IL Skills Training for Transition to the Community

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Presenters: Jane Schiele and Rebecca Payton

>> TIM FUCHS: Perfect. All right. So I will go ahead and get started here. I want to, again thank you for your patience, as you waited for us to get that settled. And we're going to go ahead and begin.

This is the latest IL-NET, IL Skills net training for the community. And today's presentation is brought to you by the IL-Net for CILs and SILCs. It's operated through a partnership among ILRU, NCIL, and APRIL with support provided by the community for independent living at the US Department of Health and Human Services. We are recording today's call so we can archive it on ILRU's website and we will break during the call to take your questions.

If you are on the webinar today, you can type your questions in the chat, and that is the text box underneath the list of attendees.

And you can enter your comments or questions any time during the call, but we will wait for our Q&A breaks to address them.

Because of the audio issues that we are having today, I would really encourage you all to use that chat feature. If you can't access that or prefer not to you are welcome to use the chat on the CART screen, the full-screen CART.

That URL is included in the webinar platform and it was also sent to you in the confirmation email. I mean, you are welcome to email me your questions as well. I'm at Tim@NCIL.org, and my email is open.

Just because we have fixed the problem here, but we had to mute the audience and because of that, I think that will be the easiest way to submit questions.

So we'll have a break for Q&A during the call and then again at the end of the call.

If you are on the webinar, of course, the PowerPoint will display automatically, and you can just watch that. If you are only on the phone today, you will want to have the PowerPoint in front of you. Again, that PowerPoint was sent to you as a PDF and a plain text document and the confirmation email. So you will want to have that open if you are not on the webinar.

Okay.

There is an evaluation for today's call. You will see that at the end. And that is -- there will be a live link at the end of the webinar. You can click that and fill it out. I really hope you will take a moment to do that. It was also enter to you in the confirmation email. There was a link to that same form.

Let's see, before I kick it off to our presenters, I just want to walk through the objectives for today's call, here on slide 3. So today, we are going to learn how to IL's philosophy and CIL staff support a successful transition process, by reinforcing the peer-to-peer approach. The skills and the services most often needed by individuals who are transitioning out of an institution and into the community. The process for assessing an individual's training needs prior to and after the transition, and how to assist individuals to develop a personalized IL Skills training plan to ensure their successful transition and integration in the community.

All right. So that's today's agenda. And with us to go through this are Jane Schiele and Rebecca Payton. Thank you for the time you put into this presentation. Jane is with us from the Center for People with Disabilities in Boulder, Colorado, and Rebecca is joining us from the CDR, the Center for Disability Rights in Rochester, New York.

Okay. And I will turn it over to Jane and go ahead to slide 4. Jane?

>> JANE SCHIELE: All right! Well, welcome. Here on this slide, it says our focus, identify, learn or relearn independent living skills.

So this is one piece of the entire transition process. Not a global training on the entire transition from institution to community. So the ILRU offers training and classes that cover transitions in the entirety from initial steps and assist someone out of a facility and gain the support in the community.

This webinar focuses on IL Skills training including assessing the individual's needs, while utilizing the crux of IL philosophy, and examples of IL Skills you can take back and utilize in your work.

Next slide.

Not only do we assist the person getting out of the institution but by building independent living skills we can help to get the institution out of the person. So if you have not heard of the phrase "we can help get the person out of the institution, but it's even more difficult to get the institution out of the person," what it means is that even though we may work really hard assisting individuals getting out of nursing facilities, the institutional mind-set has been so severely engrained in them, that it's like the bars of prison have been removed, but the person, in their mind, continues to remain in the institution or prison.

Instead, being free of the facility, and on to the next great thing, they have just moved from one room of the institution to the room of their apartment. That's where the independent living skills training is key to reengaging in life. I have heard from numerous staff that their prerogative is to keep their patients safe. Recently a woman who is a social worker at the dialysis center asked me how I had the audacity to move this gentlemen out of the facility. I reviewed with her that it was his right to live independently in the community, and he communicated that strongly and effectively in the facility, especially since he's monolingual Spanish speaking.

Then she said, he could die. Do you want that type of responsibility I also said he told numerous home health workers and CIL staff that he would rather move back to Mexico than go back to the facility. He does understand he would likely die en route to Mexico due to his need for continued dialysis. You can see the stark differences here in the medical model philosophy and the IL philosophy of dignity of risk.

Next slide, please.

Peer to peer, nonhierarchical, peer to peer approach. So as many of you know, the IL movement was built on peers with disabilities supporting ex-other, mentoring each other, the staff member's way was not entirely the right way. It will not authentically work if staff tells consumers how and why and what they must do in order to get out. It's easy to take the lead as we are in a hurry to get a lot of things done. When I think about the peer-to-peer approach, I like to think of it as if I'm in the passenger's seat of the car and the consumer is driving. I might offer some directions and we know the decisions are ultimately up to the consumer.

Start to rid the person of the hierarchy that was imposed since day one of the institution.

So since entering the institution, the consumer has been told when she will eat, what time and day she will shower and when it's lights out. Make this transition a collaborative effort. From the first day, you can start working with them to start rebuilding independent living skills such as self-advocacy and problem solving, by helping an individual identify what day of the week they would like to meet and where you would want to meet, at the center, or reserve a room in the facility.

Easy enough, and it helps to get the mind moving again.

Empowerment. Listen to the individual's experience as a peer and mentor. To fully allow the nursing facility to function on a manner acceptable to the institution, it's inherently -- it inherently must disempower the individuals that live there. We are working to help these individuals break out of the system of disempowerment to empowerment. There's power to truly listening to what someone is saying. It is easy to get into the facility and start planning the ten things that need to get completed but slow down and listen. Listening is in itself -- listening, in itself, shifts the power dynamic from one up or unequal, to equal, which is peer-to-peer and as a mentor and what can be ultimately a much more successful relationship and better move back into the community.

Next slide.

Assessment, working together to identify IL Skills needed.

Identify independent living skills together for best success in the community. Skill identification is a collaborative approach. Find out what she's interested in learning, break the skills down so they make sense too. We tend to have a lot of jargon speak that a person outside of this movement won't know. Also, it's easy for transition coordinators to have strong belief that she must absolutely learn a certain set of skills, like relearning public transportation.

When you sense these concerns, get curious. Maybe there's more to the picture than meets the eye. Through simple questions, you might find out that she had some previously bad experiences on public transportation, when she lived in the community.

Then having that information, you can help her move forward, listening, problem solving, et cetera.

Start rebuilding skills while in facility. One gentlemen I'm working with wanted to get out, go for coffee and we took a trip to a potential housing unit because as he described, I feel like I'm moving from one planet to another.

So many things we do, while working in collaboration with the consumer can be considered a time and skill building. So, for example, making phone calls together to find out information on Social Security, and together filling out housing applications.

Remember, some of those much needed independent living skills were not taught or lost in the facility. Whether the individual has been in the institution for nine months or ten years, the amount of skills that were lost in that time period is huge!

Imagine every decision in your day is made by somebody else. Unless a person is highly motivated to learn new skills in the facility, it's much easier for staff -- for staff of the facility, for the person to be complacent and don't do anything. Do what you are told. One gentlemen I'm working with has a cell phone, but doesn't know how to retrieve his messages. A basic skill that easily could have been taught by the facility or the consumer could have asked someone in the facility to assist him.

Not a lot of motivation on the institution's behalf to teach him and he lost the confidence to ask them to show him how to retrieve the messages. That is one skill that he and I have worked on together.

Next slide, please.

Assessment, a nonjudgmental approach. A nonjudgmental approach is critical to success. A nonjudgmental approach is key to building trust. We need to put aside our own expectations or stress and tune into what is going on for this person. There is usually something behind the way we all act. One woman I was working with wanted to leave the facility yesterday or better last week. She would get really angry with me and ask me why she had not moved back to her home yet. After acknowledging to her that I had heard her anger and frustration in a nonjudgmental way, she was able to open up to the real issue that was going on for her, which was that she was scared the move would never happen.

We were then able to start a more productive conversation from there.

People who feel that disclosing information will prevent them from transitioning will not share critical information. One woman I'm working with now told me that -- told me her needs for home care were minimal. Actually her home health needs were quite high. It makes sense she wouldn't want to share on the basis of survival. I understand she sees me as a ticket out of the institution. Her perception might be if she tells me too much, I might end the process of helping her move back into the community. The way in which she is thinking makes sense to me, especially since she was living in a facility two years longer than she absolutely needed to be there.

To work with this fear, I reassure folks that the more information I know up front, the better.

Empathy creates understanding, and then consider what when consumers are assessing your needs rather than their own. The environment which they are -- they have been living is one of compliance, showing up for meals, taking meds correctly, shower once a week at 4 p.m. Not asking oneself what do I need? In order to remain in compliance which is necessary in order to survive in the institution, the person may read you as to how you feel you want them to answer the questions or what you think is the right thing to do. Again, survival and in their minds, a sure way to get themselves out of there.

Keep putting the questions back on them. I will often say it's your life, you get to choose.

Okay. Next slide, please.

Assessment, get curious. Get to know the person in the curious sense, not clinical. So here's a stark difference in description. See the individual as a person who wishes to take back the reins of her life instead of the quad living in room 102. That's pretty harsh way to say it but in CILs we are conscious of the individual utilizing people first language which inherently communicates respect.

Questions to ask, questions to ask that are curious in nature. What were your interests before entering the facility. In fact, just last week, I asked a gentleman this question. I found out that he was married and has a daughter and was in the military and is deeply spiritual.

What hobbies, activities, have you kept up while in the facility? Finding out what they have kept up while in the institution will give you a starting place as well. I'm working with a woman who attends weekly Bible classes at her church. That information in itself gives me a clear idea of her ability to problem solve, organize, and physically get herself from one place to the next.

What are your passions, your dreams?

We can help revitalize those passions and dreams through our conversations. Those these dreams may feel to the individual as long past, who knows. Through our conversations, passions and dreams can reemerge. Next slide, please.

Okay. Assessment. Questions to ask. If the person has the ability, that she or he had entered the facility not knowing important independent living CILs. To support the person in finding the right resources.

First of all, find out why the person ended up in the facility, was it due to an inability to keep home care providers unable to pay the rent and ended up homeless, which worsened the disability, not having the strong self-advocacy skills to let others know they need more medical attention, giving up on their support network. All of this information is helpful to figure out what is the most quintessential skills to teach.

>> REBECCA PAYTON: Next slide, assessment, now we look at assessment from a different perspective do they go into a facility because of acquiring a disability.

Peer support and modeling are critical to successful transition back into the community. This is very, very true and actually this part of the assessment process we are collecting really important data that will help us to determine what the person's needs are.

This is also a time to maybe consider or introduce the peer-to-peer approach, that we talked about earlier in the objectives that -- that can be paired with this person, and they can see firsthand from somebody who has been there and done that, made a successful transition back into the community.

Next slide, please.

Assessment, getting back into the community. Plan an outing. This is a great assessment tool, one that we really routinely use.

When you plan an outing, the individual will utilize multiple skills such as planning the trip, travel skills, money management, communication skills, establishing a comfort level of being in the community, and offer you a chance to support the individual and assess what skills need to be caught, again an excellent assessment skill and going back to the previous slide if somebody acquired the disability, you know, or entered into a facility because of acquiring the disability, this is a really important outing to plan.

And to establish the comfort in the community, the comfort level, we suggest, you know, making the outing the consumer's choice however, you want to be prepared with some suggestions to offer, ones that we really find helpful are outings going on outings to the neighborhood, where the person, the individual will be living. That's a great opportunity, maybe visit and tour the local grocery store. There are a variety of independent living skills that could be taught in an outing like that, from going and taking the tour, getting familiar with the grocery store, going over things and how do you know the produce is fresh? Can you read a label, and check the expiration date and using the debit card which can be confusing especially if you have been in a facility for the last year or more.

You have to insert the card into a machine and it's very complicated and doing these things prior to the transition are so important to enhance the person's independence and, you know, teach independent living skills.

Teaching organic skills, as much as possible. You see that there's very extensive list of examples of independent living skills, that we found helpful. You can take that list and create it and have a discussion about where they feel their strengths are and where they feel their weaknesses are. It's always good to know and hear from the person what they -- what they assess their skills at, and help them prioritize. You want to use open ended questions, well, now we have prioritized these, what do you want to work on first?

Acknowledge that the skills you may want to teach may not match up to what the person wants to learn, and, again, that's a great opportunity for discussion, like Jane was saying.

Finding out why they might not want to work on something, why they might be avoiding it, but because you have collected all of this data in the assessment process, all of this information, this will give you a good clue about maybe some discussions that need to be -- need to be had, you know, what -- maybe we need to talk about household management because you wound up in a nursing facility because of a fall.

Teaching in the moment, when you don't have the luxury to prioritize. As the needed skills become obvious, take time to teach or reteach the skills. What I take here, don't get locked into a rigid plan. Understand the person better and for the person to better understand his or her needs and to teach, reteach, and then strengthen those skills.

Next slide.

>> JANE SCHIELE: Use what services your center is already offering. So IL Skills classes. Some of these centers have great things going on. Collect into classes and see if they are -- check into the classes and see if they match up with what the consumers are using, peer groups. Peer groups are great at allowing individuals to gain a feeling of something bigger than themselves. Seeing people already living in the community or in their own apartments can be inspirational for the person still living in the facility.

Also, they can be mutually inspiring for folks already living independently to witness and support someone who is trying to transition out.

Individual peer mentoring. If your center already has peer mentoring, you can match the consumer with a person who already transitioned out or a person whose disable reflects that of a person who is living in the institution.

Okay. Next slide, please.

Peer-to-peer support mentoring, overcoming learned helplessness. So learned helplessness can happen quite quickly during institutionalization, and it's much more engrained in one's mind the longer the stay is. The more someone has had no choice, in daily decisions, the less they believe they are capable of making these decisions on their own. In order to embrace the dignity of risk, or the right to fail at something, the individual must start to experience his or her capability in making decisions.

There's a great feeling of indifferent and isolation in facilities I have worked with and worked with folks. We have get to be the new face that can engage with individuals. We get to say what happens to you matters.

Empathize with frustrations of being stuck in the facility, that they miss getting their shower of the week because something else got changed or scheduled.

We can model being enraged and then setting forth the energy to change things together.

Excellent listening skills, we need to lose the angst of how much paperwork needs to get completed or following the exact T exactly why we visited the person that day. Slow down and listen to what they have to say. Remember to be truly listened to is a gift.

Problem solving together. We save the most important for last here. At every instance, problem solve together. Any time the individual has an opportunity to make a decision, let them do it. When I worked with folks, decisions are often put back on me. You decide.

I will put the choice back on them and I will say you are the one moving out or this is your life. Or let's figure this out together. I noticed within the confines of the institutions, it's easier for them to figure out what to do and it's easy to go to the office manager who has all of those documents. When we figured out the meeting with the local housing authority, that was one more -- that was much more difficult. But we broke it down the logistics a number of ways.

What -- what do you need to take to the meeting, his location, the transportation, the time of meeting and so the next day he successfully attended the meeting with his sister.

Next slide, please. Approaches to IL Skills one on one. We feel more comfortable learning things one-on-one. We are about to start a peer mentoring program which many of you are doing where the person who is transitioned out meets with the individual who is meeting with the person getting out. We met with a peer mentor at a local coffee shop where the consumer actually used to work and discussed how the peer mentor manages his home health services in his apartment and the community.

Modeling doing it together. One gentleman I worked with a ways back, struggled with anxiety. He remembered he had taken the city bus before but had forgotten how to since residing in the facility for seven years. We took the bus together to the Social Security office to help figure out his benefits. Doing this together, seemed to help him remember that he did know how to take public transit.

Bring a class to the facility. A peer group I had a number of years ago visited a gentleman in the facility, mutually beneficial. He was in charge of the facility, getting the room, for us to meet. It was eye opening for folks to visit the facility and we had some great conversations about their experiences as well. Work with a facility. It's hard with facilities figuring out the person, how the person can start taking their own initiative. Since the facilities do everything, it can be tricky figuring out what they are willing to allow the person to do for themselves. And there's a great concern about liability.

One woman requested medication with the facility instead of the nurse telling her when it was time to take her medication. So she was asking them herself instead of them telling her. We worked with another facility so that a consumer could call the paratransit himself for transportation instead of depending on them to do it for him. Again, it can be tricky. With your advocacy and facility willing to work with you, then these adjustments can happen.

Next slide.

>> TIM FUCHS: Okay. Here we are at questions. Thanks, Jane.

All right. So we will open up for questions now and, again, we are going to rely on the chat today given the problems we are having on the phone and, again, there's a couple of ways you can do that.

You can type your questions or comments in the chat under the list of attendees or if you are on the full screen CART, you are welcome to type your questions or comments in the chat box there. I also have my email open and so if you don't use or prefer the chat box, you are welcome to email your questions to Tim@NCIL.org. And I will read them in realtime as they come in.

All right. First question comes from Alexa. And Alexa is wondering -- she says, I'm working with a woman who responds to questions about her hobbies and interests with "I don't like any of the activities here."

Do you all have any thoughts on how I might encourage her to think about what she might like to do or might like to learn? Jane or Rebecca, do you have suggestions for Alexa?

>> REBECCA PAYTON: Yes, Alexa, that's a great question and I probably wouldn't like many of the activities at the facility either. So that's maybe where you could introduce or suggest the idea of a series of outings to maybe the local center for independent living.

Some centers offer some independent living classes, like Jane mentioned, some peer groups, or even have events like saying we had a Thanksgiving dinner and we were working with somebody fairly in the beginning stages who is in a facility or institution, and that was a great opportunity for her to get out and to socialize them from there. She kind of gave us clues. She talked about what she liked and her background and her experiences and so more of a natural, again, that natural setting to get to know someone.

Versus in the facility.

>> TIM FUCHS: Great. Thanks, Rebecca.

Okay. And Kathy, one of our participants suggested that -- she said ask her what she likes to do and what she did before she went into the facility. Even a skilled nursing center can set up a small garden for people.

And Alexa said that's the crux of her question. She -- she returns to her focus on how bad the activities at the facility are. And Alexa said it's like she needs help breaking out and finding herself and her interests there.

>> REBECCA PAYTON: Tim, this is Rebecca. I think that's why planning the outing is a really great assessment tool and it's an opportunity for that person to get to know them, like I said, and -- when you are trying to find out interests in the institution, that can be difficult.

>> TIM FUCHS: Yeah. Okay. Good advice. Thanks.

All right. We have plenty time for more questions. I will wait to see if more comes in.

>> JANE SCHIELE: This is Jane.

>> TIM FUCHS: Yes, you have some advice for Alexa?

>> JANE SCHIELE: I was really just going to add on to what Rebecca just said. I think it's a great idea as much as you can help people get out of the facility, doing activities, especially folks that are planning to leave the facility, and move back into the community, what a great way to get started by, you know, like Rebecca was suggesting going to the center or just doing some real activities, and get some real life experience.

So --

>> TIM FUCHS: Good. All right. Thanks, y'all. Okay. So I see a number of people still typing, and we'll see if any more questions come.

In Kathy has a little more advice.

Dig deeper. Find out what she's upset about. What she's angry about. I worked in a SNIF that had a whole range of I don't, and I can't, and it may than she has a valid point if all they do is sit around coloring or playing cards. If nothing else, she might need time to adjust to a physical or emotional point in her life.

So folks from disability rights and resources, suggested add IL Skills into the nursing home care plan to keep the staff accountable for the people to develop their skills.

That's great.

All right. Again, if you have questions, you can type them in either of the chat boxes. Or you can email me at Tim@NCIL.org.

We'll give about 30 more seconds just to see if any more questions come in and, again, we will have another Q&A break at the end of the call before we close today.

Kathy is wondering if someone wants to go on a real outing and needs an aide, will the facility provide an aide?

Jane or Rebecca, any experience with facilities providing a PA for folks when they travel outside of the facility?

>> JANE SCHIELE: This is Jane. It's been more my experience that when we do an outing, the individual just comes by himself or herself, with the support of the CIL. So I have not had a facility that has actually provided an aide.

>> REBECCA PAYTON: And this is Rebecca, my experience is the same as Jane's. There's usually no one from the facility accompanying the person and oftentimes that's better. This is a great opportunity to practice independent living skills, learn, practice on attendant management which we will go into later.

Let me know what you need, you know?

>> TIM FUCHS: How about transportation? Any luck getting facilities to provide transportation for those, even if they come by themselves?

>> JANE SCHIELE: This is Jane. Yes, I've had luck with facilities providing transportation to like our center or -- or another outing. So, yeah, they have provided transportation before.

I mean, again, you know, it's kind of a cross of philosophy. I mean, it's great having the person be able to work with maybe the city on getting transportation or something like, that but it's really nice when transportation just comes through easily as that can be a big barrier.

>> REBECCA PAYTON: That definitely can be. We are fortunate, we have accessible vehicles at our agency. So we often utilize those. We don't normally have a lot of luck with facilities providing transportation. In my experience.

>> TIM FUCHS: Okay. Okay. All right. A few more questions rolling in here.

Alexa says, have any of you run into facilities saying that people need so much care they can't transition out? We see nursing facilities try to argue that people wouldn't be safe without a Medicaid waiver and try to prevent us from seeing them at all.

>> JANE SCHIELE: This is Jane. Yes, I've -- multiple times I have had folks in facilities say that this person can't possibly live out on their own again, and so, you know, it's really through my experience, it's really been sticking with the consumer and what they are expressing. They say that they want, you know, while the facility is saying they can't possibly do this. Because it's the individuals who can figure out what they want for his or her own life.

>> TIM FUCHS: Yeah, and lots of participants echoing the same. Anybody who has been doing this for a while has heard that a lot. And, yeah, it's important just to educate them and keep doing what you are doing.

>> REBECCA PAYTON: This is Rebecca. That's very, very common type of message from the nursing home, but it's important also to note that, you know, people can receive 24 hour services in their own home in the community. So that's -- that, is you know, very much fictional.

>> TIM FUCHS: Absolutely. Absolutely.

And I would just point to some of the other resources that we have on transition in general. In -- you know, we have done the ABCs of nursing home transition which was a multiday training for a number of years now and we keep updating it and improving it and both Jane and the director of Rebecca's center have presented on that. That's an excellent resource for those of you wondering about the transition strategy and working with facilities. Those materials and even live video of the presentations are on ILRU's website. So I would encourage you to check them out.

Okay. Let's see Jody has a question. It says, "I have a question, how do we get the nursing home to work with individuals on the activities while they are in there, to get them involved? Most don't have that for people that may be deaf or have a disability, not able to use their hands.

So what have you all done to work with nursing homes to get them to make these activities accessible and work with people while they are there?

>> JANE SCHIELE: This is Jane. I think having folks, as far as participation and activities there, it's not drawing to my mind a particular example, but I think that would be a great opportunity to work on self-advocacy skills with the consumer at that point. You know, how do they want to be able to tell people, hey, I really want to par take in this activity, although it's inaccessible for me to get there.

I think together with the consumer and myself, I would want to be able to talk with the facility and/or support the consumer in doing that, you know, themselves.

>> TIM FUCHS: Good.

Yeah, and some of our participants chiming in as well. Nicole encouraging folks to look at the OTs, occupational therapists in the facility as a resource to help folks with the skills they need to transition. Maybe an ally that you could set up, depending on, you know, the -- the OT and the philosophies that you find at the facilities in your area.

And others just talking, about you know, the fact that the importance of educating the facility on 24-hour care and developing a plan and letting them know what is involved.

And Kathy echoing some of these concerns and just saying, doesn't the law require accommodations? Shouldn't they be able to request an interpreter? I agree.

And she suggests if they are not getting the activities they want, call the ombudsman and submit -- you know, help them help the consumer to submit a complaint. Great advice.

Good.

Yeah, the folks from disability rights and resources offering, sometimes you have to fight to get the facility to do that. Of course we know that's true. They also suggest trying to get an AP device to try to promote independence.

So again, that's really the role here is to push the facility, and to educate the consumer, you know, on their rights and to help give them the -- the resources and the confidence to -- to push the facility wile they are still there, to provide some of these activities. And to give, you know, space for the person to learn what they need to learn before they move out.

I will just check if there any more questions before we continue with the presentation.

Kathy says, in New York state, there are peer mentor programs around -- through the NFP program, the money follows the person program. She says it's called Open Door there. That might be a resource -- you know, state dependent. It might have a different name but that's good advice.

>> REBECCA PAYTON: That's great advice Tim. We have an Open Doors transition center and we utilize our peers for this reason. They are very great in working with people who are nursing homes and leaving -- alleviating a lot of those, you know, concerns about transitioning. Because the nursing home has given them very different information that might not be true.

>> TIM FUCHS: Yeah. Yeah. Good. Thanks, Rebecca.

>> REBECCA PAYTON: And you can also create your own group, cadre of trained peers as well, I mean, without even this type of a program.

>> TIM FUCHS: Yeah.

>> REBECCA PAYTON: I want to throw that out there.

>> TIM FUCHS: Good. And the folks from disability rights and resources offering that sometimes you can even get the facility to take some of the costs out of the activity budget. So you might even be able to recoup or cover some of your costs with the activity budget from the facility. Really good advice from you all and some of the folks that have been there before.

Hey, I'm going to go ahead and click to slide 18, and turn it back to Rebecca. We are going to have another Q&A break at the end of the call, though. So thanks for the good questions and comments, folks. We'll continue. And have another question break at the end.

>> REBECCA PAYTON: All right. This is the second part of our presentation. And slides 18 and 19 include stills that we found important for the successful transition of individuals from a facility to an independent living situation.

In our experience, I just wanted to share some of our experience, the skills on these two slides that deal with relationships and interactions with others, attendant management, self-advocacy, interpersonal skills, building or rebuilding, we found those to be the most difficult skills to develop.

And the ramifications are real, if people don't learn those skills. So if you don't know how to manage your attendant services, self-advocate or interact with others, whether it's the landlord, the doctor, a neighbor, or other people would are key to the transition, it's -- the person may very well wind up or be at risk of winding up back in the institution. So all of these life skills on these two slides, slides 18 and 19, but we have definitely found some of them are critical.

Next slide, and then, againA. tendant management at the top of slide 19 we found to be a critical skill to learn.

Next slide.

>> JANE SCHIELE: Okay. Self-advocacy. Put a voice to one's need. The facility inherently places fame sis on the survival of the institution as a whole, over the importance of each person. One woman told me she pushed her call light and waited over three hours to get assistance going to the bathroom.

A number of folks I worked with fear repercussions for stating their own needs. One woman was taunted for hours by the staff because she requested a couple of extra pillows and these things happen. What we can do is follow through on requests that consumers have of us if we are able, just to show them that somebody out there is listening.

Also assisting in teaching self-advocacy skill techniques both inside and outside the facility is key.

Keep asking, what do you need here? So few times living in an constitutions, our individuals ask what they truly need. Help consumers to start identifying what their needs are. With two folks I'm working with now, when I ask them what they need, often I get, nothing. It's when I start getting specific on the tasks we need to accomplish that they get more specific with their needs, especially when we assign what tasks I will do and what tasks they will do. It's at that point we can break down the tasks they need to do, that will make it easier to accomplish from start to finish.

Help people to check back into the fact that, yes, they do have needs that are very important. And on a side note, when they don't follow through, when the consumers don't follow through with tasks, don't take it personally. Find out what's going on for them. There's usually something more going on than meets the eye.

Let's see, identify medical needs, housing, and benefits. So identify medical needs. Unknown problems may arise. At one facility, they were giving a gentleman too many laxatives. He would have to have someone to change him in the middle of the night.

He let nursing staff know that he was getting too many laxatives and he's now on a regular schedule and won't need to have anybody change him in the middle of the night which is key to him moving back into the -- out of the facility and back into the community.

Self-advocacy and housing, by letting you know precisely what his housing needs are, such as accessibility needs, which city he prefers to live, in he's beginning to embrace his voice.

Benefits. Pretty much everyone I have ever talked to is angry that the facility is getting all of their check and they are happy to tell the facility they need the final check upon departing the facility. So these are great ways for them to utilize the self-advocacy skills again.

And then -- oh, gosh.

Identify Durable Medical Equipment, assistive technology and accessibility needs in the community. Identifying all of the above allows the individual to state their needs, what will help them live successfully in the community.

I have experienced nursing facility staff talking to other consumers stating that they -- what they believe the consumer needs. For example, this past summer, nursing facility staff was seeing a consumer did not need a Hoyer and could use assistive Sams. They corrected the staff by letting him know that a Hoyer, which by the way was the case.

Self-advocacy and health education.

Sorry. Here, I just lost the screen here.

>> TIM FUCHS: Sorry about that, Jane. The PowerPoint just dropped. We are bringing right back up. So I think you were about to go to slide 21; is right?

>> JANE SCHIELE: I don't know. I was following that for my guidance here. I thought I was -- I thought I touched something on my computer.

>> TIM FUCHS: No, it wasn't you. It's on 20.

>> JANE SCHIELE: Support the individuals and self-health education. I found that even though it's a skills facility, where people's health is supposed to be number one, that's not always the case. Moving around and getting healthy is not promoted.

This is an example of a work in progress but one gentleman we were working with his hands and feet were notably swollen. The institution was not taking the initiative to get this checked out. Finally through the consumer advocating for himself, along with the center's advocacy, he will see a specialist to see what is going on.

Next slide, please.

Self-advocacy continued. Provide support in making their own phone calls, writing emails, et cetera, for resolving personal situations. Use application processes and snafus with benefits and housing applications, et cetera, as teachable moments.

Okay so frustration can build when problems build. We as transition coordinators know that moving from the facility back into the community is working through numerous setbacks. I have found it important to work with the frustration that arises and show the consumer that they will reach the other side. A problem currently in our area is the shortage of CNAs. One gentleman I'm working had secured wheelchair accessible housing, however, his home health agency fell through, and he had to give up this apartment. So together, we have been calling home health agencies and finally two weeks ago, we found a new one that is opening up and will be able to provide home health services.

He was thrilled and we could see that even though there was such a disappointing setback, things are moving forward.

Now we are moving on to look into wheelchair accessible apartments.

Support them in arranging their own transportation. Coming to your cent, let them take the lead in arranging the transportation.

Encourage the person to register to vote. Some of the facilities in our area are getting better about giving people the opportunity to register to vote. Be sure to ask if consumers are registered to vote, if they want to register. It's a great way to put voice to issues that they care about.

Introduce to ADAPT. One woman I worked with had a strong heart for civil rights. I told her about ADAPT. They visited the facility and they talked about what ADAPT was and her possibly attending an ADAPT meeting.

Offer advocacy classes at the center.

Self-advocacy, systems advocacy is one of our core services. Even if it's just a one-time class, the initial class can be thought provoking and put into context in understanding of why the work the two of you are doing is so important on both an individual and system -- systems level.

Next slide, please.

Mobility travel training. Travel together or meet in the community. Get out, get out, get out as much as possible. If they are learning or relearning public transit, encourage them to do so and if need be travel with them.

I met a consumer at a far bucks a couple of weeks ago, he took paratransit and he enjoyed his coffee and me my tea.

Another consumer I met with the his apartment complex. He arranged his own transportation as well and we traveled around the neighborhood where he would soon be living.ing is important, but especially if someone is newly disabled, helping them gain the skills for vehicle transfer is key. Even if the person is not newly disabled and transferred to their vehicle previously, allowing them to practice the skill is really important.

And psychologically, both physically and psychologically towards regaining their freedom.

Okay. Next slide, please. Manage management.

Many folks I have worked with have been resistant to putting together a budget. Surprise, surprise.

I have found a good deal of the time, it's because they haven't had to deal with their own personal funds for so long, the concept seems foreign.

So assisting them no move fond the fear of not knowing and simply regain the concept of money coming through -- coming in through like their SSDI check and money going out for their bills can go far when helping them back to their lives of independence.

Support the person in opening a bank account. Offer to go to the bank to open the account or it's a great time for a trustworthy family member or trend to do that as well.

Teach skills in online banking, auto pay and more. I just say auto pay can be so helpful, especially for someone who is coming out of a facility, and feeling overwhelmed.

Next slide.

Socialization. Offer a peer group for wanting to transition out and for those who have less facilities. If you are able, offering a spear support group for those who want to get out and those who have gotten out can be vital in transition. A group like this can be true peer support whereby who has gone through a similar experience, offering to help to another who has gone through that experience, it's the crux of independence living. Invite facility residents to the center for home cooked meal. Can you imagine a home cooked meal after eating the food at a facility for so long. I number of a centers who ever that, and besides the gray food, a chance for them to be around and interact with the folks outside of the facility is really nice. Again, any chance you get them out of the stagnation, be around people who are living lives outside of the institution, allows them to experience what possibilities exist beyond the walls of nursing home.

Match up with individual peer mentors, someone who transitioned out or has a similar disability.

I have seen the curiosity and interest of consumers when meeting someone who got out. How did they do it? How did they make it on their own? Also when a person living in the community joins me at the facility, who uses the wheelchair, and my consumer who is in the facility also uses the wheelchair, it offers camaraderie. Seek out churches, old friends or community classes. Talking about what churches they may not -- they may have attended or old friends is to have more trustworthy people to check in it's also absolutely essential to acknowledge the grief of leaving as well.

This past fall, I was with one of my consumers when he was set to go. As a monolingual Spanish speaking man, his isolation was even greater in the facility where English. His eyes teared up and he cried as he hugged many people, including the nurses good-bye. It's our responsibility to understand that the community of nursing facility is not necessarily a chosen community for the consumers. It is the one they have. And that they had. So ask folks how they feel about losing their nursing home community. Talk about specific people who were special, who they would like to go back and visit.

My guess is folks have had to check out their feelings. Checking in. Taking responsibility for one's actions and reaching out to other community members, building community that will be vital to remaining the community. Invite friends from facility to new home.

Problem solve ways that they can reconnect.

A number of years ago, I worked with a gentlemen who was really -- who really wanted to get back in touch with (No audio).

>> TIM FUCHS: We will troubleshoot this and we will start again in just a moment.

Okay. It looks like we are back up and running again.

All right.

Yes we are. Thanks Rebecca, you can go ahead.

>> REBECCA PAYTON: No problem. One of the other approaches that we found really helpful is again introducing the peer-to-peer approach here. The peer mentoring where you arrange, you know an outing or you arrange an interaction where somebody can be paired with a peer and see who has an attendant as well and see how they are effectively managing their attendant services. You can see somebody else who has managed that.

Offer skill building and how to communicate needs in a way that's respectful to self and caregivers and setting appropriate boundaries and identify or knowing the difference between assertiveness, versus aggression. These are all very interrelated. I view them as interrelated and dealing with all of them at once. Again, the difference between assertiveness and aggression is a fine line and it's in -- and it's why it's very important to teach and model it, even in your interactions with the individual. People watch each other. Assertiveness is not raising your voice and being firm with what you want and explaining what you need. Aggression is quite the opposite. It might be yelling and threatening which is really going to -- it's going to negatively impact your attendant services. So -- and I can't -- again, tell you how many times this has been a huge problem for those transitioning and trying to remain in the community.

Next slide.

Organization and management of response inter. These are examples of things that are priorities and need to be managed and scheduled.

Offer skill building and how to order medications. Keep appointments or call if consumer can't make the appointment. It doesn't hurt for role playing here. You can be the doctor's office and the consumer could be calling to schedule an appointment. Reschedule it. Very, very helpful. Maintain, a calendar for medical attendant. I suggest developing that calendar. Again, the more you can get people engaged in the process, the more successful the transition will be. So actually, you know, like I said, develop or create the calendar of the person's medical appointments and their care plan, their attendant care plan.

Talking to the pharmacist. These are other opportunities to practice the interpersonal skills which we said are so critical to the successful transition.

Next slide, please.

Community resources.

This is sharing information and resources on practical resources, such as the local Social Security office, the person's bank, the bad banks, the food delivery services and community engagement resources are what -- -- the persons libraries and clubs the community resources, and what I want to reinforce here are what is going to connect the individual with the outside world and that's really going to have a huge positive impact. The more resources and the more community supports that people have, the higher probability, that they'll be able to live independently.

From there it could be a springboard to a club, but the important piece here is to -- for the person to be able to meet people with similar interests.

Next slide.

Skills for safety and survival. While I kind of at first put this up with money management, it's really not fun to go over this, but it's so important. You never know when these things, these natural disasters could happen. And this -- this kind of skill building needs to happen before the transition. They need to have these things in place before moving in. A lot of people can get disaster alerts on their mobile phones now.

Create an evacuation plan. Again, not just talking about it, but actually creating the evacuation plan, creating an emergency list. That list needs to be done before moving in.

Communicate with first responders. Again, -- if I were a first responder, what would you tell me?

There's also.

We need to see if they are accessible over time.

Extreme cold, extreme heat, on a smaller level, what if your power goes off? What if you are charging your power wheelchair. Do you have a manual wheelchair as a backup.

What if your air conditioning fails and it's 98 degrees? How do you keep cool and hydrated? I don't know if you are from New York, you remember Hurricane Sandy where you, know, a large number of people with disabilities were trapped in the high raise buildings and it was -- so you just never know. These things do occur. It's important to plan.

Safety routines. Again these might seem a little mundane but they are very important. Maintain smoke and carbon monoxide alarms. I think it's important that we check the smoke and carbon monoxide alarms when we are visiting our consumers' place. That just reinforces it, it reinforces the importance of these safety routines.

Keep a fire extinguisher easily accessible. This could have been the reason, that might have been shared with you, why someone had to enter a facility. Not keeping clutter to a minimum. Falls are a big reason for people going into nursing homes. How are emergency responders going to get in? This is a very important one. Too many of our consumers put themselves at risk, because they haven't kept clutter at a minimum.

Turn on burners only after pots and pans are in place. And turn on banking and other cyber accounts.

Being able or knowing how to check your bank account online or even through the telephone system can make sure all transactions are accounted for can identify problems early.

Household management, next slide. Offer skill building and how to cook and organize a kitchen, organize the pantry and the refrigerator and store food properly in consumers or plastic perhap, clean Vess tables, fruits fish and meet before eating and cooking. I think is an important one and always we are not just teaching how to do these things but also explaining why. Why is it important to clean your vegetables and fruits and fish before eating. You don't want to get sick from spoiled food and how to read and follow recipes and how to use the stove, oven and microwave. I find this one to be a very, very important one. And doing your laundry, and making sure you are putting money on your laundry card.

Next slide, please.

Household management continued. Get rid of trash.

This I find to be one of the two most important ones.

This is a quality of life thing. You -- no one wants smelly garbage, you know, piling up in their house and this could contribute to the clutter issue that we talked about, it could attract insects. You need to know how to separate your garbage and recycling. Take care of floors, sweeping, mopping, vacuuming and shampooing rugs as need. Take care of furniture, dusting and polishing as needed. And taking care of the bathroom.S disinfecting the toilet bowl. This is a health and safety issue. And it's really important so. It's really important to go over what kind of supplies are you going to need to make sure you have a health and safe environment here. Manage general tasks organizing and storing household goods and cleaning supplies. These are some important skills for people to so they can enjoy their home. If you have been in a nursing home for years, you deserve to be in a safe, clean, and healthy environment and enjoyable environment.

Next slide.

>> Starting anew.

Not only assisting the person to get out of the institution, but also getting the institution out of the person. I think this phrase is pinnacle in this work. The more we create opportunities for consumers to learn or relearn the independent living skills that we discuss today, the better chance they will have not only to succeed in life, in the community, but to live a more engaging authentic life in the community.

Next slide.

What if -- so how do I do if this center is not doing a lot of transitions? I'm thinking that since the implementation of the fifth core service at most centers are transitioning folks out of institutions, however, if institutions are not -- or if centers are not quite at that place, where they are transitioning folks out, develop a peer support group and invite people from the institutional facility. Let them know what groups you have -- you are having and ask her or him if there is a place to post a flyer or speak directly to folks she/he thinks would enjoy your group.

Ask facility social workers for referrals to your IL Skills program. This is a great way to make the connection and have folks start working on their independent living skills.

Offer to do a group at the local facility. Join one of the resident meetings and bring in prevalent information. Or join an ice cream social.

Ask your local ombudsperson program for referrals. Local ombudspersons have a pulse on what is going on in facilities and are a good resource for finding referrals.

Next slide, please.

>> TIM FUCHS: Okay. That brings us to the final Q&A. Nice job, Jane and Rebecca. We'll open it up for questions and as always, you can use the chat box, either in the webinar or on the CART screen.

We have also got the audio questions working. So if you are on the phone, and that's been working for you, and you want to ask a question, you can hit star pound. So it's star pound and you can ask a question on the phone. Okay so I have got some questions that rolled in while we were talking.

And let's see, Alexa asks, regarding budgeting, does anyone have ideas on how to help people who have accumulated debt while in the facility? I hear a lot of how do I fix my credit when the facility takes my benefits? I will start with you, Jane. Jane, do you have any advice there?

>> JANE SCHIELE: Wow! That's a good question. I -- I don't have anything off the top of my head. Do you, Rebecca?

>> REBECCA PAYTON: Actually -- so they are still in the facility is part of the question, right? And what they can do to repair their credit while they are in the facility. That's very difficult because as the person with the question said, most of their money is going to the nursing home. That's something that, though, you can talk about and create a budget for, for when the person is out of the nursing home and include -- try to include some money every month -- to pay towards those, you know, those debts that are looming. Those looming debts.

>> TIM FUCHS: Okay. Good. The folks from disability rights and resources offered that they use a budget calendar. It's a great resource they have through -- I assume it's Alabama extension which is a resource in their state. They say it gives them the opportunity to ask about pay day loans, Title loans and other traps that people can get into.

I also -- I know that the folks that -- the consumer financial protection pure row, CFPB, it's a relatively new independent federal agency and they have been developing a product called your money, your goals and they are actually just now tailoring one specifically for people with disabilities. And it talks about a lot of this. Why you might want a bank account. How do avoid predatory practices and other types of financial crimes and financial abuse. So that's something. Be on the lookout for that. We are helping them to get the word out to CILs and people with disabilities. So that might be a good resource as well.

Okay. Let's see, Kathy offers that she tries to give her consumers an idea of the things they might need in an emergency. She's even given out go bags for being ready for emergencies once you are in your own home. And the folks at DRR alabaster said consider checking with your State Department of health. For our center, we were provided with emergency prep kits that we gave to our consumers and other individuals. She said they also did an emergency preparedness preparation. Good idea there.

Julie is wondering how much time is provided in a typical transition? What is the average hours spend on a person per day when you assist with this kind of stuff? And the average amount of time that they are successful, a year, question mark. We know it depends. How would you answer that Jane.

>> JANE SCHIELE: Did you want to say something, Rebecca?

>> REBECCA PAYTON: I was just going to -- that's a really neat question too. But it really does differ. Everyone is unique. Every plan or transition plan or -- will be different.

Some -- but it is often ironic that some transitions that you suspect will be very quick and easy, wind up taking the longest and being the most challenging and vice versa.

>> JANE SCHIELE: And I found -- this is Jane. I found that, you know, there might be a part of the transition that is just like a lull, and there's not a whole lot going on and then boom, there's five different things we are dealing with. Some things with housing come up or looking into a home health agency, and maybe working on some issues and it fluctuates.

The time of transition depends on the individual. I let the person know that this can take up to a year or more. So just to get that person's, you know, site and understanding that it's going to be a longer process tomorrow.

>> REBECCA PAYTON: And after you do the assessments, the needs assessment with somebody, the initial needs assessment, you can gauge and let that person know when you are experiencing what this transition will look like in terms of time.

>> JANE SCHIELE: Yeah.

>> TIM FUCHS: Similar question from Alexa. In your experience, how long it can take to acquire different levels of skills and I -- take a shot, if you would like. I think that might be difficult to answer in general, Alexa but if you want to ask here or follow up later in regards to specific skills, I'm sure we would be happy to put something together.

Alexa also passes on a question from Doris at her center. Doris asks do any of you all offer pretransition independent living skills classes before someone is fully committed to making the transition and then move to more intensive skills classes while you are in the transition process? Do you all do any preliminary work like that, with folks in the facility?

>> REBECCA PAYTON: Yes, this is Rebecca. Go ahead, Jane. Go ahead. Please.

>> JANE SCHIELE: I was just going to say, I love it when folks come to classes or I can help to get them involved in the community, as far as like, our center offers some classes on how to keep your housing. We found over the years that we have actually been able to acquire some housing vouchers and people get into housing, about you then they lose the housing.

So something like that is great when we can offer it. And doing that at different levels, whether they are, you know, fully ready to go, you know, commit to the transition or not, I think is great when they can get out and engage in those kind of classes.

Okay.

>> TIM FUCHS: Rebecca, what were you going to say some.

>> REBECCA PAYTON: I was just going to say that a lot of our -- we don't necessarily have formal classes. Our transition coaches or our IL team as a whole as a team -- it's always a team approach, are providing these independent living skills pre, during and post transition.

>> TIM FUCHS: Okay. Great. Okay. Lavesta asked, I'm a new staff member and our center is growing transition services. To learn more about the step-by-step process and logistics would you all recommend the ABCs of nursing home transition? Is that where I should start? And Lavesta, yes, that's a great. Sharon Finney from ILRU shared the link to those materials earlier in the call. But you can also get them on ILRU's website, and -- there's Sharon. She just shared them again. Start there and let us know how else you can help. As the IL-Net, the folks from ILRU and NCIL and APRIL, we don't just organize these kind of concrete trainings. We also do a lot of TA work. So check out the materials and let us know what else you might need or what other questions you might have, but like I said, you've got the PowerPoints. You've got work sheets, schedules, you've got live videos of presentations with tons of real world stories. So, yeah. Check that out and let us know what else we can do. All right.

We might have time for one more question that we sneak in but we are going to have to wrap up in the next minute or so here. I see a few more people typing. I will try to sneak one more in.

In the meantime, I will go ahead to this slide 36 here, and here is the -- that link to the evaluation that I mentioned at the beginning of the call. I know some of you are in small groups, but if you could fill this out, as an individual, we would really appreciate it. We want to hear from each you.

And before we close, I want to do a couple of things, and first of all, I just want to apologize again for the technical problems today. It seems like we had a few different things going on and I appreciate your patience. We will have a fully archived version of this training, that you all can access within 48 hours. Usually much sooner on ILRU's website. I also have, of course, the full transcript for folks that experienced delays there. So please let me know. The archived copy you can access on your own but if you would like a copy of the transcript sooner than, that I would be happy to share it with you.

Oh, let me see if we can sneak in this one question, since we started a couple of minutes late. This person says, we have a situation where administrator of the nursing home is also the guardian and isn't this a conflict of interest for the consumer?

Wow!

Jane, have you ever run into anything like that? Do you have any advice for them?

>> JANE SCHIELE: Wow! That's amazing! Yes. That's a conflict of interest and my -- and my perspective, it's a conflict of interest, especially -- I mean, how is that for that individual who is trying to get back out? I mean, if they do want to get back out? So, yes, I do see that as a conflict of interest. You know, you should have local ombudsman that you can talk to. They are the rights -- you know, people that can discuss the rights of consumers that are living in nursing facilities. It might be a good idea to talk to them about that.

>> TIM FUCHS: Great advice.

>> REBECCA PAYTON: I agree with Jane, definitely. Mm-hmm.

>> TIM FUCHS: Great. Thanks for letting me sneak that in. It's a little after 4:30 on the East Coast here, so I will start to wrap up. Jane and Rebecca, thank you so much. Thanks to you all too for your patience with our slow start, but really, a great presentation today. Really good advice, and I appreciate the work that you all have put into this for the last couple months and weeks to get us ready and to share your experience.

So really, my sincere thanks and to all of you too for taking time out of your day. Thanks so much for joining us today, folks. We are going to go ahead and close. I hope you all have a great afternoon. Bye-bye.

(end of session).

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