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PUBLIC HEALTH LIVE!

The Money Follows the Person Program: Facilitating Return to Community-Based Settings

Moderator: Hello, and welcome to Public Health Live! -- The Third Thursday Breakfast Broadcast. I'm Rachel Breidster, and I'll be your moderator today. Before we start, I'll would ask that you please fill out your evaluation at end of the webcast. Continuing education credits are available after you take our short post-test and your feedback is helpful in planning future programs. I also want to let you know that the planners and presenters of Public Health Live! do not have any financial arrangements or affiliations with commercial entities whose product, research or services may be discussed in this activity and no commercial funding has been accepted for this activity. As for today's program, we will be taking your questions throughout the hour by phone at 1-518-402-0330 or by via e-mail at phlive.ny@gmail.com. Today's program is entitled the *Money Follows the Person Program:* Facilitating Return to Community-Based Settings. Our guests today are Erika Robbins, a Vice President at the Lewin Group Center for Aging and Disability and Lindsay Miller, the Executive Director of the New York Association on Independent Living. Thank you for joining us.

Moderator: Good morning, Erika, thank you so much for joining us.

Ms. Robbins: Thank you for having me.

Moderator: To get us started today, can you review what the objectives are for today's program.

Ms. Robbins: It's our hope that as people listen to the webcast, that health care professionals learn more about the Money Follows the Person demonstration and, in particular, how that demonstration has helped people to move out of institutional settings such as nursing homes into community-based settings such as homes and apartments of their own. It is also our hope that as people listen to the webcast that they'll have a better understanding in the role of transition specialist as well as peer staff in helping not only individuals to transition, but also providers as they work with people to move. In particular, we have four core objectives of the program. One is to help describe the purpose of the Money Follows the Person demonstration. We also hope that individuals will be able to articulate one principle of the Olmstead decision, identify steps to take when an individual expresses an interest in returning to the community and list three ways that a transition specialist can help in an individual move.

Moderator: Excellent. Thank you so much. Now can you tell us a little about The Money Follows the Person or MFP program and what exactly is it?

Ms. Robbins: Sure. The Money Follows the Person demonstration is a federal grant program that was originally enacted through the Deficit Reduction Act of 2005 and it was amended through the Affordable Care Act of 2010. In the federal grant program basically provides states with enhanced federal match that they receive as individuals moved from institutional settings to the community. They receive that enhanced match for the first 12 match after a person transitions and those funds have to be reinvested into the development and growth of community-based

services. Additionally, the grant program provides supplemental funding to support services that the state might want to test or try out including services that are not traditionally available through the Medicaid program. The Money Follows the Person demonstration has four core goals and one of the goals is to help individuals transition or to actually move from institutions to the community. Also, one of the core goals is to help states to actually take the learnings from that transition and reinvest that into breaking down the barriers that keep people from having choice and control to begin with. And then, of course, with any grant program or any program that the state develops it's important to have quality and continuity of care and those are the four core goals of the MFP demonstration. We know across the country that there are 43 states and the District of Columbia who participate in the program and so far as of 2015, over 63,000 people have transitioned through the program. In New York State, they have transitioned 2,300 as of the end of 2016. When we looked at 2015 data, we found New York has the 11th largest transition program in the country. It's really quite phenomenal.

Moderator: Excellent. When did New York apply for this grant?

Ms. Robbins: New York applied along with a pretty large group in early 2007, but like many states it took some time to actually develop the transition component of the program. So transitions through the program didn't start in New York until 2008. In the initial year of the program or a couple of years of the program the independent living centers helped support identification and outreach and the waiver program, the 1915 C Waiver Program, provide the transition support. It wasn't until 2014 that New York awarded a contract to the New York Association on Independent Living to provide not only transition specialists, but also peer support to people. So later in the webcast you'll hear from Lindsay who will talk a little bit about the New York Association for Independent Living Open Doors Program.

Moderator: Now can you talk about why exactly MFP is so important to New York?

Ms. Robbins: Sure. Well, first, it's important to understand the evolution of home and community-based services before understanding Money Follows a Person because Money Follows a Person demonstration is just one tool of many that are there to grow home and community-based services program.

Moderator: Sure.

Ms. Robbins: So what's important to understand, and I'm sure many of the viewers already know that Medicaid was enacted in 1965 and largely to serve low-income Americans. As time has gone on, Medicaid has become a patchwork of programs to serve the most vulnerable including people with disabilities. It wasn't until 1981 through the Omni Bus Reconciliation Act that the 1915 C Waiver of the Social Security Act enabled states to develop home and community-based services. What's important to note is that in the initial enactment of Medicaid, nursing facility services are a mandatory benefit, whereas home and community-based services are optional. Even though Congress enacted the 1915 C of the Social Security Act, it still was an optional benefit. So growth of home of community-based services actually took quite some time to actually build because it wasn't a requirement of states to build a program. So it wasn't until the Olmstead decision in 1999 that we started to see a lot of growth in home community-based services at that time. It's really been this growth that's been a catalyst to change and has kind of created programs like Money Follows a Person to help states to build out their Olmstead decision.

Moderator: So what does the growth of home and community-based services really look like?

Ms. Robbins: Well, we know according to a new CMS report that long-term services and support accounted for 25% of the Medicaid budget and within that 25% home and community-based services are 53% of the total, which is really great when you look at the trend over time. So as you can see on the table, in 1981 home and community-based services were only 1% of the full LTSS expenditures and so they represent 1%, which is around 13 billion of the Medicaid program. By 1990, home and community-based services was 25% of the approximately 70 billion spent in long-term services and support. Then by 2014, it was at 53% of the 152 billion. I think the key piece to remember is not only is HTBS growing, but the expenditures is growing considerably from 10 billion in 1980 to 152 billion in 2014. The crossover point, the point at which home and community-based services exceeded institutional services was in 2013, so really recent. Most of the growth in home and community-based services has been in the last 20 years. I think one of the pieces I wanted to mention to you, Rachel, is that while there's been a lot of growth in home and community-based services, we still have a long ways to go when it comes to community integration and inclusion. It's not enough just to help a person to move to the community when a person does not feel part of the community that's not really realizing choice and control either. So I think inclusion and integration is an area that we still need to maintain focus on.

Moderator: Absolutely. Thank you for making that point. You mentioned earlier the Olmstead decision. Can you talk to us about what exactly is the Olmstead decision and what is its significance?

Ms. Robbins: Back in 1995 or approximately in that time period there were two women in the State of Georgia who were institutionalized and they really wanted to move back home into the community. They were unable to do so because the programs and services available in the state were just not there for them, so they filed a lawsuit. They represent many people, not just in the State of Georgia, but across the country who really had a desire to move to the community and were not able to do so. This lawsuit made its way to the Supreme Court by 1999, and the Supreme Court held basically that these individuals in essence, were discriminated against. When Congress passed the Americans with Disabilities Act in 1990 they did so to sever the historic isolation and segregation of people with disabilities. Since Congress enacted that act the Supreme Court felt that it was their intent to that people have the ability to live in settings of their choice and that not doing so is a form of discrimination. And so, in part, they based their findings on the Title 2 of the Americans with Disabilities Act, which requires state and local governments to provide options to individuals and to ensure that people are served in the most integrated setting possible. There is a component in the implementing regulations around Title 2 that's called the Community Integration Component. This component requires states to really think about programs and services and implement activities in such a way that they're enabling individuals to have that integration. The kind of deciding line or the bar that they use to measure is they basically say do individuals have the ability to interact with individuals without disabilities? How well is that interaction happening? And that goes back to the inclusion and integration principle that is often the marker used to measure services and support even today.

Moderator: And now how does MFP or Money Follows the Person, how does that interface with Olmstead?

Ms. Robbins: They are very complimentary. MFP is one tool in the tool box of tools. It's certainly not the only fix. It's not a band-aid. It's meant to be a tool that states can use to help them meet the Olmstead obligation and help them change their system. As I mentioned earlier one of the key goals of the Money Follows the Person demonstration is to break down the barriers in state

law and budgets and how state and local government do their business. It's to break it down so people have more choice in the community. It's a very important tool and very much complimentary and in the State of New York MFP is definitely a key factor or a key support to the state's Olmstead activities.

Moderator: Now that we have a good foundation of what MFP is, can you talk a little about how individuals engage in that program?

Ms. Robbins: Sure. Congress when they enacted the Money Follows the Person demonstration through the Deficit Reduction Act, they spelled out some clear eligibility guidelines and the Affordable Care Act modified these guidelines slightly, but the guidelines of eligibility are very clear. You first have to come from an institutional setting and an institutional setting could be a nursing facility, an intermediate care facility for people with developmental disabilities. It could be a hospital. It could also be an institute for mental disease. You have to have a combination of consecutive 90 days of stay, and if that consecutive 90 days could be in a combination of those institutions or it could be in just one as long as there is a consecutive 90-day stay then you meet the first requirement under the program. You also have to voluntarily agree to participate and you have to have at least one Medicaid stay or claim prior to transition. You have to meet the requirements of the program you're going into, so if you're going into a 1915 C Waiver Program you'll have to meet those levels of requirements. One of the other last pieces that you have to do is you have to move into a qualified setting. Those are all required in order to participate.

Moderator: Can you talk to us a little bit more about what you mean by a qualified setting.

Ms. Robbins: A qualified setting is also outlined very clearly in the law. It was Congress' intent that individuals who transition through the MFP program don't go from one institution to another.

Moderator: Sure.

Ms. Robbins: So when they enacted the law they used the term community, but they actually defined that term because they didn't want individuals to move from a nursing facility into a community residence that's also large, 16 beds or located on the grounds of an institution, so they were very picky about where an individual could move to. So in the law, an individual can move to their own home or back home with family. They can move into a group home as long as that group home is with no more than four unrelated persons, so small, or they can move into an apartment as long as that individual has control over a lease, there's lockable access, they have their own cooking, and sleeping areas in that apartment. The reason that piece is critical is because there are some assisted living facilities that do not meet the requirement that's outlined in the Deficit Reduction Act because some assisted living facilities don't have that lockable access or cooking area. When states help an individual to transition into the community, they have to maintain compliance with these rules. They can't just move a person. It has to be into one of these settings, and we know from some data that was released in a report with Mathematica policy research and this was based on 2015 data, that 43% of individuals who transitioned moved into apartments, 34% into homes that they home or lease, 13% to group homes for persons unrelated and 10% in assisted living. Just to give you an idea of where people are going.

Moderator: It certainly sounds like a great program. I wonder, is there a way that you can know if individuals are happy with their choice to engage in the MFP?

Ms. Robbins: Yes. This program, because it's a large grant and because there are so many states that are engaged in the grant, there's obviously a very large evaluation component to the grant. Viewers who are interested in the evaluation or quality side can find a lot of information on the resource guide that's part of this webcast. I would point them to the Mathematica policy research. You can actually google Money Follows a Person and look that up and they have tons of resources going back to 2007 and 2008. The quality framework that's used around Money Follows a Person is multifaceted and one of the key components of that evaluation and the quality framework is a survey called the quality of life survey. This survey was developed many years ago and is actually built off of the participant experience survey that some state programs have used with their Medicaid waivers. This survey does measure quality not just in are you happy with your living arrangement, but also do you feel like you have choice and control over services? Do you feel safe? It has those types of questions in it so it gets different aspects of a person's quality of life. We know from this survey that overall, life satisfaction is higher and individuals who participate in the survey, answered the survey prior to the transition into the community at the one-year point and at the two-year point we are able to see somewhat longitudinally about how they feel about their satisfaction.

Moderator: That's excellent. Considering the surveys and considering the fact that you have longitudinal evaluation, what have we found about one's quality of life before and after their transition?

Ms. Robbins: Well, what we've learned is that after transition there is an increase in overall life satisfaction. So at the point of baseline which is prior to a person's transition to the community, overall, nationally the number was about 48.5%. I'm sorry, 62.5% of the people said they were happy where they lived in the institution, but at the two-year point their overall life satisfaction with their circumstances went up 80%. It's about an 18% increase overall. If you recall earlier, I mentioned the importance of community integration and inclusion. One of the key pieces of the quality of life survey really gets at whether the person has a perceived barrier and they feel like they're barriers to the inclusion in their community and they're asked that question also pre and post, what we've learned is that when people are asked that question while they're in an institution, 48% to 49% of them say I feel there are barriers to my ability to engage in the community, whereas if they're asked that question at the two-year point, it goes down to 28%. Twenty-eight percent of them still say I'm not engaged in my community which is still way too high because we don't want anyone to feel like there are barriers to engaging in the community, which goes back to why there is still need to work on that particular area, but at least it's going in the right direction. People feel more connected when they're in the community as opposed to an institutional setting.

Moderator: And that just makes sense. Even just hearing you describe it. Of course, if you're removing a person from an institution getting them into the community. You're closer to the community, for sure. Now, what has the survey said about individual satisfaction?

Ms. Robbins: Some of the satisfaction overall is higher across the board, but there is a marked difference in terms of overall life satisfaction with certain disability groups. In particular, other impairment types or people with physical disabilities. We know to give you a little bit of a marker compared to New York, New York had an overall life satisfaction of 39% at baseline. So prior to transition and post transition it went up to 93%. So its way higher than the national average, a 55% increase in overall satisfaction, which is really great. It says a lot about the types of support that people are provided in the community and it probably says a lot about how they feel in the institution, as well. So there's a lot to be said for the data that's in that survey tool.

Moderator: Absolutely. What about quality of care? I would imagine that is something we would be concerned about, as well.

Ms. Robbins: As I mentioned earlier, the quality of survey does have questions about the people that are in the home providing support for them and we know that also increases. While a person is in a nursing facility, about 75% of them said I feel like my quality is good in the nursing home. Then when they move to the community they felt like their quality of care based on direct service workers or people in the home went up to almost 88%. So it also was an increase.

Moderator: Excellent. Really positive data.

Ms. Robbins: Very much so.

Moderator: So given the Olmstead decision and the goal for community-based living how engaged are MFP participants in the community once they transition out of the facility? I know you spoke about some of the numbers and how we have more work to do, but how engaged would you say that folks are?

Ms. Robbins: There are several key questions within the quality of life survey and there are five or six of them that when you put them together they created community integration index. What we know is there's one question in particular and it's about whether participants have the ability to do everything they want to do in the community. That question is asked again prior to them leaving and after and what we know is in the institution 47% said I can do everything I want to do and at the two-year point it goes up 70% that I can do what I want to do. That 70% is still too low because when you're living in the community and you're engaged and you're included you want to become part of the community and belong to the community and so that number should be much, much higher. So it's definitely an area to grow in. As I mentioned earlier, we were talking about the 55% increase in New York in overall life satisfaction. We know that when it comes to the barriers question I was talking about. That New York, when people are in the institution, 61% of them say they have perceived barriers in engaging in the community, but post-year, it drops to 32%. Even in New York the numbers are still too high when it comes to actual inclusion. It's definitely an area to work on and I know in the State of New York they do plan to use the quality of life survey even beyond MFP demonstration. This will be a key area that will be worth monitoring over time to see if that gets better.

Moderator: So despite the need for improvement on some of this it seems like overall you've painted a pretty convincing picture for why this is a benefit to the individuals who have the opportunity to participate. So I wonder now that we understand that, how can an individual who is living, say, in a nursing home, find out about community options including possibly the MFP?

Ms. Robbins: There are many ways that an individual can find out about how to transition out or to get help. There's one key way I wanted to try to highlight during this webcast because it's a really important component that the federal government and the Centers for Medicare and Medicaid Services put out in the early years to strengthen this community integration piece. That is something called the Minimum Data Set. And the Minimum Data Set is basically an assessment tool that nursing facilities are required to implement and it's been in place for a long time and it's something they're required to do on all persons that enter in a nursing facility or live in a nursing facility. As long as they are certified as Medicare or Medicaid they have to implement this tool. This assessment tool measures physical, psychological and psychosocial components. There's a section within the tool called Section Q, and that section is really about discharge planning.

Back in 2010 the federal government put a lot of energy into enhancing Section Q or the discharge planning component of MDS or the Minimum Data Set. They've actually did a lot of pilots and training with nursing facilities as well as survey agencies trying to get people to spend a little bit more time on active discharge planning. It's this component that's critical because if the nursing facility in there with individuals and they're asking them periodically and assigned times whether they want to learn more about community options, it's giving individuals more information so they can make informed decisions about whether they want to stay, want to go or want something different in their lives. So there is a question in there that I'll read it off to you to make sure I don't get it wrong. There's Question 0500 of the Minimum Data Set and it basically asks the individual, do you want to talk to someone about the possibility, keyword possibility, of leaving this facility and returning to live or receive services in the community? This question is so important because the question is not really about do you want to go? Sure and they go tomorrow. It's really not about that. It's about asking the question to find out if they have interests, so that you can share information, so they can make informed decisions about whether they really want to stay where they are.

Moderator: So the beginning of that conversation with that Question 0500 is really starting to have the conversation and explore the options that are available.

Ms. Robbins: Yes. When the Minimum Data Set changes went into place in 2010, The federal government required state Medicaid agencies to designate local contact agencies and they call them LCAs and every state had to identify a local contact agency and it could be a mix of people, could be area agencies on aging or independent living centers, it could be the state Medicaid agency themselves that decide they'll be the local contact agency. In the State of New York, it's the New York Association on Independent Living that was designated as the local contact agency and what that means is when a person answers yes that they want to know more information, they're required, required to refer that to the local contact agency. So any time a person says that, that referral must go and in the State of New York that is NYAIL and you'll hear later from Lindsay who will talk more about the Open Doors Program.

Moderator: Excellent. Now, overall, how well has MDS Section Q helped to generate referrals?

Ms. Robbins: It's been spotty. Not just in the state, but across the country. And I think because there's been a lot of misunderstanding and interpretation of 0500 does or about what that section of the Minimum Data Set does. There are a lot of nursing facilities that are under the impression that they don't need to do a referral if they don't believe a person's appropriate or if they believe that the person's skills or needs are too great or if they believe that the guardian or the family won't want it. So they kind of make a lot of judgment calls I think unnecessarily and I understand why they do it. I think its human nature to be protective of the people you support. So I think in many ways nursing facilities are -- they get a little nervous about, well gosh, if they open the door to the community what if a person doesn't do well or if they're hurt, and there is a reason why people feel hesitant. What's important to remember is the question is really not about moving the person tomorrow or moving them in five or ten years. It's not about that. It's about information to inform them of options that we all want to have in life. So sometimes you have to put yourself in their shoes. If you were the one in the nursing home would you want someone not tell you what your options are? No, you'd want to know your options. That's the point of it, to get information essentially and because there have been such spotty information around this particular area, the Department of Health and Human Services Office of Civil Rights released a guidance letter just last year in May, basically telling the nursing facilities you need to do what you need to do. This

is a civil rights obligation that you have. This is the rights of all people to be where they want to be and live in the way they want to live and that's not any different for a person in a nursing facility. The guidance that was released by the federal government is something that we want to the try to highlight to nursing facilities to look at that and get familiar with the civil rights obligations to help individuals to understand what's out there, what's possible.

Moderator: So what steps can facilities take, then to ensure that they are complying with these civil rights obligations?

Ms. Robbins: I think the first thing to do is to get to know your local contact agency, which in New York State is the Association on Independent Living. So if you don't know who they are take the time to invite them in to do education and training. Build relationships with them when you know of a person that has an interest, don't get nervous or anxious about that. Just talk to the local contact agency, to NYAIL about that, and then also look at -- take a look at your own procedures and how you implement Minimum Data Set and really give thought about whether you truly are affording people that opportunity. Then, just become familiar with the person-centered nature of the guidance and keep in mind that it truly is about choice and control and giving people a chance in life and even if a person doesn't avail themselves of that opportunity that's okay. They may decide that this is where they want to live and that's okay, but at least that opportunity is given and the information is there.

Moderator: Absolutely. Thank you so much for everything you've shared with us this morning.

Ms. Robbins: Thank you. Thank you for having me.

Moderator: Now let's take a look at a video produced by the Open Doors Project through the New York Association on Independent Living on the impact these programs have had.

Roll-in Video Footage

Kelly: I felt great to be out of the nursing home.

Narrator: Kelly spent three years in a Rochester nursing home more than 70 miles from her son and mom Sheryl in Syracuse.

Sheryl: So we had to drive her. I was driving her two or three times a week.

Maria: I love it. I love every bit of it.

Narrator: Maria is thrilled to be in her new apartment after her transition specialist found the necessity sit-to-stand apparatus she needs to get into and out of her wheelchair. Maureen left the nursing home for her own place thanks to the Open Doors Transition Center.

Maureen “Mo”: Now I’m independent. I can do it on my own.

Ms. De Beaumont: At its core, Open Doors is really about helping people return to the community.

Narrator: The program works through independent living centers across the state who employ transition specialists and key members of the team that would make the move back to the community happen.

Ms. Arnold: I've had someone say that they feel trapped in the nursing home. Just going to speak with the individual and speaking with their families to have them know that they have choice, know that they have options and that they can live out their life independently at home.

Ms. Carter: This population, to me, it hits a part of my heart because I have seen firsthand how important it is for people to be surrounded by their loved ones and to be in their own setting, to be in their own home, and they have a better quality of life.

Ms. De Beaumont: One of the really nice things about the program is because the transition specialists are local. They know what's available within that community and so the transition specialists really can connect you with resources that are available.

Narrator: Open Doors transitioned Mo into her new apartment only to find the cumbersome front door was a struggle.

Mo: I couldn't unlock the door. It was too heavy to pull open. I couldn't get it open.

Narrator: Open Doors reached out to an area independent living advocate who got an automatic door installed.

Ms. Clark-Abolafia: He came right over here. He did what needed to be done to get that in place and that made her life even much more valuable and a lot of times things can be disconnected and fall apart, but we are here to make sure that doesn't happen, so we can always be that person to go to.

Mo: Open Doors make that happen.

Ms. De Beaumont: Open Doors is funded through a grant from the State Health Department as part of a federal Money Follows the Person Program, so there is no cost to the individual or their family members. The only requirement to be a part of this program is to be someone who is in a nursing home and who is expressing a desire to return to the community.

Narrator: Another key part of the team is the peer advocates hired by Open Doors as a special resource to those looking to transition back to the community. They've been there.

Mr. Roman: Someone asks me how life is like being in the community with a wheelchair. They were pretty happy because I was in the same situation then.

Mr. Belden: I just look where I can help and I keep people's hopes up.

Ms. Cohen: I am kind of a point of contact to the outside community, and the outside ideas of what's possible. A lot of it just helping people feel comfortable to get what they need.

Narrator: Sometimes a common thread provides the comfort.

Mr. Simmons: So you're an air force vet. When did you serve or what was your job? My father was in the air force, I'm an army vet or my son is an army vet. As soon as I started to say that their eyes lit up all of a sudden they just opened up and it made a world of difference.

Ms. Andrews: For me, it's all about making sure that people with disabilities in general can live their lives to the fullest.

Mr. Roman: What makes me feel good is able to take someone's attitude from being in a negative state and bring it up to a positive state.

Ms. Cohen: When I see them in their own places and making their own decisions, there's no better feeling to that.

Mr. Simmons: It's definitely a job I look forward to every day.

Narrator: Looking forward through Open Doors to a renewed quality of life.

Mo: I tell anybody get into that program, quick if they want to get out of the nursing home.

Maria: I am really glad, and I am overjoyed.

Kelly: I am very thankful to the Open Doors Program.

Sheryl: Trying to get her taken care of and trying to get her out of there. They did it all. I wouldn't have known what to do, didn't even know where to start. They were awesome.

End of Roll-in Video Footage

Moderator: So Lindsay, welcome back. Thank you so much for joining us. Would you start by telling us about your organization and its connection with the federal Money Follows the Person Program that Erika just described for us?

Ms. Miller: Sure. As Erika mentioned every seat is required to have a local contact agency that accepts the Section Q referrals, so my organization, the New York Association on Independent Living serves as that entity in New York State. So NYAIL, the New York Association of Independent Living, is statewide membership association for independent centers across the state and ILCs are community-based not for profit organizations that provide a range of advocacy services and support to people, all disabilities of all ages. ILCs are unique in that they are run by people with disabilities for people with disabilities. More than 50% of the board of ILCs is made up of people with disabilities and the majority of ILC staff are people with disability, as well. And ILC provides a range of services and there is a core set of services that includes peer mentoring, independent living skills and training, individual systems advocacy, information and referral services, and transition services. Then the services vary depending on the center and the part of the state they're in or what the needs are in the community, but all ILC services are focused on helping individuals to live independent lives in the community. Since inception independent living centers have focused on transition and diversion services, so helping individuals that either avoid unnecessary institutional association or to transition back to the community from an institutional setting. ILCs are predicated on the belief that people with disabilities are the best experts and their own needs and that with the right support and services all people regardless of disability can live an independent life in the community. That's why the ILC philosophy and MFP goals line up perfectly together and ILCs are well positioned in New York State to help the state meet the MFP goals.

Moderator: It certainly sounds based on what you're describing that the philosophy, the independent living philosophy is very much aligned with the MFP. Can you tell me more about that?

Ms. Miller: Yeah, absolutely. An important component of Money Follows a Person is to make sure that all individuals have the opportunity to access community based services and live in the most integrated setting. So the idea that individuals should have control over their own decisions including where they want to live is a key component of not only independent living centers, but of the Open Doors Program. It's important to recognize that older adults and adults with disabilities

are a diverse group with individual needs. Oftentimes, professional staff may believe that it's good for the person and what the person wants is not the right thing for them and they may have bias to do that and older adults have cognitive deficits or people with disabilities should be protected or that they need help in making decisions. Oftentimes, healthcare staff or loved ones, feelings can come into play and can influence an individual's ability to make the transition back to the community. It's important that NYAIL and the Open Doors Program have the opportunity to meet with the individual and to explore their possibility and to help set up the right services and support to make that transition. I'll talk more about how we do that.

Moderator: So can you tell me more about NYAIL's role as the local contact agency?

Ms. Miller: Sure. In 2014, New York State contacted NYAIL to develop transition and peer services to help service a bridge for individuals looking to leave an institution or long-term care facility and move back to the community. NYAIL's program which is known as as Open Door Services serves as that supportive that bridge and there are two components to the program and there's the Transition Center Project and the Peer program and I'll start by telling you about the Transition Center Project.

Moderator: In starting that conversation, can you tell us what is the goal of the Transition Center?

Ms. Miller: Absolutely. The goal of the Transition Center Project is to identify potential participants that are living in nursing facilities, intermediate care facilities or developmental centers and help facility transition to one's community of their own choice.

Moderator: And can you talk about how that program is structured?

Ms. Miller: Absolutely. So within NYAIL we have a transition coordination team and that's the staff that helps run the statewide program, so it's comprised of a project director, the statewide transition specialist, a transition nurse and social work coordinator. All of our staff have experience working in the community and accessing different community-based support and helping to facilitate transition. The transition nurse is important because many of the people we are working with may have complex medical needs that need to be considered when developing a transition plan such as wound care. Oftentimes we find that either individuals or their family members expressed some concerns and anxiety about making the transition and that's where the social work coordinator comes into play or that individual or staff member that number can help either talk to the transition specialist or to the individuals and their family members themselves to talk to those concerns and help address it. And then we have independent living centers across the state over 40 transition specialists on the ground providing the hands-on transition services to individuals that are interested in making the transition. They are based at 23 independent living centers total, so we have nine, what we call Regional Lead Independent Centers and they're based in the DOH nine regions that serves as service the regional hub and help coordinate the work in their area. We have additional transition specialist staff across the state and the reason we spread them out as much as possible because we really felt that having the local knowledge about the services that are available is key to ensuring a successful transition. The community-based services that are available in Ulster County vary to what's available in neighboring county like Green.

Moderator: Sure. For those of us who aren't as familiar. Can you talk about the term transition specialist and what exactly does a transition specialist do?

Ms. Miller: Sure. The transition special starts by meeting with the individual and they can also meet with the family members, the discharge planner and other key players that would be involved in the transition and they just start by telling them what's available. We find that oftentimes people don't know about the service and support available to help them in the community. They assume that based on their needs and based on their disability that the institution is the only place for them and that's not the case. Then, we would help describe the differences between the various programs that are out there, the differences of services, and help them decide based on what their needs are what program may be the best fit for them.

Moderator: How does a transition specialist help to actually facilitate a successful transition from an institution perhaps back into the community?

Ms. Miller: The job of a transition specialist is different for every individual that they're working with. No two transitions look the same, but we start and it's a collaborative process and we start with working with the nursing home discharge planner, the care managers, the service coordinator and of course, the individual and a family member and really put together the person-centered transition plan. So this would include putting in applications for the nursing home transition and diversion and traumatic brain injury which is the 1915 C Waiver here in New York that Erika referenced or perhaps applying or putting an application for managed long term care. Then, the transition specialist role will vary depending on what the individual needs. Their role is to identify the barrier that is preventing that individual from leaving the institution and help resolve that barrier. And a key component of that is identifying community resources. It may include finding housing and connecting the individual with the benefits adviser and they can also work with the family members. Then, they often tap into other community resources including within their own independent living center that brings some of that out of the box thinking so perhaps a home modification program, a loan, to get assisted technology or the trade program that also provides assistive technology. Once, an individual transitions, we follow up with the individual to make sure that the plan we put in place is working successfully for at least a year and we do complete the quality of life surveys that Erika made reference to at the time of transition and 11 months post-transition, as well.

Moderator: I would imagine that this entire process of helping someone move from the institution back into the community would be fairly complex and involve a lot of different things. So what types of needs specifically does that transition care specialist or transition specialist work with?

Ms. Miller: Yeah, so a key component to developing a successful transition plan is making sure that the individual has what they need on day one to succeed. To that end, we provide what we call community preparedness education so that's looking at their needs and making sure that on day one the transition will be successful for the person. So many of these individuals that we're working with have been in institutions for years so it may be as simple as helping them to write out a check and learn how to set up online billing so that they can pay their bills, you know, getting back into their routine and understanding how to develop a shopping list and make sure you're planning meals for the week and making sure you'll have food throughout the week. Erika talked about it's not just about making the transition and it's about making sure that they are integrated in their community. So because we have transition specialists that are so immersed in their community they're aware of community-based resources that the nursing home discharge planners may not be aware of like transportation options through the church or local support groups. So really making sure that the transition is successful on day one and that the individual is truly integrated in their community.

Moderator: It certainly sounds like an excellent program and well thought out from the beginning when you're meeting with all of the people involved to that extensive follow-up. How does the person find out about this program or how did people hear about it?

Ms. Miller: Let me start by saying I know Erika mentioned MFP eligibility and while we do track that for state reporting purposes we accept referrals for anyone who is interested in returning to the community. We will work with anyone. Of course, we do get referrals from the nursing home staff via the MFP Section Q, care managers, service coordinators and family members. In the OPD program in New York they're undergoing a significant transformation and they're actively, you know, expanding community-based opportunities for individuals and helping to transition people, so they're referring people to us directly and we're working with them, as well. We've done a great deal of advertising throughout the state using a PSA that's very similar to the video that we just watched and of course, our transition specialists are available to do education within their local communities and NYAIL's staff is available to educate on a statewide basis, as well. We're trying to get the word out and make sure that everyone who could benefit from the program is aware that it exists.

Moderator: That's terrific. Looking at this potential transition, I would imagine there are a number of potential barriers that a transition specialist might face when they're working to help someone transition back into the community. So can you talk about what those common barriers might look like?

Ms. Miller: Absolutely. The independent community has long identified the lack of affordable accessible integrated housing as one of the biggest barriers to transition. I think that we're finding that certainly to be the case as we are doing this work through the Open Doors Program, as well. New York State over the last couple of years has really done a lot to try to increase housing opportunities particularly for people with disabilities including through our Olmstead Housing Subsidy Program that was recently launched and NYAIL also administers that provides the housing subsidy specifically for people transitioning out of nursing homes. There is some work in that area, but housing remains to be a barrier for many people. Lack of aid is shown particularly upstate in the rural areas where there is significant travel to and from one's home. We do try to educate individuals regarding the Personal Assistance Program, which would allow them to hire their own aids which could be a neighbor or family member, but the program does require the individuals to be self-directing to manage their own aids and their own care and that's not for everyone. Then another common barrier is just the lack of informal support. A lot of individuals we're working with don't have family or a strong network within the community, friends. Many of the programs that we help connect people to do require that you have that network to serve as a backup. If, for example, your aid needs to cancel one day and the aid service or the aid company can't find an aid to fill in you need to kind of have the informal support to make sure that you're not stranded or abandoned. So we do try to come up with some creative solutions to help address that barrier and the other barriers, but they do remain to be some of the top issues we see.

Moderator: Sure. Now you also mentioned earlier that there is a second component to Open Doors. Can you tell me about that?

Ms. Miller: Yeah. So in addition to the Transition Center Project we also have the Peer Program which provides a unique service that's not otherwise available to nursing home residents.

Moderator: What is the goal of the Peer Program?

Ms. Miller: The goal of the Peer Program is one-on-one peer support to individuals and families who are interested in transitioning into the community.

Moderator: So how do you provide one-on-one peer support to individuals who are transitioning?

Ms. Miller: So transitioning back to the community especially for individuals who have been in institution for a long time can be a really scary process and a scary concept and talking to someone who has been there and done that or someone that has similar needs to you and accesses community-based services and lives independently in the community can have a real impact. So we have over 100 paid peers staffed at ILCs across the state that can provide this one-on-one support. Peers are people with disabilities and many who have transitioned from an institutional setting back into the community and all of which who have first-hand experience utilizing community-based services. We do our best to match individuals who share similar characteristics. We would match on the type of disability, their age, perhaps if they have shared military experience and then the peers go in and meet with the individual and they share their individual experience of living in the nursing home -- or in the community, and they can answer any questions the individual may have and help ensure that some of their concerns or help relieve some of their anxieties and then they -- we also have been recruiting what we call family peers because we do find that oftentimes a family member who is interested in transitioning is really is hesitant about that. So we have family members of individual who have transitioned and who have a family member who is living in the community with a significant disability and living a successful integrated life and they are available to talk to individuals that are interested in transitioning, but who share concerns. And the transition specialist are often ones that refer to the program, but peers could be the first point of contact, too. There may be some individuals who are so anxious about transitioning that they don't even want to talk to a transition specialist yet, but they may be interested in talking to the peer and talking through some of their concerns with transitioning and then they can be referred to the Transition Center Project, as well.

Moderator: That makes sense. Moving forward a little bit, how do Open Doors staff work with nursing facilities? Can you explain that for us?

Ms. Miller: We recognize that social work discharge planners, social workers, and nursing discharge planners have high caseloads and there's so much that goes into just one person's transition plan. So we can really be a resource. We're available to help in any way possible and it could be as simple as us being the ones that help track down a specific document that the individual needs to enroll into a community-based program like a birth certificate. It could be going out to look for an apartment. It can be helping to identify community-based resources to help integrate the individual even a pharmacy that may deliver once the individual is there. We can work together to develop that person-centered plan and we can serve as that point of contact that will make sure that on day one everything comes together and the transition plan is a success. Then nursing facilities may also have individuals that they think would have a higher quality of life in the community and who are expressing anxiety about not wanting to make that transition and the Peer Program could come in handy there, as well.

Moderator: Excellent. How would someone go about making a referral to Open Doors?

Ms. Miller: There are several ways you can make a referral. You can contact NYAIL directly or contact the local independent living center. We do have on our website a list of the ILCs that staff transition specialists and we have a referral form on NYAIL’s website and we do have an 800 number. There are several ways.

Moderator: I want to thank you so much for the information you shared with us so far this morning and we will be back in just a moment for question and answer.

Question & Answer Segment

Moderator: Welcome back. We've got quite a few questions and we'll try to get through as many as we can. The first one, Erika, is for you. What is the role of a managed long-term care manager in relation to section Q?

Ms. Robbins: The role of a managed long-term care person or manager, their role is to help support and coordinate, so if an individual is wanting to transition out of an institutional setting like a nursing facility and they're already engaged with NYAIL it's important for that care manager to build a relationship with NYAIL and to help support that coordination of services when that person moves into the community. Also, it would be a recommendation that that care manager become familiar with the nursing facility rules and regulations and how the nursing facility works especially with the Minimum Data Set to help support the provider as they identify people who might want to move to the community.

Moderator: Thank you. The next question we have. Lindsay, are Open Doors, Money Follows the Person and NYAIL all the same organization?

Ms. Miller: We are all closely connected. Money Follows the Person is a federal grant that New York is one of 44 states that's participating and NYAIL contracts with the state to provide Money Follows the Person here in New York and we do that through our program named Open Doors.

Moderator: Excellent. Thank you. We have another question. What if a person for whom discharge is not feasible answers yes to Section Q? Do I still need to send the referral?

Ms. Robbins: Yes.

Moderator: I think I heard this during the show, but if you guys want to expand on that?

Ms. Robbins: Because the purpose of Section Q is to help identify people who are interested in learning more about what's available in the community so there's no harm in submitting the referral and they should submit they referral. The only time a person would -- or nursing facility wouldn't need to, is if there's an active discharge plan and an active discharge plan means they're known by Lindsay and the NYAIL team. If they're not known by NYAIL, then a referral should be made.

Ms. Miller: Certainly, as I spoke to, we come in with a different set of eyes and expertise about community-based supports outside of the traditional service system that are available. So certainly, we would come in and maybe we'd come to the same conclusion with the individual, but certainly the referral should come through to us and we would come in to meet with the individual.

Moderator: Great, thank you. Lindsay, how do I know that a referral to Open Doors was actually received?

Ms. Miller: So we do have a policy of responding to all e-mail referrals that we receive, and then once we do receive a referral we are expected to go meet with the individuals within ten days. So there are certainly areas of the state, particularly in downstate, where due to capacity we don't always meet that timeframe and we are working with DOH collaboratively to try to address those capacity issues, but certainly, you know, a nursing home discharge planner or social worker can

always contact NYAIL or the independent living center directly. We can let them know if we've received their referral.

Moderator: Thank you. Erika, can you explain why the Olmstead decision is important to the field of long-term care?

Ms. Robbins: I think the Olmstead decision as I mentioned during the presentation, it's a catalyst to change, and I think what makes it special is its actual individuals saying I don't want to live here, I want to have choice in my life. The Olmstead decision has really pushed the growth of home community-based services and have shined a light on the importance of inclusion and integration. I think it's the impetus to a lot of activity even when you look at some of the more recent opportunities that Congress has passed with in the Affordable Care Act and it's really about giving people more opportunities and giving states more tools such as not just 1915 C Waiver Program and the 1915 I, J and K. These are all options in the Social Security Act that give states the ability to grow home and community services and if it weren't for Olmstead that probably wouldn't have pushed so fast so far. We still have a ways to go, but it's going in the right direction.

Moderator: The next question that we have, Lindsay, what if a resident wants to go home to the community, but the family doesn't support the move?

Ms. Miller: Open Doors will certainly work with the family member to talk through some of those concerns. In our experience prior to admission with the facility, oftentimes the family member has had to provide a great deal of support without much assistance, so to them the idea of the individual moving back to the community seems like a big burden to them. We can ensure there's sufficient supports available so that that's not the case. Ultimately, we do believe it's the individual's right and their choice to make, so if the individual wants to move to the community we can help make that happen and that may include finding their own place to live outside of the family member's home or outside of their network.

Moderator: Thank you. Why are transition specialists qualified to help a person return home?

Ms. Miller: Well, transition specialists are very well connected in their communities and they're very understanding of the various resources available. They all work within independent living centers, which have been doing transition and diversion work for many years. Many of the transition specialists themselves have served as service coordinators in the past so they are uniquely qualified to help link individuals to home and community-based services.

Moderator: Excellent. Thank you. What if an individual responds yes to Question 0500 and they were previously referred to Open Doors and found they were found to be inappropriate for discharge.

Ms. Miller: They should certainly still send the referral. We will make contact with the individual and nursing home discharge planner and try to assess whether the circumstance that prevented their discharge previously is still an issue. If there's even a question as to whether that is still the case we would come out and meet with the individual again and do another assessment.

Moderator: Excellent. Well, thank you both so much for all of the information that you shared with us today. I think you've really helped to paint a picture of not only what the program is, but what the benefits are to the individuals who participate. So thank you so much.

Ms. Miller: Thank you.

Ms. Robbins: Appreciate it.

Moderator: And thank you very much for joining us today. Please remember to fill out your evaluations online. Your feedback is always helpful to the development of our programs and continuing education credits are available for today's program. To obtain nurse continuing education hours, CME, CHES and Social Work credits, learners must visit www.phlive.org and complete an evaluation and the post-test for today's offering. This webcast will be available on demand on our website within two weeks of today's show. Please join us for our next webcast on March 16th, Healthy Communities: An Assessment and Implementation Framework to Achieve Inclusion of Persons with Disability. Additional information on upcoming webcasts and relevant public health topics can also be found on our Facebook page. Don't forget to like us on Facebook to stay up-to-date. Now you can also let us know how you use Public Health Live by taking a brief survey on www.phlive.org. I'm Rachel Breidster. Thanks for joining us on Public Health Live!