephone contact with the person, and we incorporate the use of other available resources such as a community outreach specialist, housing specialist, physical, occupational therapy, some DME specialists as well as looking at home modifications. All of these things can enhance the goal taken.

Some key takeaways I hope you can come away from this are setting goals is essential to engaging individuals. An activated patient is more into achieving their goals. Goal setting is an on-going process, and it has to happen with the individual. Measuring the goal can be accomplished by percentages and by pieces. It doesn't have to be an all or nothing type approach to goal setting. I would like to thank you all at this point, and I would like to turn the presentation over to Laura.

Laura Sankey: Thank you, Sandra. Good morning, and thank you for having me today. Today we are talking about person centered planning. I was asked to provide a bit of color commentary on how this concept plays out in one of our managed care markets.

Centene is a managed care organization serving over 11 million members in 24 states. Today, I am going to be focusing on our Michigan plan, Fidelis Secure Care, currently being rebranded as Michigan Complete Health. Fidelis participants in the financial alignment demonstration and operates an MMP in Wayne and Macomb counties. They, in turn operate, with Concerto Health who operates clinics in those regions and provides care services to Fidelis members.

On the previous slide, you were seeing our agenda, which includes showing how this supports person centered planning, identify what matters most to our members and describe how to use that information to motivate and engage our members to achieve their own person centered goals.

As I mentioned, Concerto operates as a delegated entity for Fidelis. They perform the level one risk assessments. This is the actual physicians on staff for over half of the Fidelis members. They see them in the clinics as well as in the community when appropriate. They are located in close proximity to the population served such as apartment buildings in nearby Detroit who house mainly dual eligible beneficiaries.

Clinics themselves are disability competent and were designed with a member in mind. They are built on parking lots where the clinic has zero steps, wide doorways. They also have these really great adjustable exam room chairs and tables for the frail and elderly, which they can sit down and it just kind of tilts back. They have these wheelchair accessible skills and a reflection room for sensitive discussions. They've got a health education room where classes are offered on topics such as diabetes and cardiovascular care. That clinic becomes the hub for that member's care coordination. It encourages that cross collaboration between the staff members, including the care managers who coordinate with the Area Agencies on Aging and the prepaid inpatient health plans or PIHPs who handle that behavioral health component. Of course the PCPs are there, along with the pharmacist who performs the medication reconciliation, a dietitian on board, LTSS coordinator who can work with those AAAs, and a disease management educator. All of them are able to come together in that one setting to really support that member holistically when needed.

While the clinic lays out the design to support that member, it is that person centered training that makes it really impactful. At an enterprise level, Centene has put a lot of effort into building out our member engagement in person centered training modules over the last twelve months. Our Texas health plan worked from the Institute of Person Centered Practices to develop a three day program focusing on what it means to be person centered, and we're in the process of rolling that out to our plans including Fidelis.

In addition to focusing on that person centered care planning, the court goes deeper and covers things, foundational topics for disability rights, guardianship alternatives, cultural competency, person first language, communication styles and active listening techniques. Motivational interviewing is also included in that training. Those methods are then shared with store managers in gathering the member's values and preferences.

By asking probing questions and digging deeper into what the member wants and values, we are able to start collaborating within that interdisciplinary care team and develop plans that meet the needs of that member based on best available evidence.

In addition to the Centene curriculum, Fidelis participates in state provided trainings, including self-determination. While all of this is certainly appropriate for our care managers to understand, we understand that other departments across the organization need to be educated to truly create that personal culture across the enterprise. These teams go through product trainings that reflect the overarching goals of the program and outline the importance of member choice regardless of the physical or mental ability. Teams like the provider networks or member connections, which is like our community health workers or our marketing health teams, start to reframe with those concepts in mind. They start to promulgate the importance of choice when communicating with their stakeholders. They move away from telling somebody what they need to do towards providing members with options and allowing them to choose what the best decision is for themselves.

Person centered life planning is a process that guides exploration and action on a member's wants, needs, and goals resulting in a balanced life plan, which allows the member choice over their own care and to live a satisfying life in their own community. So we really believe instead of asking what is the matter with, we need to start asking what matters to you.

Finding out what matters to a person is key. It is about asking a member what's most valuable to them, what makes them happy or excited, what makes them feel satisfied or fulfilled, what do they want in their life, what hopes and dreams or routines do they prefer? We also need to consider what's important not to be in a member's life. Finding out what needs to be absent can help create a care plan that lessens the

amount of stress a member has and shows the member we are truly listening to them. Determining what is important to a member and helping them achieve that contributes to better outcomes.

In addition to asking a member what is important to them, we certainly need to be identifying what's important for them, and we're usually pretty good at this already. Our nurses, care managers, and service coordinators know how to put those services in place and keep a member healthy and safe. They provide information on medical and behavioral health diagnoses, educate members on preventive measures, and ensure they've got the equipment and services needed to remain safely in their home. We work with our members to ensure they've got a sense of well-being and that means we not only are able to report suspicions of abuse and neglect or exploitation, but we educate the member on what that is and how to get help if needed.

Another part is the need to feel valued. If a person does not feel valued, it can certainly affect their physical and emotional status. When a person feels they've got no value, there's little to live for. It's really important for a member to feel valued and make that valuable contribution within the community.

Here are some examples of some important questions to consider with our members. By asking important questions like “how do you want to spend your day?” and recognizing the member's got the right to make choices such as “who are your providers?,” or “what treatments do you wish to pursue or not?,” we're able to develop that truly person centered plan. We've identified that nobody really wants to do what is important *for them* unless it identifies something that is important *to them*.

How do you achieve that balance? It is really the role of our care managers to simply help guide that member through that process, including anyone they want to include as part of that I ever team. We have to remember it is all about the member, and that member is the driving force for any person centered life.

How does this play out within the Fidelis/Concerto model? In Michigan, the care plan is called the individual integrative care support plan. It includes all the items here as well as the member's preferences for care, services and support. Also, it prioritizes their lists of concerns, goals, and objectives. If members make appointments to come into the clinic, staff do the care plan usually the day before the visit. It allows the PCP to review the information and prepare for that visit. The PCP also uses a system called P360, which includes claims data, any care gaps the member might have, houses the care management notes from conversations in the past and also includes the member's electronic health record. All of this information is available to that PCP to holistically look at that member in preparation for their visit the next day.

At the time of the initial assessment and subsequent reassessment, members ask about their desired level participation on the interdisciplinary care team and who they want to have on that team. This can include family caregivers, variety of providers, pharmacy staff, as well as clergy men, any others as appropriate and as requested by the member. So for members utilizing Concerto PCPs, this becomes easier as many of those members are located within the clinic. I said there was over 50% of the Fidelis members assigned to PCPs at the clinic themselves. This makes easy to collaborate with the integrated care team members in the clinic themselves. Of course, for community physicians it becomes a little bit more difficult. So it's the role of that care manager to quarterback that collaboration and engage those external providers based on the request of the member and include them in the integrated care plan concentration.

Another unique feature is its use of the care bridge. The care bridge is the Michigan technology solution to house information about the member. The integrated care bridge record (ICBR) is the individualized member record and allows secure access for members as well as those that are on the ICPCU. That care

bridge becomes more important for those community based providers outside of that Concerto model. It is up to that manager to update them about the care bridge and make sure they understand how to use that tool for collaboration. The care bridge becomes the electronic hub of all information around that member, so it draws people toward that collaborative effort of sharing information back and forth and keeping people informed about what's going on with that member.

We understand the importance of supported decision making and allowing those individuals to really make their own decisions and stay in charge of their life while receiving any support they need. Concerto staff are able to explain the program services and healthcare options to those Fidelis members. Information is presented in a culturally appropriate manner that takes into consideration the member's condition and the ability to understand the information. Those with limited cognitive ability might have chosen a designated representative or supporter, and we ensure that supporter knows they can help a member understand their option, their responsibilities and consequences of those decisions. They can certainly help them obtain and understand information relevant to that decision. Even help them communicate their decisions to the appropriate people, but they can't make the decision for the person with the disability. It is very important understand all of that support that goes into giving that person information to make that decision and not assuming that decision for them.

Members are also informed of the option to self-direct their own services. Our LTSS coordinator explains that choice to self-direct when the care plan is updated. The process is strictly voluntary so the member can consider the various arrangements and choose the extent to which they want to self-direct their services. That LTSS coordinator is available to help inform them, navigate them, tell them what's available, connect and refer them as the member requests.

One of my favorite parts of the monthly contract management team meetings that we have with CMS is the sharing of success stories. Each is obviously unique in their own way but all heartwarming stories to improve quality of life for our members and certainly for person centered life planning. In this example, our member had been discharged from the hospital and adamant she didn't want to live in a nursing home. Due to the close relationship that family had with Concerto and their care coordinator, the daughter contacted the care coordinator within hours of her mother's arrival back home to report changes in her condition. She was agitated and upset. The care coordinator reassessed that member. She was asking what was important to the member. She said her husband was the most important thing to her, and she didn't want to leave him home alone in the home they had shared for 48 years. The review was completed, and from there, the care manager had her marching orders and what that person centered goal was: to remain independent at home with her husband. The coordinator took steps to get the LTSS performed and assisted the member in getting those supported services to remain in the home with her husband. Shortly thereafter, the daughter brought her mother back into the clinic for a follow-up visit and had tears in her eyes. She said no one in her whole life had helped them like Concerto and the care manager had helped them by getting all of those services for her mother and helped keep her parents together in the house they lived in for 48 years. To me, this is just one example of many that I hear about that demonstrates what that person centered is all about. It is about listening to the member's wants and needs, providing them with options and allowing the member to make their own personal choice.

Our key takeaway is to recognize the importance of staff training on person centered care. We need to put in the time and effort to ensure our teams understand why it's so important. As I mentioned, our approach is to make sure various departments have that understanding that it's not just about care coordinators. We need to encourage our teams to ask those probing and thoughtful questions and drive to what is important to the member. Team members need to be educated and able to inform members of those care choices available to them through supported decision making and self-determination options when appropriate.

With that, I thank you for your time today and I will hand it off to Robert.

Dr. Robert Schreiber: Thank you, Laura. So, I am going to take supported decision making and goal driven care and apply it to older adults.

We are going to provide an overview of a program that actually does this called Vitalize 360 and explain how it can be used with beneficiaries in all different types of settings. Then, we are going to provide a member's perspective through Janet's story. Janet is here with me, and we are going to have a conversation specifically focusing on how providers worked with her, to understand her goals and values in care plan and how that's been different than what she had been used to.

In full disclosure, I am the Medical Director of the Vitalize 360 program. This is a program that uses a coaching and assessment system that combines an innovative and person directed approach to wellness coaching with the power of information derived from a scientifically grounded assessment system. The program engages, challenges, and inspires individuals to live a full, healthy, vibrant life and enables communities to do appreciable improvements in successful aging. The program is now being done in approximately 34 communities across the country, including supportive housing where Medicare, Medicaid, and dual populations live as well as people with disabilities. We also have this program in community continuing care retirement communities and community care retirement communities at home. We are also now piloting this in community and senior centers.

The core components of Vitalize 360 are the following. First, the importance of resident engagement. We heard about the importance of engaging and understanding what people need but getting them activated has been a real challenge. This is something that the health system has not, in the past, been paying attention to.

Secondly, we have a meaningful conversation. It is not an assessment, although an assessment is done with the individual and a senior coach, and it's done in a manner that allows for data collection and documenting the issues that come up in the discussion. Thirdly, we take what we've discussed and put it into assessments and software. We have a software program that has been specifically geared to what the individuals and coaches want to see to help them make decisions. There are validated assessments done and developed by an international collaborative to improve the life of vulnerable persons using a comprehensive assessment system. There are two particular assessments. One is called lifestyle survey which is self-administered and subjective, and then there is the health and social checkup, which is more objective health focus and identifies potential risk that may require support and is done by the senior coach. The responses are entered into the software, which allows for tracking health outcomes for the individual as well as a population over time and then it allows for us to assess how we're doing for the goals of the individual and population.

Another way of looking at this is that older adults are the CEO of their health and wellness. We heard from Jonathan about people being the captains of their ship. This is the same type of concept. Sort of the way of looking at this is imagine you had a community where people were walking around with a placard on the front and back where what really mattered to them was listed. So you are objective when you are interacting with individuals and you try to help people achieve that goal. Setting meaningful and passionate goals is what this program is about and with one of the goals of maintaining a fulfilling purpose in life. We do this by empowering people to reach their goals and reach their full potential and achieve the best possible life.

So Vitalize 360 is really about changing the culture. It is a different way of doing things, and specifically

we want to maximize a person's potential for vitality. By doing that, we are going to reduce healthcare costs and improve the value of the care they're being given or the services or supports that they have. This improves population health and lends to sustaining individuals in a sustainable way in their later years of life.

What I would like to do is take you through this actual process. At first, we have an appointment where the senior coach invites the individual to come and have a discussion and an assessment is done. A reflection and a worksheet is given where individuals are given some homework to go home and talk about and think about what it is that's really been important in their lives, what have been some of the barriers, and what are some of the things they really want to achieve.

After that, the coach talks to others that may work with this individual. Again, we get permission to do this. The individual does some homework and then they come back in for a second appointment. This is where there's development of a resident's personal goals, an action plan, and this is based on what matters most to the individual. In addition, we used the output from the assessment to inform the individual of some opportunities based on what they want to do, what they want to achieve, what matters of areas that they may need support on, and what they want to focus on. What do they want to do?

After that plan gets established, we share the plan. We get permission to share the plan with people. This could be anyone from a social worker or a home care coordinator. It is important to share what this individual's goal is and what they're trying to achieve. The individual can also take that life care plan and their life goal to their healthcare provider and also to family members to talk about what it is that matters most.

The coach will check in with them quarterly, as well as people on the team will be checking in, to see how the individual is managing and reaching and find out what is challenging to them in meeting their goals. Then on a yearly basis, the resident comes back, we see they achieve their goals or if they're not attained, do they need to be revised or do new goals need to be developed? So, that is sort of the process.

I want to talk a little bit about this vitality plan. The intent is to focus on what matters most in older adults. Many times they are living and doing but not thinking about what it is that is really important. This gives them the chance to identify what their values, strengths, and accomplishments are and determine whether or not they want to pursue other goals or do they want to do things they maybe didn't have a chance to do in their younger life that were important to them. Based on that goal, it forms the foundation for a plan. I want to focus on this because it's different than what we've been hearing. In a sense, it's not really a medical care plan. This is a life care plan or a vitality plan. Most people extend the majority of time outside the health system. How do they want to spend that time based on what matters most? So the goals that individuals reach for have to be realistic, and that's where the coach works with them. Sometimes they are big and audacious goals, and other times, it may be just connecting more with their family, but there are specific action steps that inform those decisions. There is also a summary report that comes out based on the assessment that helps the coach and the individual reach those decisions on where they're going to focus.

So there are five health related values or domains that occur on this. One is functioning. An older adult functioning is what is most important, because if you can't function, you can't do the things that really matter to you. We also focus on health and wellness, and how they need to take active charge in taking care of their chronic issues and what they can do in terms of behaviorally to improve their health.

Connections with others is very important. Life enjoyment and pleasure, having fun is another piece that

we focus on and then engagement and a sense of purpose. This is what comes out of this approach, and people are able to achieve various aspects of these five domains.

We have outcome reports on the individual community and population level. There are nine primary indicators gathered through these measurement tools. Then there is a risk adjusted score to compare populations. The nine primary indicators include outcome reports that involve mood, cognition, social life, satisfaction with life, ED or hospital use, physical activity, community engagement, falls and pain. After we do that, you will see in the next slide there's a composite score. These reports can be used for a variety of purposes. They can be used by clinicians and administrators to actually look at what's happening with their population over time and benchmark their population's health with their peers in the hope of identifying best opportunities of improving care. In addition, individuals can see what's happening to themselves over time, and this will allow them to develop an action plan and determine whether their goals need to stay where they are.

When we take those nine indicators, we roll them up and put them into a composite score. This is sort of a report card, and we have three reference points, a 20th percentile point, a 50th median and an 80th percentile. Now, these scores can be done in assisted living populations and even in nursing home populations. We can actually make certain that we call those populations out and compare them, but in fact, this can be done across all different populations. This gets us a summary score of how a population is doing. So, again, they're risk adjusted that allows for comparisons between many different sides.

Before we turn this over to Janet to give you some key takeaways, we need to have a patient engagement strategy that is holistic and that focuses on what matters most rather than what is the matter with the individual. Medical providers need to help individuals make healthcare decisions based on their goals and values but specifically for what is important in their life as well as what's involved in their healthcare. The shared decision making is a natural by-product of this approach where we actually have people working together to help support each other in the sense of we can work to help you achieve your goal and by you working with us we can make our community and our organization better.

With that I'm going to turn it over to Janet to share her story.

Janet Donnoe: Thank you. This is my first year participating in the Vitalize 360 program, and even though I'm new to the program, I can already tell that I've got a better understanding of what matters most to me at this point in my life and why.

As a result of my conversations with my coach and going through the steps that Rob outlined, it's become clear to me that not only is it important for me to do what I can to maintain my health and stay active so I can have a satisfying life for as long as possible, but it is equally important to me to be able to control and be actively engaged in determining what happens to me in the different types of areas that affect the quality of my daily living.

As a result of my discussions, I've developed a couple of goals. One of them is to refocus on things that I had been doing a year ago to regain the energy and feeling of well-being that I had had when I was regularly exercising along with eating a balanced diet and avoiding foods that trigger my sensitivities.

I discovered this makes a big difference in how much I enjoy life and what I experience on a day-to-day basis. I was pleasantly surprised that when I met with my Gerontologist that they were already aware that I was engaged in this pursuit and had included it in a discussion during my first appointment.

One of my other goals is to look to the future and start to build working relationships that I can trust and rely on to represent what's important to me when I am no longer able to advocate for myself.

This is one of the things about the Vitalize 360 program that is very different than the experiences that I had for about 20 years when I was trying to support my mother and ensure that her life satisfaction was included in the decision making related to not only where she lived but the types of activities that she received support to participate in.

So far I'm very pleased with my experience with the Vitalize 360 program, and I'm looking forward to working in that structure to ensure that I feel that I will be represented in the future as I age.

Dr. Robert Schreiber: Janet, that's very interesting. There is a couple things that you mentioned that I wonder if you can sort of give us a little bit more information about. In particular, you mention your values and goals and how that's important not only to have people understand them but to use that as a spring board for moving forward. Can you talk more about why that's so important to you, and why you feel that that needs to happen and doesn't usually happen in the care delivery as we know it?

Janet Donnoe: For me, sometimes the devil is in the details. I know that what I see out of my window in the morning is important to how I live my day. It's not something that is usually thought about in providing care, but as I age, that may be one of the primary ways that I get satisfaction from my daily life. In fact, I actually made a decision to select my new living space based primarily on that factor, and I can report that for every day since I've moved into that space, I look out the window and my mood shifts.

Dr. Robert Schreiber: This is really fascinating as you bring this up. Your values and goals are a way of determining how you want to live in the future, what is important, and the point of even just where you live, the environment you live, and having choices of what you want and what you don't want.

Janet Donnoe: That is correct.

Dr. Robert Schreiber: Have you thought about this prior to doing this program? I mean, had anybody ever stimulated you to think about this type of approach in the past?

Janet Donnoe: Nobody has stimulated me to think about this approach, but based upon the presentations today, one of the things that I realized is that I had been creating a person centered approach when I became an advocate for my mother and she was no longer able to advocate for herself. The healthcare system hasn't been supportive of that, and I saw that for a person that I loved and was concerned about. It was important that my satisfaction be included.

Dr. Robert Schreiber: Yes, well said. Thank you, Janet. That has been really very informative to me including the fact of understanding what is important to you and how you want to live. I think that probably relates to a lot of our discussion today, and I'll turn this back over to Karen because I'm sure there's going to be a number of questions that have been stimulated today. Thank you.

Karen Cheung: Wonderful. Thank you so much to Jonathan, Sandra, Laura, Rob, and Janet. We learned about creating culture supported, shared and equal decision making, and we heard some great concrete examples of these concepts in action between Rob and Janet. I think it was a great example of an interaction in dialogue for understanding what matters most to a patient. This has been really informative.

We have some time for questions from the audience, and we did see a couple of them come through in the

chat window. So go ahead, if you have questions, type them into the chat, and I have one that I'll start off with. I think any of our secrets can probably answer this question, but Rob, you may have referenced some of this during your presentation. What validated tools do you use in assessments to determine individual strength of capability?

Dr. Robert Schreiber: That's a really great question. In terms of the approach, we have a tool that we use. It has not been validated. It's more of a total that's a reflection sheet in terms of having individuals go through their life experiences, and as Janet just mentioned, the things that give them pleasure and joy. So in terms of the approach, it's more of an approach to get to a goal, and in terms of the validation, we recommend having a conversation where we ask individuals to reflect. The validated process is a senior coaching process or coaching and reflection process. So there is actual certification for individuals to actually learn this approach, but the worksheet we had was really predicated on the feedback we had gotten from our members as we piloted this. This has been a work in progress for about seven years, and we then refined it. The coaches process are evidence based approaches, and there are certifications. I hope that answers the question.

Karen Cheung: Thank you, Rob. I have a series of follow-up questions for Laura based on examples you've given. Laura, how many of your clients with complex care programs have intellectual and developmental disabilities? Do you have an answer to that?

Laura Sankey: I don't have that breakdown in front of me. I do have the breakdown specifically for our markets and how many we have at institutional waiver versus community. That might be helpful to the person querying. For Michigan, we've got 4% that are institutional, 9% that are considered waiver, and then we've got 88% that are community based in that market.

Karen Cheung: Thank you, and then specific to the success story that you shared, how would have helped that member if they didn't have the resources to stay at their home with their spouse?

Laura Sankey: As part of that MMP program, we've got those waiver services, and part of that example was a matter of getting that member to go through the additional steps of going through the LTSS waiver assessment to see if they can fit for that treatment part of the benefit. In this case, they did and so that's picked up on the Medicaid side of that benefit of the program. These are all full duals that are in this program.

Karen Cheung: Is Care Bridge a Centene product?

Laura Sankey: Care Bridge is specific to the state initiative. It was state driven. That's their version of it. In South Carolina, we have something similar called the Phoenix system. It's driven by the state. All of our managed care organizations in this program in the Michigan market are using that care bridge. It's not specific to Centene.

Karen Cheung: Thank you. I have a question for Janet. It's also a follow-up question to something you had said earlier. Do you feel that people are scared to talk about aging, issues, and all associated with end of life planning?

Janet Donnoe: I think that the healthcare system is operating within a set of assumptions that constrain what's available to an individual. I've been fairly healthy to this point in my life. So if I look at the aging process and what's needed as people's capabilities decline, I rely on, as I indicated, my experience being an advocate for my mother. She received very good medical care, and I was included in the medical

discussions. Where I had difficulty was being able to be heard and to put resources in place that were truly critical to how she experienced her life day to day. It wasn't my opinion of what I thought she needed. I could tell by the glint in her eye and the smile on her face when things were working for her and when they weren't. I'm pleased to say that, by and large, she was able to live a happy life to almost 100-years-old.

Karen Cheung: This is a question for all our speakers. How do you balance independence and safety who have cognitive impairments?

Jonathan Martinis: I can jump in on that because I get that a lot. That often comes up when people ask me if you engage in supported decision making, how can you guarantee people won't make bad decisions or won't be taken advantage of? I always answer it this way: I can't, and I won't. In fact, I guarantee you that people are being taken advantage of who use supported decision making in the same way that I guarantee you that people without cognitive impairment are being taken advantage of or led astray by people they trust.

The comeback, though, is that there's never been a study that has shown that people under guardianship who lose their right to make decisions are inherently safer, and there have been numerous stories of people who have been subjected to abuse within guardianship and who have lost their rights and still been led astray. If we are looking at two options, losing rights or not losing rights, each of which can result in people being hurt, the one I'm going to at least try first is the one correlated with increases in self-determination. Self-determination has been correlated by research with increases in safety. That's not to guarantee that people will be safe. You can never do that, but at a minimum, you can attempt to empower independence, which itself has been correlated with safety, at least as a first step. None of us are inherently safe ever. All of us can be safer, and research suggests those of us more self-determined are safer.

Sandra Fournier: This is Sandy. One of the takeaways that, yes, it is a difficult decision when there's risk involved, and we don't know if the person really understands the risk, but that becomes part of where our service to the person is. It takes on an added importance. What techniques are we using to educate the person about risk, and what type of risks are we identifying for the person, and how do we relate that to the person? How does the person relate to that? It becomes a challenge, but if we do things correctly we are educating the person, and through self-empowerment, they're able to make better judgment calls.

Dr. Robert Schreiber: This is Rob. I don't know if Laura wants to go too but I am a Geriatrician, and it's a great question. I'm going to take it more from the medical perspective from a gerontological perspective. This really comes down to the autonomy of the individual based on their values and goals. I have many individuals who have cognitive impairment that are clear about how they want to live, where they want to live, and as the dementia progresses, those values and goals usually do not change. So we are taking risks a lot within the individuals, but it's documented. The family is involved. We do have to report this sometimes to elder protected services. They're aware, but oftentimes we're able to support people even into advanced dementia, at which point then we oftentimes have to activate the healthcare proxy. We keep guardianship in place, but that proxy is there to help that individual lead their least restrictive life based on their values and goals.

There may be bad outcomes and we can't guarantee there won't be, but more times than not, they're able to live and die in their home rather than have to have their wife and values and goals sort of abrogated. It is a risk but it helps to have those open conversations and understand what matters most and document that. You do not get into medical/legal trouble, and in fact, the family and the patient's satisfaction and

their care experience oftentimes is highly rated.

Laura Sankey: Part of our focus too, as part of person centered planning and member engagement, is really engaging that family. So a great portion of our membership is frail and elderly. As we recognize, the patterns that start to emerge, we tend to try and wrap in those family supports and create a caregiver program that allows people to see, what it is, these progressions, where are we going with this, and the sooner you can identify those and start to have those conversation much earlier, you can start to document those preferences so as things do progress we've already had those conversations, and it's not too late.

Karen Cheung: Thank you all.

I have a question from Andrew who's a social worker that I'm going to read off and wanted to get everyone's reactions to. Andrew says, as a social worker, he appreciates this approach to client patient care. Having said this, his concern is that the clients that need guardianship services may fall through the cracks for funding and since there's a push towards this approach recognizing truly and physical mental deficits. So in California, this is already happening. It's becoming increasingly difficult to access guardianships for clients. Reactions to that?

Jonathan Martinis: I can respond to that this way. I maintain I am not here to say there should never be a guardianship. I am here to say that we must be very careful before we take rights away, and I think we must do what the state laws say. California's state law, for example, talks about guardianship being the least restrictive. They call it conservatorship, but things like that shouldn't happen if there are less restrictions available. Shouldn't we explore options first? If a person truly is impaired to the point where he or she can't make decisions and there's nothing else that can help, of course conservatorship in California or guardianship in other places is appropriate. What I'm suggesting is we should not rush to that because the rights at stake including autonomy, self-determination, and the positive life that comes with it are so important that they should not be cast away before we try to empower them by other means.

Dr. Robert Schreiber: This is Rob. I'm just going to echo what Jonathan said. In my experience, and I deal with highly complex frail older adults with multiple morbidities, many of which have dementia, and it is very rare that we have to pursue guardianship. As a matter of fact, I would say over the last four years I've had three of them. Oftentimes, we can work with the family and community supports to actually keep the individual and their goals and values up front. If we have a family that's supportive or a friend that knows the individual, oftentimes we're able to make that self-determination and autonomy without having to go for conservatorship. I know the funding streams are decreasing all over, but my sense with that, and I agree with Jonathan, this is not to say it won't ever happen but I think that the number of conservatorships can be dramatically cut down if we truly have a patient centered value goal driven approach.

Karen Cheung: I think we have time for one last question. Are there specific research articles that associate guardianship with poor quality of life?

Jonathan Martinis: I know of no article that has associated guardianship with improved or worsened quality of life, and I think that makes sense because guardianship is nothing more or less than a legal construct. It's what happens with the guardianship. There are guardianships and state laws, and I can cite several of them that say the guardian is supposed to involve the ward in as many decisions as possible and maximize his or herself determination. If we do guardianship in that light and as moving towards the person being more independent, then it can be a supported decision making. What the research says is that when people lose their rights, when they are denied the opportunity to be part of their decision making

and have their lives, well that's correlated with worse life outcomes. The problem is that too often guardianship is equated with that or guardians feel they need to make all the decisions for the person. It's not that guardianship is equated with it, but that loss of determination is equated with a worse life. I can cite you chapter and verse on that.

Karen Cheung: Thank you, Jonathan.

At this time, we will close this presentation. It's been really informative, and there's been a high level of engagement from the audience. If you have additional questions or comments you can e-mail us at RIC@Lewin.com. The slides for today's presentation, a recording and the transcript will be available on our website as well. A huge thank you to all our speakers, and thank you to everyone for attending and participating.