

**Strategies for the Implementation of Disability-Competent Care
Stimulating and Supporting Participant Engagement
June 10th, 2015 - Transcript**

Cathy: Ladies and gentlemen, thank you for standing by and welcome to the "Strategies for the Implementation of Disability Competent Care" conference call. At this time, all participants are in a listen-only mode. Later we will conduct a question-and-answer session. Should you require assistance on today's call or if you would like to ask a question, please press "*" then "0." As a reminder, this conference is being recorded.

I would now like to turn the conference over to our host, Mr. Chris Duff. Please go ahead.

Chris Duff: On behalf of the Lewin Group, I would like to welcome you to our presentation on stimulating and supporting participant engagement, the fifth session of our 2015 webinar series. As Cathy stated, my name is Chris Duff, and I am a disabilities practice and policy consultant working with the Lewin Group.

The Medicare and Medicaid Coordination Office at the Centers for Medicare and Medicaid Services has contracted with Lewin to develop technical assistance and actionable tools to support providers in their efforts to deliver more integrated, coordinated care to Medicare-Medicaid enrollees.

First I'd like to introduce you to our platform for this presentation. If your slides are not advancing, please push F5 on your computer keyboard. Also please note the icons at the bottom of the screen. The second icon from the right allows you to download the slides for the presentation.

The Q&A window is open next to your slides. Please enter any questions you may have regarding the material, and we look forward to discussing them during the Q&A portion of the presentation.

Beyond the Q&A feature through which you can submit questions and comments at any time, we will be using instant polling to ask specific questions to help guide our presentation. To demonstrate the process, here's the first question. In what context do you interface with persons with disabilities? As a health [center] staff member; a community-based health care provider; long-term services or support provider; a community-based coordinator and navigator advocate, or other?

You can take a minute to make your selection, and we'll review them shortly.

This series consists of eight webinars running on Wednesdays at this time through June 24. All webinars will be recorded and are available along with a PDF of the slides at this link, www.resourcesforintegratedcare.com. That's resourcesforintegratedcare, one word.

In 2013 we published a comprehensive disability competent care self-assessment tool describing disability competent care in three pillars. The first, individualized care coordination provided by

an interdisciplinary team. Second is redesigned primary care delivery. And thirdly, flexible long-term services and supports. This is our third webinar series focusing on specific components of disability competent care. Resources from past webinar series and this one are available on the RIC website.

Our previous webinar series were all more content laden with little time for discussion and Q&A. For this series, we're switching it around with only summary content being provided to allow more time for discussion. We would like to solicit your opinion on this series as well as past webinars and supplemental resources. Please take the time to complete our survey at the end of this webinar and send us your ideas for future topics and content.

At this point, let's go back and review the results of the first polling question. Most of you are within health plans, though I'm really very pleased there's so many community-based coordinators because that's really the focus for right now in this webinar is the community-based services and support. I'm glad to hear that health plans are increasingly thinking about that and trying to learn about that.

Today we have two highly seasoned and experienced providers.

Dr. Patricia Yeager has worked for over 35 years in disability services and advocacy fields in West Virginia, Pennsylvania, Colorado and California. She completed her PhD in human rehabilitation at the University of Northern Colorado and has worked as a consultant on a variety of projects involving independent living, civil rights for people with disabilities. She became CEO of the Independent Center in 2011, where her current advocacy work focuses on ensuring that the state's health care program for persons with disabilities is accessible and useable by the disability community, increasing accessible housing and transit options and ensuring local governments are complying with Title 2 of the Americans with Disabilities Act.

Gavin Kerr has served as an executive leader in several large health care systems in Pennsylvania before assuming leadership at Inglis in October of 2008. At Inglis, he is leading the evolution of the organization from an institutional model of care to a person-centered model in which service delivery and daily decisions are made in the community and in the neighborhood. This has involved transforming the organization through innovative initiatives including establishing a new model of care to enable nursing home-eligible residents to live independently in the community at substantially lower cost, expansion of Inglis housing to provide over 100 new homes for persons living with disabilities, and the implementation of adaptive technologies to enable consumers to redefine their abilities and achieve new levels of autonomy, independence and engagement in life.

Today's webinar is focusing on a key component of the third pillar of disability competent care: flexible LTSS. Historically persons with [physical] disabilities and functional limitations have been isolated, lacking opportunities and options for community. This presentation will explore the role and importance of community in all of our lives, especially those who have had limited opportunity to participate in their community for a range of reasons.

The presenters will talk about strategies and approaches to facilitating and supporting community in both formal and informal ways and settings. Our communities enrich lives emotionally and physically. None of us can survive as an island. Our health and wellbeing depends on each other and communities.

To provide the presenters' additional context, I would like to ask an additional polling question. Are there many organizations in your community providing opportunities for people with disabilities to participate in their community? Yes, many options; few options; only one or two, or none that you're aware. You could submit, and we'll review those results before I turn the presentation over to Patricia and Gavin.

I think at this point we're probably ready to review the results, if you could do that. The results of the last polling question, if possible. Yes, many options; few options; only one or two. That's actually more people saying many options than I had anticipated, and so, I'm pleased to see that. I think our goal here is to talk not only about the ones that people know of but to kind of talk about some new models and some new opportunities.

With that as foundation for your perspective that will help guide Patricia and Gavin in their comments. So at this point, I'll turn it over to Patricia.

Patricia Yeager: Good afternoon, everyone. I'm really pleased to be able to share some information with you and hear your questions and perspectives on community participation for people with disabilities. Really what we're talking about here, the basic question is the quality of life depends on good health and being engaged, and that's whether you have a disability or not. The question before us is, how do people with disabilities achieve a high quality of life, both have good health and are engaged in their community?

Historically people with disabilities are very isolated, either through shame or lack of access or the culture that they're within, that they live within, so that isolation really leads to in some ways more problems than the health issue does. Let's go to the next slide.

Okay. I want to talk a bit about the barriers that people with disabilities have to community participation but particularly health care. We have a problem--many people with disabilities have a problem in accessing facilities and equipment, whether that be in medical providers' offices, whether it be the YMCA down the street, the movie theater if you're deaf. There's a lot of physical barriers that occur both in the health care facility and in the community.

When we talk about being able to get weighed on a--I'm going to specifically talk about health care here. If you are in a wheelchair and you go to your doctor, and you don't get out of that wheelchair, I would say to you that you have not had an examination. If you can't get on the table and lay out and be examined as everyone is examined, then you haven't really had a good checkup. If you can't get your weight, how can the doctor prescribe the accurate amount of medicine? If you cannot read your prescription bottle, how will you keep track of what your prescription says you're supposed to do?

All of these things are problems that people with disabilities face when they face the medical system. And they also face a lot of negative attitudes. It takes longer sometimes to deal with a person with a significant disability, so when the office staff roll their eyes and say, here he comes, I don't have time for them, it does not make us feel very welcome.

When we communicate with providers, providers can speak very fast. They can speak very detailed or not detailed at all. And how do I keep track of this? How do I--and will I be understood? Will he or she take the information that I'm giving and factor it into whatever diagnosis or whatever suggestion medically that the health care provider is providing?

So in a lot of cases, it seems to us that the medical profession sort of feels like, well, if we can't fix you, then we can't do anything for you. And for us, it's not about being fixed; it's about living the best quality of life with the functional limitations that we have. Most of us are healthy. Many of us are healthy. And we manage our functional limitations, and we ask to be seen as real people with just, you know, I'm a person who doesn't hear very well. I wear hearing aids. No big deal in my situation. However, if I go into a doctor who doesn't look at me or puts his hand up or wears a mask, I'm done. I can't understand what's going on.

Most of us do not want to put ourselves in that situation, so when you can't get in or it's difficult to get in, the provider doesn't look at you as a real person with value and as having equal input into the situation, typically then you do not want to go to health care. You don't want to go to the doctor. You don't want to go anywhere. You don't really want to engage that system. It leads to distrust, avoidance and isolation, and it means that the person will not seek health care until they are very, very sick. We know that that adds many dollars to the situation at hand. If there was more trust, they would be seeking out services and medical assistance much quicker. Next slide.

That was a little overview of how people with disabilities experience health care in a broad brush. Now I want to talk a little bit about the independent living centers. Centers for independent living are non-profit organizations. There are about I think 400 across the state, across the country. Many are federally funded. Most of them are poorly under funded.

We are really unusual in that we're non-profit organizations who really strictly adhere to the standard of we are run, we are governed, managed and staffed by predominantly people with disabilities. And it must be people with a wide variety of disabilities. It can't be just all deaf people or all blind people or all people with MS; it has to be a wide variety of people with disabilities.

And the reason for that is that while we have different functional limitations, we all experience negative stigma and stereotyping in the same way. People devalue. They look at us; we look different. They devalue us without getting to know us. And so, there's power in large numbers, and when we get together and compare our stories, there's a sense of we're not alone, and we begin to change our perspective on this disability stuff.

So the centers are staffed by people with disabilities. The board and staff must be at least 51 percent people with various disabilities, so we understand the issues that someone coming in to see us experiences.

One of the most important things that happens in an independent living center is peer support. I'm thinking all of you can probably think of a situation, maybe you're buying a house or you got married or you got divorced or you lost your spouse or lost a child, and that your community around you, people who had a similar experience, was very important to your healing process. That is true also for people with disabilities. And when I speak about healing, I'm talking about the notion of coming to accept your disability, and I'll talk about that in a minute.

So as you can see on the slide, the centers all must, by federal law, provide five core services. We all do different things after that, but the five core services--peer support, information and referral--I just broke my back; how do I learn to cook in a wheelchair? Where do I go for a good doctor? How do I get bus service? That's information referral. Individual and systems advocacy, people come in needing help with their landlord, needing help with the school system, university system, that's individual. But the best part is when we get past the individual and look at systems change, and that's what I'm engaged in here is system change with the Colorado Medicaid-Medicare system to make sure that our health care system is accessible and useable by people with disabilities. So there's a whole group of us that work on this, and that system change is a group of people working to improve the community for the greatest number of people.

Independent living skills training is always fun. It's whatever that person needs. Some people will come in and say, I need to learn to cook. Other people will say, I need to learn to use the bus system. I need to learn what my rights are. I need to learn how to speak for myself. Normally they come to that realization. They don't come walking in with that.

But it's whatever it is that they are seeking to choose to do. And again, another hallmark of an independent living center is that it is not our goal, it is your goal. And so, the person with the disability, we do not do it for them, which can be pretty aggravating for that person because they're used to people doing things for them. We're of the idea that you can learn to do this yourself, and we will be here every step of the way but we aren't doing it for you. That can be a frustrating concept to understand, but the skills training is where that gets confronted.

And the last one is the newest. This is transitional services, and this happens in two populations. It happens when we move people out of nursing homes, and independent living center have been doing this for quite sometime, so we have a lot of good experience of moving people out of nursing homes and re-establishing them in the community of their choice.

And then the second transitional service is looking at or working with youth who are graduating from high school and looking towards a world of work. So it's youth 16 to, I don't know, 25, maybe, that we work with to help make that transition from living at home and going to school to being out in the community and functioning as an adult.

So those are--then you'll have lots of other services that different centers will provide based on the money that they can raise and the need that their community comes up with. Next slide.

So what does community involvement mean to persons with disabilities? So really, it's so simple, but the devil's in the details. It's about asking and listening and acting upon suggestions

from people with disabilities. So if you're a health care plan, you probably ought to have a committee, an advisory committee, of people with a variety of disabilities that you can run by-- get their opinion on various policies, procedures. What's the access like? What's communication like? How are the doctors treating you? Get it directly from the individuals.

You need to be asking us our opinions and suggestions for how to fix whatever isn't working well. We are often seen but hardly heard, and certainly our views are rarely sought out. And I think that that is one of the key things you can do to increase participation.

Oftentimes able-bodied people will make assumptions about what we need and develop something far more elaborate and more expensive than what we need, and we are masters at figuring out the cheaper, quicker way of doing things because we don't want to spend any more money or take any more time than we have to.

So again, asking us and letting us determine what we need, when, where and how will give you so much guidance, it will make your job so much easier. If you're sitting there looking at all these different functional needs and thinking, oh my god, not only does one size not fit all but many sizes don't fit, how do we do all this, we're the masters of that. And if you ask us, we will tell you. We will give you suggestions.

Paternalism, which is when you tell us what you think we ought to be doing, leads to non-participation and non-compliance, and if you create dependency where that person is plugged into you or your system, it becomes expensive and it is really not helpful. Next slide.

I talked a little bit about this. I'm going to run through it. I don't want to take Gavin's time away from him. One of the most important things that a center does is to get a person--especially people who have newly acquired disabilities, you have to be able to incorporate that functional limitation into your self-image and realize you're still an okay person. There's research, many years of vocational rehabilitation research, that shows that if a person does not come to accept that disability, that he or she will not move ahead.

And what I always say is that if you are still mourning who you were, you will not be able to step into who you are right now. And one of the ways I know that someone has really adjusted to their disability is when they say, you know, it's a pain sometimes to have this disability, but it has really--I wouldn't give it up because it has given me so many other gifts. That's when I know somebody has truly adjusted. It takes some time. It takes peer support. It takes seeing role models who live successfully with the disability. It takes encouragement to try new things, new equipment, new services. It takes education really on how to be a person with a disability. How do you speak up to your rights? How do you ask for things in a way that gets results? And you reduce isolation and depression through active engagement.

But if you are thinking about yourself as that poor little cripple who can't do anything because that's the stereotype that the able-bodied world has put forth, then you're going to have a lot of trouble moving forward.

Okay. I do want to say one thing about recreation. That is one of the ways that we move into peer support, people going out and doing things together. That's very important. All right, let's keep moving. What's the next slide?

Okay. We can talk about the Independence Center really quickly. We're located in Colorado Springs. We have about--we serve--the Independence Living Center serves 600 people throughout our six-county area. We also provide the core services, and we operate a home health program that serves about 230 people ages six to 103 in their community. You can see the other types of services that we provide in the community. Employment is always fun. We get people jobs that want to go to work, and we have specialized services for certain populations that require that. Next slide.

How we engage people. One of the ways that we--we have a very modern building that is colorful and fun and professional. People know when they come here, they're here to work. The waiting area, the area where people come in, is set up sort of like a Starbucks, and we have some snacks and coffee and that kind of thing that people can purchase. But generally, they sit down with strangers at the table, and they know that everyone who comes in has some connection with disability, so they then strike up a conversation. Staff will often go out there and sit and have conversations with folks. So, that informal peer support starts there.

We have a peer support program where we have all the people in the program on staff have disabilities. We run--recreation starts there. We do all kinds of--they're talking about sky-diving here pretty soon. I think we'll have to check our insurance. But they go out and do things, and they start up conversations there. We have lots of sports, lots of various activities. We have peer support groups, men's group, women's group, older individuals who are blind group, different groups that people can join and participate.

And then, we train volunteers with disabilities to be able to do one-on-one peer support. This is active listening. It is not--and it is some brainstorming about how to solve problems. It is not counseling in a traditional sense. Next slide.

I'm going to just let you go through this. These are all independent living skills that we offer in the community. You can see transit, cooking, money management. And pretty soon we're going to be working on fitness for everyone. We have talking pedometers for blind people and others kinds of equipment that allow people to exercise. Next slide.

These are services in the community. We have personal care services we deliver from the independent living center. We have assistive technology, benefits counseling, employment services. One of my favorites is the systems advocacy. It's amazing. We have a person with dementia who works with our systems advocacy group, and people have to queue her to stay on topic, but she's a fabulous speaker in front of City Council and the county commissioners, and it really lights up her life. Next slide.

So we know how to engage people with disabilities in the community, and what we're now working on is how to improve health care. And we know that participants need access to health care, which is why we're doing all of this work. We know that caregiver support and training

needs to happen. People who are working in the homes need support in how they--these are often unskilled providers who need to work together. We need to stop people from using 911 and the emergency rooms by getting them quicker medical access in their homes, and we expect that if we can improve the quality experiences--I'm sorry, improve the participants' experiences with health care, that we will improve their quality of life and their ability to engage. So, that's where we are headed in our work.

Most independent living centers do not want to get involved in health care. If your center is like that, I suggest that you gently take them by the hand and show them some fee-for-service opportunities to pay them for what they already do with consumers to engage in the community, and you will have a really healthy partnership as a result.

So, that's it for me.

Gavin Kerr: Thanks, Patricia. This is Gavin Kerr, and I am the president of Inglis. We are an organization that's committed to helping people with physical disabilities really achieve their goals and live life to the fullest, to essentially redefine who they are given whatever the disability they're facing is. We serve about 1,000 people in the Philadelphia region. If there's any message you take away from Patricia's presentation, it's this: people with disabilities are really just like you and me. They have the same hopes and fears and desires that all of us have, but because of either bad genes or an accident or just plain bad luck become functionally impaired.

Our focus is on the people with the most significant disabilities and complex health care needs, so for those of you who are working in the insurance world, the people we serve are your most difficult clients. And we provide them with a full spectrum of services in the community. We provide housing. We have about 261 apartments and still have a two-year wait list, which is a huge challenge for everyone. And then we also have a unique long-term care facility that serves young people with physical disabilities.

The people we serve, about half of them have multiple sclerosis that has progressed. Another 25 percent have a whole variety of neurodegenerative diseases, from ALS to one person who has a very unique disability that's only been diagnosed four times in the world. Our population has an average age of about 47 with a range from 18 to 103. Our 103-year-old is also one of our most avid computer users, after learning at 101. So life never stops for any of us. Can we go to the next slide, please?

One of the things that we've spent a lot of time talking with consumers about is, what is it that you want and need in your life so that we can do a good job of meeting those needs? As we talked, we just reconfirmed that they're no different than the rest of us in so many ways. And so, we did a lot of research with the positive psychology research that's been done around the world and came up with this model, which is really the same model for me as it is for anybody we serve.

We all are looking for a meaningful purpose, a reason to get out of bed and do something greater than ourselves. We want to do worthwhile work, whether paid or unpaid, though preferably paid. To have a chance to make a difference in someone else's life. For someone who becomes

disabled as an adult, going from being independent and caring for others to being cared for is emotionally absolutely devastating, so trying to find ways for people to give back is an important part of a meaningful life. And then finally, the opportunity to love and be loved. In the six years that I've been at Inglis, we've now had six weddings among our consumers and consumers and staff. We've also unfortunately had one divorce, so just reinforcing the fact that we're all pretty much the same.

If we go to the next slide, one of the areas that we're very, very focused on is how do we help people really live great independent lives? There's a model of independence that's just this virtuous cycle that often is broken.

The first thing you need is affordable, accessible and safe housing. A place where you can live, and if you use a wheelchair, you can get in and out of and you can use the bathroom and the kitchen and all of the things that go with it. One of the unusual or unexpected things for me in coming to Inglis was to find that in America, so many people become impoverished within five years of an adult-onset disability. And so, affordability becomes hugely important.

Once you have housing, you need to have disability competent and coordinated health care. Patricia talked about the many challenges people face in getting health care and the reasons they don't get health care. We've done some analysis with Milliman, looking at the claims data for all of the people who live in Pennsylvania who are either in the waiver programs for Medicaid or are in the waiver program--and are in the waiver programs and also participate in Medicare.

The average days per 1,000 for this population of about 5,000 people is 8,986 days per 1,000 versus 749 for able-bodied people of the same age. We then looked deeper to try to understand that. The vast majority of the admissions come through the emergency room and are for things that are really manageable but get out of control when people don't get access to care. Urinary tract infections, horrible wounds are two of the most frequent. That results in an enormous amount of cost, much of which is the result of both lack of access and lack of coordination of care.

We have a gentleman who lives in one of our apartments. He's 58 years old, was born with cerebral palsy and had a stroke about six years ago. He is unable to speak, so he uses his eyes and his tongue to communicate and lives very successfully independently. In fact, about four years ago was in Holland for about three weeks, touring.

Unfortunately, someone came into his apartment (inaudible – audio drops) and in the process of getting him to move out of the apartment and into respite care for four days, he developed a wound. To make a long story short, he has six different agencies that serve him. They weren't talking to each other, and after a course of about 18 weeks he had lost both legs, had a major coronary, spent 2.5 weeks in the ICU and had his life disrupted in such horrific and expensive ways that it was hard to imagine. And that's where the coordination becomes a huge problem.

So once you have affordable housing and coordinated and competent care, then you need the supports for daily living. People who we serve tend to be quadriplegic, so they'll have three or four people who care for them during the course of the week. It's not unusual for someone to

miss a shift--and therefore not get out of bed, get bathed, toileted, fed--and to turn over every 12 to 16 weeks, even though they do this most intimate work. So getting affordable, coordinated supports for daily living is essential.

And then finally, having engagement in a meaningful life and the opportunity to have transportation to get you there. Engagement in a meaningful life means whatever it is that you really are seeking in your life. Work, social relationships, opportunities to be a part of a community both able bodied and disabled. And so, we are really working to build a system that can meet those needs because when any one of them is broken, then people lose their independence because they wind up in the hospital, they wind up in bed, they wind up in a nursing home, and costs skyrocket. Next slide, please.

So in order to fulfill this, we did a lot of research and wanted to share with you the outcome of the research with over 150 consumers and 88 organizations that serve people with physical disabilities.

Priority 1, 2, 3 and 4, and would have been 5, 6, 7, 8, 9 and 10 if we had agreed to do that, is housing because without housing you can't have much of a life. So housing is critical. Supports coordination and attendant care was 2. Employment, financial health, transportation. And I was really surprised to see physical and emotional health as far down the list as it is. Adapted computing and technologies, which can just open the world to you. And then the opportunity to be engaged in education and other activities. So that's the top ten list based upon our consumers' discussions.

In summarizing it, really there's just a handful of priorities. The first is in many, many forms, housing is the absolutely essential number one issue that needs to be addressed.

The second is really helping the people who are caregivers, both family caregivers and professional caregivers. I don't know if any of you are caring for an elderly parent--I happen to be doing that. You get a good feel for what it's like to try to manage a very complex, uncoordinated health care system. That's what consumers and their families deal with every day who are living with a disability.

And then having attendant care that really can meet your needs, is reliable, trained and consistent and allows you to live with dignity, wellbeing and true independence.

The fourth priority is really then taking technology and really applying it very, very well. A power wheelchair for someone who needs it opens the world, the ability to access their apartments and to live without need for an attendant. To turn on and off the lights using home controls that have now become incredibly inexpensive allows people to live more independently and reduces the need for attendant care, which can add up to thousands of dollars of savings.

And then the whole connection through the Internet to your friends, your family, to be able to send an email or Skype with someone you love. We have a woman who I just was visiting yesterday, and when I got there, she was Skyping with her granddaughter in California. And she

had just gotten set up online. It was the first time she'd ever seen her granddaughter, who is now four years old.

So those are the things that people are looking for. We're trying to develop systems to enable them to achieve that, and I think it's really important to really think about the word "enable" versus to allow or to provide. Because people want to be independent. You and I would probably--I know at least I would be a horrible person to be a nursing home resident because I would drive everybody nuts, complaining about why can't I do this, why can't I do that.

So we are both trying to transform our long-term care facility but provide a whole new way for people to live in the community with disabilities that fulfills that virtuous circle of the five key elements. And so, it's really built with a life plan and helping people think through, what do I want to achieve in the next segment of my life? Having coordinated health attendant care and engagement services. A social network of care that engages your family, friends and volunteers in providing those supports. The technology to then allow you to achieve those goals and build the abilities and independence you want. And then finally to really be able to use capitation to integrate Medicaid and Medicare services, which is really the primary funding source for this population.

So we're well on our way of trying to create a new way for people to live. I think if you take one thing away from this conversation, it's something that Patricia pointed to, and that's that each and every one of the people you serve is an extraordinary person facing extraordinary challenges but who has desires, goals and dreams just like we do. And if we can listen and connect to helping them pursue those dreams, we'll have made a huge difference in their world and in the people that they live with.

So, Chris, I'll turn it back to you.

Chris Duff: Thank you very much, Gavin and Patricia. I appreciate it very much. At this point, what I'd like to do is open up the phone line. Cathy, could you give some instructions to the listeners?

Cathy: Yes. Ladies and gentlemen, if you wish to ask a question, please press "*" then "0" on your phone. You will hear an acknowledgment tone. An operator will then gather your name and further instruct you. If you are using a speaker phone, please pick up the handset before pressing the numbers. Once again, if you have a question, please press "*" then "0" at this time. It will be just a moment for our first question.

Chris Duff: Thank you, Cathy. In the meantime, people can also feel free to ask their questions in the Q&A on their computer if they wish. In the meantime, I'm going to ask another polling question to kind of help get this discussion going, and the polling question is, does your role working with participants with disabilities include supporting their community participation? Yes, but as a secondary priority; periodically, or no. If you could respond to that, I would appreciate it. I think there's a degree of perspective that we're wanting to try to get at here as we jump into the discussions.

So I'll start with the first question that we have gotten, and that is this person said, I certainly agree with the premise of the importance of community in all of our lives. What I struggle with is what I can do as a care manager, especially a care manager in the health plan.

So, Patricia, why don't you start with that, and, Gavin, (inaudible).

Patricia Yeager: Well, struggling with this issue, I think the main thing--the best way to struggle with this issue is to ask people with disabilities to help you, and to gather information from the community that you're trying to serve. Ask questions. Find the community agencies that work in your area and engage them in how to help people, how to work with them. But primarily engaging the individuals themselves, their family, other people who have significant disabilities, to educate yourself about what's possible and what is it that they want to see happen.

Gavin Kerr: I would add--the only other thing I would add to that is ask people as you would anybody, gee, what do you really like to do, what do you love to do? One of my favorite stories is there's a gentleman who lives in one of our apartments who is 68 and a truck driver who was injured in a truck-driving accident, and he's a real curmudgeon and didn't do much. So one of our support coordinators, who are similar to care managers, just sat and talked with him for a few minutes and realized that he loved 1950s and '60s music.

And so, she put him in touch with our computer folks so that he could access the Internet to get '50s and '60s music, and it was like the gateway drug for him because once he figured out he could do that, he then figured out, oh, well, I can do email and I can communicate with my friends and my family. And now he's a very competent computer user.

But it's just figuring out what's that thing that you love that goes beyond necessarily the clinical work that you would normally be having a conversation that can be incredibly healing.

Chris Duff: Backing up on what both of you said, I think about those who I see as really leaders or mentors and how they have full and complete lives and interact in the community. And go and talk to them and look at them and say, so what is it that makes that work for you? Why do you do it? Where do you feel that you belong?

An example is fitness centers. Many people that I worked with back when I was in Minnesota just simply did not feel comfortable in fitness centers, for obvious reasons. And so, what we tried to do is tried to stimulate options to work with that, both getting some rehab providers to develop more fitness options but also then work to build in some special programs or classes within existing YMCAs or other facilities where there would be--where you wouldn't be the only person with a disability in that activity.

So again, it's just watching those who are good at it and asking them how do they make it work.

Let's go back and look at the results of that last polling question. People do see it as a responsibility of their work with persons with disabilities. I'm very pleased to see that. I can assure you that's not what people would have said a decade ago, where we were all focused on health and health care and what they do after that was kind of up to them. So I'm very pleased

that people do assume some responsibility for at least attending to that issue and engaging people in it.

Here's another question we've gotten in from the community. We have many adult day programs in our service area, but I just don't see our younger, cognitively intact participants fitting in there. The problem is that they are our only alternative to pay for such services. What else can we do?

And I think you would both have comments on that, so, Gavin, why don't you start this time?

Gavin Kerr: I get that. When we were working on upgrading our program and designing our new life program, we were talking to consumers, and one guy who was 35 said, you know, I've got to be honest, I'll never go to a day program. I don't want to sit and stare out the window. So we said, well, gee, what would you like? And he said, well, if it were like Starbucks, I would. And you heard Patricia talk about her waiting area being like Starbucks.

I think really spending some time with some of the community groups to talk about what could be a more fun experience not just for younger people but for older people as well. So we have a day program. Today they're having a concert. Yesterday they were out doing some fundraising. We work hard to bring people in from the outer community to engage both as formal speakers but just to hang out.

But to get people to think about, gee, if this was a place that you came every day, not for work but for both care and engagement, what would you want it to be like? And I think people tend to respond very well to that.

Patricia Yeager: I come from a different perspective here. None of us on the phone, on this call, probably go to an agency to socialize, and so we have really changed the paradigm to have classes at specific times, to have support groups, and we have a menu of activities that people can choose to come to or not. We have employment services. One of our staff here came out of our home health side of the organization, so he gets home health services here and he works for us. That was a stunning thing for the home health staff to see that he could go to work.

One of the things I've been toying with in thinking about a [PACE] program for younger people is to have a volunteer coordinator on staff who will work with that individual to see what kind of volunteer work he or she might want to do if they weren't ready to actually go to work or their health was in such a way that they couldn't sustain work.

But it's getting them out into the community and having choices, like a community college almost. But we do support groups here, but we rarely hang out here. It's always out in the community somewhere else.

Gavin Kerr: Patricia, I agree with that completely with one additional thought, which is in many cases, the people who come to our program are people for whom they are young adults and they need the incremental support during the day because the people they live with are at work. And so, that is the one--we try to do the same thing that you do, but that's the one slight difference in the population that we serve.

Patricia Yeager: You know, when we start to talk about young adults, 14, 16, 18, 20, we're going to have to look at that maybe a little bit different than people who are truly young adults with the ability to live on their own or manage their affairs. So it's a little bit different take, you're right.

Chris Duff: Actually, I think you guys both presented a really interesting continuum of looking at it. I'm just going to throw a few things I'm aware of out there. There's a program in New York that has a wheelchair maintenance and repair class and program for all of your gear heads who use wheelchairs. And people go there several times a week because they love hanging out and working on other people's wheelchairs. So that's one thing.

Again, they listened to the people, they found out people were hanging out at the wheelchair repair place because they were gear heads. Assuming that's still a term people use. So that's an example of listening to the people and then responding accordingly.

So I think the whole continuum is really what's of value.

One of the questions--you raised a question around transition, Patricia, and I'm talking about transition from childhood and adolescence into adulthood. Can you talk a bit more about what CILs and maybe even yours in particular do to help go through that transition? It's a difficult time for everyone, not to mention those who also live with a disability.

Patricia Yeager: Well, in our building we have a kitchen, a teaching kitchen, and it's a happening place down there. The high schools around the area will send students to us, and we have a great instructor. I get such a kick out of him. Edgar is probably 40 years old, and he looks like he's 18, and so they all gravitate to him. And he teaches how to cook, how to be comfortable in the kitchen, how to be safe, clothing, washing, caring, all the things that you have to learn to do to be able to live on your own.

And they talk about their feelings about it. They go out on outings. One of the classes he teaches is positive thinking, so that when the kids start saying, I can't do that, I can't do this, he really nips that in the bud.

And so, we do a lot of training in the classroom and then field trips, and they learn to start hanging out together and doing things. So that's one of the main ways that we help younger people feel comfortable in the world, by addressing many of their fears about what it's like out there.

We do have employment services, and we work with vocational rehabilitation and the school districts to help kids either go to school, continue on or find jobs or career opportunities wherever we can.

Chris Duff: Thank you. Gavin, you talked about--and I'm very familiar with all what you guys have been doing for a long time around technology. Can you talk about some of the work you've

been doing and some of your vision for things in the future, and how that affects people's ability to function in their homes and their communities?

Gavin Kerr: Sure. Thanks. A quick personal story first. My son was diagnosed with cancer when he was 12 and became physically disabled as a result and had very few days that he could go to school. But he was a very savvy computer user, and so he had all of his friends at school. He played World of Warcraft, so he had thousands of friends around the world. And he did all of his schoolwork online. So he lived a very full couple of years despite the fact that he couldn't necessarily physically get there.

So when I came to Inglis and saw the work we were doing with adaptive technology, I knew that by providing technology, we could open the world for folks. We could open the world for learning, for communicating, for connecting, for education. And so, our adaptive technology program literally can get anyone on the Internet who can move their eyeballs, using eye gaze technology.

In addition to that, we also have invested a lot of energy in working with Comcast and other providers to help them build more accessibility into their basic tools so that people can use the X1, for instance, to control not only their TV and media with their voice, but also so that they can control their environment, opening and closing doors, opening windows and blinds, turning on and off various things in their home. Really getting some control so that they can have greater independence.

And the newest thing we're working on that I'm really excited about is 3D printers. We just recently bought a small 3D printer, and it's been really exciting to watch the folks that we serve really get excited about using it, learning a new skill, and potentially even getting an employment skill that is cutting edge that other people aren't getting a chance to develop.

One of the things that they're doing is most of the people we serve are in power wheelchairs. We partnered with a local university, Drexel students, to really design very customized joysticks for their wheelchairs that fit their hands perfectly and adapt to whatever their mobility capability is. That could grow into a business that's consumer owned and consumer driven in ways that will be very exciting to watch.

Chris Duff: Thanks very much. Cathy, are there any questions on the phone lines?

Cathy: We did not have anyone queue up at this time.

Chris Duff: Okay. I'm going to take one more question, but first I'm going to call your attention to the link on the webinar participant survey--or, to the webinar participant survey. We'd very much appreciate your taking a minute at the end of this webinar to complete it. But we're also going to ask one last polling question, which is, which aspect of community participation would you be interested in exploring through future webinars or resources? First-person stories; practical examples of communities such as Patricia and Gavin; work with opportunities to bring--with the opportunity to bring your own example and situation forward for discussion, or other

ideas. The key issue is the creativity that's required to support and enable, as Gavin said, community participation. If you could answer that, I would appreciate it.

The last question we're going to take is from Mary Martin. I think it goes back to what was discussed earlier, which is how do we engage in community organizations. And she said, any suggestions on how to engage our local center for independent living in some activities and approaches that you guys have talked about? I broaden that to beyond the centers for independent living and other community-based organizations that just simply aren't demonstrating the leadership or creativity that you guys have been.

Patricia Yeager: Can I answer that question?

Chris Duff: Please, yes.

Patricia Yeager: It's a matter of communication, and for independent living centers particularly, they're going to be nervous about talking to a medical professional or to the medical field, so if you start talking about the need for community engagement, how do we get people engaged in the community and we need your help in doing this because this is what you all are good at, I think you can forge a partnership with them. And start to maybe do a focus group with their folks and say, what kind of activities would improve your engagement, and by the way, it might make you healthier.

So if you can approach it from that standpoint and downplay the medical side of everything, I think you might find that people are more willing to work with you.

Gavin Kerr: The other thing I would add to that is it's really amazing how powerful wine and cheese is. The folks who serve people with disabilities are a fairly fragmented community of small providers and they get very little opportunity to share their ideas and best practices. And so, I think, building on what Patricia said, if you were to host a wine and cheese, some kind of networking, to really just start a conversation around how to make better services and really use creative approaches, I think you'd find you'd have a lot of luck getting people out. There are a lot of people doing some very cool stuff, so if you want help finding resources that would maybe be a guest speaker, we'd be happy to help you with that.

Patricia Yeager: Absolutely. That's a great idea.

Chris Duff: Gavin, do you have any final comments?

Gavin Kerr: The last thought I would share is one of the frustrating things that the folks we serve has is that oftentimes able-bodied people with very best intentions want to be caregivers and to protect them. And for all of us, there is a fundamental dignity and joy in being able to take risks. And so, as you do your work with the consumers who you're doing support coordination with, try to really create the opportunity for people to take risks. Some of them you will think are crazy and will make you very nervous, but there's an amazing power of letting people take a risk. Whether they succeed or fail, the risk itself was worthwhile.

Chris Duff: Thank you for--I think that's a great final comment. Thanks, everyone, for attending this webinar. You will receive information about any further webinars or resources that are available on this or other topics related to disability competent care. I'd like to remind you that next week we will be talking about LTSS services, especially in relationship to transitions and relocation.

Thank you for participating and please remember to fill out the questionnaire. Goodbye.

Cathy: Ladies and gentlemen, that does conclude your conference for today. Thank you for your participation and for using the AT&T executive teleconference services. You may now disconnect.