IL-NET T&TA Center for Independent Living Presents

The Role of Individual Advocacy for CILs & SILCs

Presenters: Tami Hoar, Mark Dixon, Sarah Goldman

June 4, 2024
Live captioning by Ai-Media

MARY-KATE WELLS:
Hi everyone, welcome. We will give folks a couple seconds to log on. Awesome. Well, hi everyone. Welcome to today's IL-NET webinar, the role of individual advocacy for sill and sills. My name is Mary-Kate Wells, my pronouns are she her, and I am the program director at the National Council on Independent Living or (indiscernible) for visual description of myself I am a white female with short reddish hair wearing over the ear headphones, and I will be moderating today's webinar.

Just a few accessibility considerations today. Captions are available for this webinar. Two click show captions in your zoom menu bar to turn them on, we also have captioning running on an external link. The link will be put in the chat, and you can click that to just size of fraud, color, contrast, and other features.

ASL interpreters are available today, and should always be visible. If they are not visible, or you are having trouble seeing them, please let us know, and we will help troubleshoot that with you.

We also have Spanish interpreters available today. In order to access that, you can go to the zoom bar on your screen and choose the language you would like to hear the presentation. Public chat is turned off today, but you can chat with the panelist and the host. We ask that you reserve the chat for questions of technical support only.

You can use the Q&A box to submit questions for presenters. To submit questions at the bottom of your screen, you can click the Q and a box, and you will be answering questions at the end of the webinar. And there is a number of ways that you can engage with the Q&A.

You can either put your question in the box, or you can email them to me if that is more assessable. My email is Mary-Kate@NCIL.org. Next slide, please. Today's presentation is brought to you by the administration for community living at the department of health and human source services in conjunction with the IL-NET. Next slide.

The IL-NET training and technical assistance center is operated by higher LU in collaboration with NCIL, April, and the University of Montana, and on the screen as the logos of the four organizations. Next slide.

The IL-NET training and technical assistance Center provides training and technical assistance to Center for Independent Living, statewide Independent living councils, and those state entities. NCIL is a partner of the IL-NET center and we support the coordination of these webinars. Next slide.

Today we hope that you will learn and take away the following objectives. First is training strategies for independent living staff, and consumers on individual advocacy. Examples of consumer engagement and individual advocacy, and how individual advocacy can lead to systemic change. Next slide.

As always, we hope that at the end of the webinar, that you please fill out our evaluation form. The link will be going in the chat, and there is also a QR code. We appreciate any time that you can give us to do that. Next slide.

Alright, so getting into it, today's topic is the role of individual advocacy in centers for independent living. And we have three awesome presenters today
to offer three different perspectives.

First we will hear from Tami Hoar, the Executive Director of Summit independent living center in Montana, and she is going to talk about the role of individual advocacy from the center perspective. We are then going to hear from Mark Dixon, and advocate from Virginia, to hear from the consumer and self-advocate kit -- advocate perspective.

Lastly what we hear from Sarah Goldman, the director of administration and use initiatives with the Florida Independent living Council. And Sarah will talk about how individual advocacy has led into systems advocacy in her experience.

Without further ado, I am going to add invite Tami onto the screen and kick us off with the first speaker. Go ahead, Tami.

TAMI HOAR:
Hi, I'm glad to be here today. I'm Tami Hoar, Executive Director at Summit (indiscernible) in Montana, we are one of four centers for independent living here in Montana. And today, I would like to introduce myself using the pronouns she her, and I am a middle-aged white woman.

And as a person with a non-apparent disability, I am often overlooked as having the lived experiences as a person with a disability. But for most of my adult life, I have spent time in the emergency rooms and in doctors’ offices going through lots of prescription drug trials, different things trying to find the right combination of things that would work for me.

I have missed lots of family events, community events, had to miss out on a lot of work, left half carts of groceries in stores, different things like that. I do have that experience of, you know, those challenges and those barriers.

I've spent, since the early 2000's in independent living here in Montana. Several of those years as an executive director, at another exact center for independent living, and I stood away for a few years and went to work at one of the largest corporations here in Montana. Got some experience as an HR administrator, getting a lot of experience in employment law, working very closely with the legal team.

And then after couple of years and just really missed independent living and working within the disability community, so I found myself back here as a director at Summit independent living, and really can't be happier. So excited to be here.

So go ahead and go to the next slide, please. So, I'm here today to talk to you about, more just individual advocacy start. It is a core service, but where does it actually begin? It starts with everyday conversations. Every day, and every conversation in every communication that we do, and it is really part of all of our conversations, and in mic medications with staff in everything that we do we talk about individual advocacy. It is why we are here.

It is the consumers, and we are consumer directed. Our IL philosophy is nothing about us without us. It is fundamental to why we exist, who we are, where we come from, it is how we ensure that our mission and values align with this philosophy by having these ongoing discussions about the services that we provide, and how they are accomplished.

So, how do we do that? It is a part of everyday, it is a part of who we are, and the conversations that we are having in the hallways is part of the communications that I send throughout all of the emails that I said, it is part of our staff meetings.

It is the core of what we do. So, it really begins in every day, it is embedded in everything that we do. Next slide, please. So, it really does begin with our new staff. When we are hiring a new staff person, the most important part of hiring is in the orientation process. And it is more than just getting to the paperwork when you hire someone new.

You don't just hand off the paperwork and have them fill out their W-4's and their I-9's and those things and call it good, and send them off on her way. It is a plan process that includes as self-paced training. We use ILRU. There is such great it's (indiscernible) training there. Some of the videos, while they might be older videos, they are still so great.

They really capture the movement, what it was like for Ed Roberts, and all of the June (Unknown name), -- Jim (Unknown name). All those initiators of the IL movement. Those videos are our history, and where our disability roots came from. It is so important for new staff to get that, and you have understanding of where we come from, and those self-paced trainings through ILRU really give new staff that important background into where they are going to go.

So, we do a lot of background work. We also give new hires time to acclimate to where they are. Understanding our policies and procedures, and really understanding what does it mean. Where are you as a Center for Independent Living really undertaking an understanding the philosophies of who we are, and what does it mean to be consumer directed.

So, we do all of that before we send someone in to meeting with the consumer. We also often pair up new hires, and do a lot of shadow work with current staff, and sitting in with those staff while they are meeting with new consumers, sitting in on phone calls, really to understand how you do intake paperwork with consumers. How you ask questions, how you let the consumer drive the conversation.

A lot of that is done before we send a new staff person out into the wild, and have them start doing the work on their own. And then there is a lot of follow-up and men touring with those -- mentoring with those more senior staff to make sure that they understand how to move through these processes with the consumers, and making sure that you are staying focused on the consumer.

That the consumer is the one driving the services, and driving where their goals are going, and where the services are growing. Next slide, please. So individual advocacy at Summit, so through a variety of IL classes, some independent living offers the opportunity for individual consumers to gain new or improved life skills such as self or individual advocacy in our explanation of our goals.

What does that actually mean? When someone comes here, or they have been referred to was, or they come to us on their own, they have an appointment with an IL staff person, and they are really just sitting down and being able to tell their story, and talk about what is happening with her life.

Sometimes she'll come to us and they just really kind of don't know what they are asking for. They just know they need some help, or someone told them to call us and go see Summit. Through the conversations of letting them tell their story, a lot of things start to come to life that maybe they need help with budgeting, or they need some help, maybe the living situation that they are in is not where they want to be. So sometimes it is a whole host of things.

And then were talking through it with the IL staff person, they can start to set out a priority of what is most important first, and what are some other things that they want to work on, and maybe they have goals of going to school, finding a different employment, or going into employment.

It is really being able to sit down and really talk through things and really decipher themselves what their goals are, and then being able to set that individual plan, and how are they going to meet those goals.

So then setting up objectives, and water each of those objectives going to do to meet that goal that they set for themselves. And again, it is not as staff person directing the conversation. It is through the consumer telling their story of what they want, and where they want to go.

And this really, this brings me to the quote that I like. My favorite author, Bernie Brown, she is a research psychologist, but she does podcasting, and she does some other Ted talks in different things, but she has some really good insights, and she has is quote that I like. She says "when we have the courage to walk into our story and own it, we get to write the ending." And that again is by Bernie Brown, and that is where I see that our IL staff do with consumers that come in.

Is they really help people identify for themselves what their story is, and where do they want to go with it. It is not the staff, it is not our staff who get to say what the ending is, or where the path is that the consumers are going to go. But they are there to help them to decide where they want to go, and help them write their story. So, it is about that individual advocacy, building up their self-esteem, their self-determination. What do they want to do? What is their goal, and how do we help them get there? It is not the staff saying this is what you should do, this is what I think you should do, it is all about the consumer and what do they want to go, and we help them get there.

We help them outline the goals, help them outline their objectives of how to get there. But it is really all about the consumer, and if they choose to go that way, great, and we will help them get there. Next slide, please. Individual advocacy summit again, it looks like stuff offer individual consumer meetings for guidance.

Sometimes it is helping to get some complicate it processes. So, filling out paperwork. Medicaid paperwork, Social Security paperwork. That is daunting for anyone! It does not matter your educational level or anything like that. If you are in a stressful situation, those kinds of things are unmanageable to try to get through. To just look at it and just start on those processes is unbearable!

And it is hard to start. So, a lot of times, what our staff do is just sit down with individuals and just start the process.

Just take a look at the paperwork. Help to start to answer the questions. In helping the individual see that it is just answering a couple of questions, maybe just going through the first couple of pages during the first visit. And maybe come back and finish it another day. Our staff do not do it for the consumers. We do not fill out the paperwork for them.

And we do not act without the individual present. Even with our release of information, which does not give us permission to do anything for the consumers.

We are always doing it with the consumers. So, if a phone call has to be made, we can talk with the consumer, help them build up their self-esteem, and their confidence so they can make the call themselves. We can be there with them while they make the call to be there for their support. But we do not make the call for them.

We can help a mentor them and coach them on how the call will go. Maybe give them some options of, well, they might ask this question. What will be your answer to that?

Maybe even doing some role-playing with them so they can have that built up in them and maybe some muscle memory of, yeah, I have practiced this so I can do this.

But we do not do for the consumer. That is an expectation they have upfront when they come in with us. We do not have any magic wands, we cannot jump people to the front of the line for housing or anything like that. But we can help.

We can help fill out paperwork. We can print out some applications. We can do those kinds of things. But we do not do it for them.

And that is really important for consumers to understand that. Because sometimes they have us thinking that we are the expert or we were told to come to you and you will do it for us. So, that is an important expectation that needs to be set in the beginning.

And that does not help anyone in the long run we are doing those things for them. Or if we are making calls for them or if we are just filling out the paperwork and answering questions for them. That is not what we are doing. That goes against the nothing about us without us.

So, it is really important that we instill that in our staff from the very beginning. That is not individual advocacy. We are not helping prepare people for any future situations if we are doing that for them.

Some things that we can help consumers with and that we do a lot of, is helping people maybe compose a letter to their landlords or maybe like an impact statement, something like that that are really hard to come up with on your own.

Especially if you are stressed and in those situations, it is hard to compose your thoughts. So, those are some things that our staff have helped individuals do. Again, that support and helping people compose their thoughts and getting them down on paper. Again, we are not doing that for them. You're not putting words in their mouth. We are just helping them compose the thoughts they already have and getting them in an order on paper.

Those are lots of things that we can do with that with our folks, so. Let's go to the next slide, please.

Individual, oh, there you go. Consumer driven service. So, individual advocacy is you do -- Easy to become personally invested in as staff. Staff have to be careful about not to take on the decision-making.

So, helping consumers identify their goals and identify those objectives, those steps on how to meet those goals, staff have to be very careful to take that step back and make sure they are not the ones making the decisions for the consumers.

But really helping the consumer identify ways that they can meet those goals and helping them set out a plan for that. Staff are there to mentor and prepare consumers for success, not just for their current situation, but for what might come in the future. That is what I was just talking about. About how we do not do it for them, we do not take that ball from them and just do it for them. That sometimes might be easier.

Because we have seen those situations. We have the experience to do that. But that is not helping them on that next situation comes up. The next time they have to call the power company or the next time something like that happens.

We are helping them build those skills so that they have it for the next time something comes to that. So, follow-through is not a decision for the staff. If a consumer chooses not to follow through on their goals or their plans, that is their choice. And that is, again, consumer driven.

It is consumer choice if they decide to continue with the path that they have set up for themselves or not. And that really is dignity of risk.

That is consumer choice. That is consumer driven. That is what we are about. It is all about that choice to do what they choose.

Whether we feel it is right or not, whether we would want that for them or not, that is their choice. And that is the dignity of risk that we all have, everyone has that right to make those choices.

That sometimes really hard for staff to sit back and know that someone is not following through with the suggestion that they have made or with some really important phone call that they need to make or following up with some paperwork.

Or an appeal process. But that again is the consumer choice to do that. OK, next slide, please.

So, individual advocacy, how some Independent Living does it. I sort of mentioned this, we start with setting expectations. We do not hold any magic wand. Paperwork is overwhelming and we do help guide consumers through the process, but we do not do it for them. We do not just take it from them and fill out the answers, we do help through it, and we can be there to help answer questions or to help clarify how something is stated.

Or to help them come up with the way a question might be worded. it might be confusing. So, we help them answer those questions, but we do not do it for them. One of the most important things we do is we set reasonable meeting times and we will consumers to it. We set ourselves to it. If we have set a meeting for 2 o'clock, we are ready and prepared to have the consumer come in at 2 o'clock.

If we say the meeting will be an hour and a half, we hold it to an hour and 1/2. It is very (indiscernible) to go through this paperwork and very challenging when you are already stressed and you are in a situation that is adding stress to it, your add-ons that you are a person with a disability, you have other challenges, you have health conditions, and you are now in the stressful situation.

We have to be very mindful with that with folks we are working with. And help them understand, too, that it is OK to set this into chunks of time and to keep working through that.

And it is OK to do that. This also helps empower the consumers to let them know that we are holding to what we say we are going to do if we are going to meet you at 2 o'clock and the meeting will be an hour and a half, we will hold to that.

It is also good for our staff. I emphasize that with our staff, too, that we need to take care of ourselves. We need to pay attention to our health and our well-being and to be able to be there for the next person that comes in.

And we cannot do that if we are not taking care of ourselves as well. Next slide, please. So, individual advocacy and action. We have a consumer who this person has participated in several of our different services, so classes, some social activities in different things. And some individual advocacy.

So, Consumer "J" has been meeting with an IL specialist over the last few months. Consumer "J" was unhappy with his vocational rehab counsellor. Consumer "J" felt his VR counsellor was not listening to him, so he did not feel supported.

So, on his own, Consumer "J" went to the supervisor and expressed his dissatisfaction with his vocab rehab counsellor. The same things he told us, he did not feel supported, he did not to listen to. He felt like his vocab rehab counsellor was treating him like a number. Like a case number and not listening to them. So, he told all of these things to the vocab rehab counsellor, and he ended up being reassigned to a different vocab rehab counsellor.

He told me the story himself will stop and he is really very happy with the new counsellor that he has.

This is a perfect example of individual advocacy and action full, so we develop that on his own. He took the initiative after being through these classes, coming to these activities and things with us, that he had that initiative himself that he felt like he could do that on his own.

And now he is really happy with his vocab rehab counsellor.
, Please. So, keeping an eye on the ball.

It is important to remember who should be holding the ball. It should always be the consumer. Once staff take the ball away, the staff is ultimately taking away the consumer (indiscernible) and the consumer self-determination. The consumer should always be the one holding the ball. The efforts are always consumer driven, no matter the outcome.

So again, dignity of risk. Nothing about us without us. It should always be the consumer who is holding the ball, the consumer should be directing the services. And never should it be the staff person who is holding the ball and making the choices and making the calls and doing things that the consumer.

Or making those choices. It should always be the consumer who was holding the ball. And that is what I have, and I will turn it back over to Mary Kate. Thank you!

MARY-KATE WELLS:
Thank you so much, Tami. It looks like we have some great questions for our discussion. I will invite Mark to turn his camera on.

Awesome. We can see you, Mark. And I will hand it off to you.

MARK DIXON:
OK. Next slide. Good afternoon, my name is Mark Dixon. I am from West Virginia. My pronouns are he and him.

Which is part of the (unknown name) region. I am an African American and I am wearing glasses. Today, I am going to share how self-advocacy has been a part of my entire life.

I will share some of my stories€¦ From public school to college and the community. The pandemic€¦ Next slide, please.

Start, I started advocating for myself in elementary school and continued in middle and high school.

Elementary school, SCA presidency. Middle school, extracurricular activities. High school, mathematics course and Ramp.

Yes. Next slide. I did not read that, let's go back to the previous slide. When I was in elementary school, I told my assistant I wanted to go for the Council Association president. I came home and when I came for my campaign the next morning, I went to different ones around the school building. -- Rooms. And I asked people to vote for me.

When I was in middle school, extracurricular activities were important. I would talk with the teachers to see if I could participate in their activities. Which include operations€¦ They said yes. After high school, they offered (indiscernible) did not offer geometry Track, geometry class for special education students. I went to the guidance counselor, and my mother a certified economics teacher to teach me geometry at home.

My guidance counselor called the school board office and told us that mother (indiscernible) independent study. Then I had to sit with my mother four hours a day during the summer for the junior year of high school.

For the week of summer long. I earned a good grade. As I was about to graduate from glow Chester has glaucoma (indiscernible) -- glow Chester high school. I wrote the superintendent of the school; a memorandum specify that I needed a ramp to allow me to access the stage.

The assistant principal in charge of graduation made the, made sure that ramp was available for me, for the use of the standing. The night of the graduation ceremony, it was raining. So that everybody uses the ramp to safely get their diplomas. Next slide.

As I was transitioning from high school, there was a lack of information given as to available programs for people of disability. (indiscernible) how the independent center of northern Virginia suggested that I apply for the Virginia (indiscernible)...

It supports in the community. This was my first time communicating with the Center for Independent Living. First, I studied (indiscernible) community college. First (indiscernible) for microcomputer application certificate.

And then (indiscernible) associations degree. The Virginia community college system was (indiscernible) for disabilities. For example, when I was part of the (indiscernible)... Allowed me to do presentations, demonstrating how to do (indiscernible).

Next slide. Three years after I graduated from high school, the CNL, the local CIL starter, (indiscernible) outreach program. I learned about (indiscernible), and achieved a better life experiencing it on that account. Then Linda Gurley from (indiscernible) suggested that I go to their medical clinic program for independent living.

The topics included nutrition, finance, (indiscernible)... Outreach program has benefited me because I got medical, (indiscernible)... Through our state protection and advocacy (indiscernible). I got the opportunity to meet with the (indiscernible) account.

(indiscernible)... That did not charge a maintenance fee. I received a scholarship from (indiscernible) the financial Center for Independent Living years later. I was asked to serve on their committee regarding (indiscernible) and served as the community secretary.

Next slide. I attended independent living skills at independent living center in northern Virginia, and I participated in their virtual training programs. (indiscernible) for independent living in Virginia. I learned about how to be involved in a date (indiscernible) coalition for people with disabilities during the height of the pandemic.

The independent Center of Northern Virginia offered virtual independent living skill training events. (indiscernible) I was allowed to attend the center (indiscernible) even though it did not live in their service area. I learned about various (indiscernible) and one of the independent centers (indiscernible)...

Was advertising (indiscernible) and I attended a couple of these with fellow. I get an email for the (indiscernible), and she says that she was interested in building a coalition of its own. (indiscernible)

Register, educate, and user power. In 2022, I received (indiscernible) participant of the year award. Next slide. The ark of Virginia formed a self-advocacy (indiscernible), an alliance of self-advocates (indiscernible) 2021.

At first, (indiscernible) and then (indiscernible)... Then, a couple years later, the ark asked me to serve on their board. (indiscernible) representative on the Virginia Board (indiscernible). Next slide.

The pandemic (indiscernible). Thank you all for the many boards committees that focused, webinars, coalitions, which have been able to participate largely. (indiscernible) allowed me to connect with people with disabilities (indiscernible).

Lots of my communications (indiscernible) came from because of the sharing of information from an individual center of northern -- North Virginia (indiscernible) and The Arc of Virginia, when you are advocating for yourselves, you are advocating (indiscernible).

I would like to talk, because my father has served as a role model for me, because he had been advocating me all my life. Thank you. Next slide. Next version.

MARY-KATE WELLS:
Awesome, thank you so much, Mark. And you said it a couple of guy times I love what you are saying that you advocate for yourself, you are often advocating for others. I feel like that needs, I love that. So, thank you.

We have lots of questions going the chat. Please continue to add questions for our speakers in the Q&A box. And now I am going to invite Sarah Goldman to share about individual advocacy leading to systems advocacy. Thank you, Mark, and handing it over to Sarah.

SARAH GOLDMAN:
Thank you, Mary Kay. My name is Sarah Goldman. I am a director of an administration at the initiatives of the Florida Independent living Council. My pronouns are she and her, I am a young white woman with medium brownish hair. I am wearing a white shirt, and I am sitting in my office, in my wheelchair. I have a physical disability called cerebral palsy, and I just want to share a little bit of my story, how that led to my journey to individual advocacy, and then also how that has led to systemic advocacy, and my role working with youth here for independent living. Next slide.

I grew up in Connecticut, as I mentioned I have cerebral palsy. Growing up, my parents were amazing. I had the most wonderful family support. My parents always taught me to believe that just because I was disabled did not mean that I could do other things appears my age. I was (indiscernible) in school, but even though I was mainstreamed, I do that because I had a disability, that my experience was different, then my nondisabled peers.

For example, my afterschool activities, 2 to 3 days a week look like going to physical and occupational therapy while my nondisabled peers got to go to soccer practice, or dance class, and those are all things that I never really had the chance to really be a part of when I was younger.

Also having cerebral palsy, my muscles are very stiff, and due to the mobility aids that I use, navigating the snow and the cold weather makes minor muscles varies difficult it makes it very hard user mobility device when there is ice and there is no.

When I was 13 we moved to Florida so that I could have better accessibility, and also better mobility to be in a warmer climate year-round. Next slide. When I moved to Florida, I got involved with Paralympic sports, and so that allowed me to try different adaptive sports for the first time in my life. Such as swimming, wheelchair basketball, wheelchair tennis, track and field, and it was also there that I learned about the program (indiscernible) the leadership quorum and I will refer to it as YLF, so if you hear me saying YLF, that is the Florida Youth Leadership Forum.

While F is Ashley national program, and it is in 30 states, and it is a leadership training for students with disabilities currently housed here at the Florida Independent living Council.

And the delicate that our participants engage in a series of leadership training, mentoring and activities to build social and communication skills. And YLF participants in the history of disability rights movement, and also develop the skills needed for independent living.

I was 15 years old when I applied to go to their Florida Youth Leadership Forum, and it was my first trip away from home. Having a disability, my mom was my caregiver full-time growing up. She was the person who helped me get dressed, showered me, and helped me with all those other activities of daily living.

So, for me to go away from home for five days for the first time seem like a daunting task. But through YLF, they provide all the accommodations that I needed to be able to have this experience so that I had caregivers on site, and it was really the first time that I learned that I could have a life after school ended.

Kind of like what Mark was just talking about previously. Before I had attended YLF, I believe that I would be 80 years old, living with my mom and dad. I didn't think that there was resources or opportunities for me to go away to college, or to be able to work independently, and live in my own apartment, and through the Youth Leadership Forum, I was able to find that there were resources, and there were people that gentlemanly wanted to help me move onto the next phase of transition. I think the most meaningful part of the Youth Leadership Forum is that all of our delegates who are first time participants, they are assigned to small groups that are led by peer support leads.

These peer support leads are actually alumni of the program that have gone through these leadership forms themselves. They get this -- provide that peer support and that peer mentoring for first-time delegates. These small groups or where the transformation happens. It allows for deeper discussions about what they are learning, and it also provides meaningful friendships.

I have met some of my closest friends. I attended YLF in 2007, it is 2024 and I still have a whole network of friends that I met at the Youth Leadership Forum that are still in my close circle to this day.

One of our councilmembers here, Whitney Doyle, she is still a friend that I am in touch with. And I actually was a bridesmaid in her wedding a few years ago. So, it shows that when you find peers that understand the lived life experience of disability, how much that helps individuals feel connected and also embrace their disability.

Next slide. You might be wondering what my YLF experience had to do with the impact on my individual advocacy journey. As I mentioned earlier, I do not believe I was going to be able to go away from home or to be able to attend college.

But I was able to. I graduated from high school and attended the University of Central Florida in Orlando for my undergraduate degree. And Florida State University for my graduate program, both in social work.

With those opportunities that I used to learn how to advocate for myself, from going to YLF, I was actually appointed by the Gov. here at Florida I was the first youth that was ever on the Gov.'s commission on the jobs for Floridians with disabilities. As you, I was able to give voice to youth as they were transitioning out of school and into employment and what those gaps where and how we could better advocate for those things here in Florida.

After I graduated from Florida State University, I got employed with the Florida legislator where I worked as a legislative aide for four years. I was able to help so many constituents across the state of Florida. And study a wide range of policy issues. It was also a great way for me to not know what the issues are -- were with transition for individuals with disabilities and to help give voice to those policy issues.

Next slide. As I transition into employment, there were more barriers I had to face as a person with a disability. I will explain the graphic that is on the screen.

I call it my vicious cycle motivation. This is what happens when an individual tries to gain employment. So, we will go to the next slide so I can explain the graphic.

The diagram will go back on the previous slide in a second. But it is a circular diagram that reflects what happens, the vicious cycle, that often happens when an individual with a disability begins working. It is a circular flow that has seven text boxes.

And moves in a counterclockwise way. The first box is supplemental security income. So, SSI or Social Security qualification. That leads to box 2, which is often how you get Medicaid qualification.

Box 3 is now that you have Medicaid, you can secure your needed care for personal care assistance. But that also can look like other things like (indiscernible), which are employed -- employment related work experiences. That leads to box 4 which is once you have your support through Medicaid to live independently, you can actually gain employment.

But to box 5, you are -- earn too much money. From the income you are getting from your employment. Which then leads to box 6, you lose your Social Security. And in turn, your Medicaid eligibility and your care and supports.

Which leads back to the top at box 7, you have to give up your employment. You can go back to the previous side so folks can view the graphic. This is what happened to me. I applied for a full-time job and the legislator after I graduated from school. And I learned that if I made a certain amount of income, I was going to lose all of the benefits of Medicaid and personal care assistants that I needed to continue living independently. I had case managers tell me that getting my Master’s degree was a waste of time.

That it would be better for me to work part time because I would be at risk of losing my benefits. And I just knew as an individual advocate that was not the answer. That was not the end of the story.

So, I did a lot of research. And I found that 46 states have programs that allowed individuals with disabilities to keep their Medicaid while working. And unfortunately, Florida was not one of those 46 states. So, through my work and the legislator, I was able to help begin the process to get this done in Florida.

I remember telling my former boss at the time but if I worked for her in the legislator, that I would have to keep my income under a certain amount of money. And I will never forget that I thought she was going to fall out of her chair of disbelief.

She said if we work together, I want to help you fix this. Next slide, please. We can go forward one more, perfect. Thank you! It took us about three years, but with the help of other grassroots advocacy groups here in Florida and other individual advocates, we were able to pass a working people with disabilities program.

In the Florida legislator back in 2018. This allows individuals for disabilities! With disabilities who are on a Medicaid waiver here in Florida to earn 550% of the federal poverty limit, which is one of the highest in the country.

We actually modelled after Colorado here in Florida. Also, allows individuals to save up to $15,000 in assets. So, we are not penalized by the $2000 asset limit. And it also allows individuals to have a retirement account without considering that an asset.

It was through this that I realized systemic advocacy that I wanted to ensure that the generations after me, the youth after me, did not have to navigate all of these barriers that I had to go through throughout my transition journey.

Next slide. Here we are, full circle. We started with the Florida Youth Leadership Forum at age 15. And now my job, the Florida Independent living Council, is exactly that. I get to help oversee estate plan, which I will talk about in the minute for youth.

And as part of my role, I get to be our Florida Youth Leadership Forum director. So, I started in Tallahassee as a 15-year-old for the first time away from home and here I him as the young, 32-year-old, living in Tallahassee, helping youth and showing them that independence is possible.

That advocacy and finding your voice is possible. My role as a director provides the opportunity, again, to support and elevate the new participants delegates, with their individual advocacy journeys. And I tie in my experience with the legislator. Because every year, we take the Youth Leadership Forum participants to the state capital for a day.

Where they get to sit in the Florida House chamber and represent chairs and practice what a mock legislative session looks like. So, they get to speak about issues that are important to them and debate and vote on each other's bills.

Next slide. So, how does YLF relate to independent living. Throughout YLF, we sent her a lot of our workshops on individual advocacy and also the Independent Living philosophy.

We also do to our personal leadership plans, which empower participants to make their own choices and set their own goals. This is huge!

We have participants that come to the Youth Leadership Forum and they have been told by their parents what they can and cannot do. And it is until they feel empowered to know, what do you want to do three months from now?

What do you want to do one year from now or three years from now? What are your goals, what are your dreams? And for them to be able to use their voice to express that, our peer support leads are able to help them find, like, ways they can help find people to support them in that goal and also, once they get that, how they can achieve that goal.

There are other individual advocacy opportunities and systemic. I talked about them, going to the Capitol for a day. You also get to practice public speaking and introducing our speakers that come to the Youth Leadership Forum.

And then my favorite, disability identity discovery and pride. We also have a lot of participants, twofold, one that come to the Youth Leadership Forum and do not know that they have a disability.

Their parents maybe never told them due to fear of what they might think if they have a disability or what that might mean to the family if they find out they have a disability.

So, they think they are there to help others with disabilities. Once they discover that they, too, have a disability, it clicks. Blindfold moment for them. The second fold is the people that come that have been bullied in school, that have rough experiences trying to make other friends.

And really providing that community for them to know that they are in a safe place where they can fully express themselves and be accepted for who they are as a person with a disability is something that I just love getting to see every year.

Next slide. So, you might be wondering what happens after an individual leaves YLF. I know for me, I do not have a lot of resources. This is why in this day and age, this generation has so many great ways to get involved. I will talk about to specific ways. The first is the Association for programs for the role of independent living, hopefully many of you on this color familiar with APRIL, they provide something called the youth steering committee.

So, this allows youth to plan an entire conference for the April conference each fall. And they do everything grassroots. They plan the speakers, they plan all of the scheduling, the panels, and it is youth empowered. Again, getting them to use their voice, to get back on what is important to them. We have had several youth from Florida actually join the steering committee.

And be able to be on the executive committee to help plan that conference. They also provide the lead on collaborative. This again is just continued self advocacy and systemic advocacy training for youth with disabilities to help them become better advocates in their community.

Next slide. The second that is more specific to Florida and our state Independent living Council, is our youth committee. Our youth committee is comprised of your consumers from our centers from independent living. -- Youth.

It also consists of individuals that have graduated from the leadership forum. So, their alumni. We also have two Youth Court leaders who work at our centers for Independent living you are able to help give voice to some of the issues they are seeing with some of their consumers and what is important to use at their centers as well. -- Youth.

The youth committee members get to practice their individual advocacy by participating on the board. They learn Roberts rules of order and to be able to watch a young person with a disability make a motion to speak up and say, "I support that." Or, "I would like to remand your motion." Watching them be able to advocate and speak up is a great tool for them as they move forward into adulthood.

Another way that -- that they get to exercise their individual voice to contribute to our estate plan for Independent Living. This is also called a SPIL. So, our youth committee just recently finished writing our next three-year estate plan for youth. So, they come up with the goals, the objectives, and the activities and get to have input and use their voices to write that SPIL.

Next slide. One of the things we utilized as a youth committee when we were riding our next state plan or are SPIL was the youth specific public forum.

We are required to host public forums as part of writing our state plan for independent living. So, the youth committee said, "why don't we do when just for youth?" We would love to see what issues are important for you.

So, Florida held its first ever youth public forum last year. We transition with one of our -- we partnered with one of our€¦ And when I tell you that even as a 32-year-old I do not know what was happening on that youth public forum because of (indiscernible) and the ways that the youth committee was able to engage with younger individuals and younger consumers with disabilities.

I had to just sit back and watch because it was so amazing to see that peer to peer support! And empowering other youth with disabilities through their peers to say, "hey, I want to hear what is important to you." I want to hear your voice, what do you think is important? So, giving youth a chance to participate in that public forum to allow them to use their individual advocacy skills to affect systems change.

Next slide. Otherwise our state Independent living Council provides individual advocacy or our role in that, again, we talked about public forums. I will share when other public forum that has been very impactful here at the Florida Independent living Council. We partnered with (unknown name) health and simply healthcare last year to do a general public forum related to personal care assistance.

And everyone that attended that public forum utilized a personal care assistant or had systemic barriers that they were facing around personal careful so we had a 21-year-old who joined our Public Forum that he was a newly acquired spinal cord injury.

He called in from his iPad on Zoom laying in an institutional hospital bed. And he said, "I am 21 years old but I cannot get adequate personal care assistance in my community and I need to be in a place where I can be taken care of." Knowing this individual had so much potential that they could and were more than capable of living in the community independently, showed us that we needed to do something about this in our estate plan.

Our chair, Bob Melia of our counsel, he also has a spinal cord injury and he said let's bring this to the state plan. So, we created a workgroup under the state plan for independent living around personal care assistance.

This led to goals and objectives being written in our new state plan around the systemic barriers, but more importantly, as a workgroup, again, of just individuals that utilize personal care assistance to be able to share their personal stories and to be able to share their systemic barriers to lead to that soon, hopefully, systemic change here in Florida.

Next slide. To wrap up, I will discover a few more ways that we at the Florida Independent living Council or state Independent living Council's have roles of individual advocacy.

Independent living network day at the capital is when all of our centers for Independent living and their staff or board members or consumers come to our state capital and share with legislators issues that are important to people with disabilities.

And in -- the independent living community. We also hosted back in fall of 2022, and hopefully early next year, a Florida independent living conference. This was an opportunity for all of our centers of independent living to bring their staff and have peer support for the best ways to reach consumers to brainstorm on the individual level to share consumer stories and find better ways to help advocate.

And like Tami was talking about, essentially empower their consumers to advocate for themselves. Next slide. So, to wrap up, I just want to clarify that the Florida Independent living Council state Independent living Council's, we do not provide direct services. You might be thinking, "well, YLF is a program." It is not. It is education and training. And that is what we do here at the Florida Independent living Council. We are estate plan, we can provide that education and training. We also do education and referrals. We do not do it in-house.

We get people to refer us to call us almost daily to talk about their issues with housing or issues with transportation.

We then refer them to their local Centre for Independent living. In turn, that Centre for Independent living then follows up to provide individual advocacy support to continue that self advocacy training or individual advocacy training.

And help them create their individual independent living plans. Next slide. I believe that is all. I will turn it over to Mary Kate for a Q&A.

MARY-KATE WELLS:
Awesome. Thank you so much, Sarah. I really enjoyed your talking. About how much individual advocacy and system advocacy can have a role in our very intertwined.

And has centers and SILCs can partner and, you know, build young folks and others self advocacy skills.

So with that, we have a bunch of questions for our speakers. I will read some of the questions and invite our speakers to respond. I also have some backup questions because you will have sparked some curiosity in me.

So, I will start with this first question. I believe it is for Tami. So, I will invite Tami to turn her camera on. These first few are probably for you, Tami. The first comment from Catherine says, "love that you mentioned, in quotations give staff time to acclimate. If they are not acclimating, what have you found helpful? What strategies have you found helpful in supporting staff?"

TAMI HOAR:
I think the best thing to do is kind of what I was talking about is the job shadowing.

So, having staff sitting with, you know, the more seasoned staff. So, having them spend time, really, shadowing them. Sitting in the office while they are doing case notes. They are so sweet. So, having set next to them when they are entering their INR's or the case notes from the meeting with the consumer. Sitting in with the consumer meeting.

And maybe once they have done that a few times, then maybe kind of, you know, co doing that meeting the next time. Maybe asking some of the intake questions while some of the season staff is sitting there doing it. Kind of eventually, just doing a bit more and more and more with the consumer meeting during the intake meeting then during the follow-up meetings.

Then having that season staff just checking in with them as they are doing a little bit more. And just really having that mentorship there in place. I really think that is - the only way you can do it is to do it yourself was up you can only do so much is sitting next to someone.

You really just have to start doing it yourself will stop that is the only way you can learn. But having that to support that person next to you to say, "yeah, that was really great. Next time you might ask it this way. Instead of just reading from your list, putting your head down and allowing person -- the person to talk and tell their story." Having a support, I think that is the best way.

MARY-KATE WELLS:
I'm sure that helps staff with different learning styles as well. The next question, I think Tami probably can answer. Someone asked, "do you have a policy to address if consumer misses a meeting due to disability related issues or outside (indiscernible) such as transportation being cancelled or transportation no-show?"

TAMI HOAR:
I would not say it is a policy per se, I think it is really up to each staff person. You know, reaching back out to the consumer or did they call themselves. And really, it ultimately is up to the staff person what they have left in their schedule. You know, contacting the consumer and talking with them about when can they get them back into their schedule.

What does that look like? It might not be tomorrow, it might be next week. That is kind of what it has to be because the staff person cannot then push other people out of their schedule. But of course, life happens. We know that.

So, it is really up to the staff person, what their schedule looks like, and of course, we will work with people for that.

And those kind of things that come up. And definitely, you know, we know life happens. It happens to us, too. And sometimes our staff, things happen last minute. You know, they get sick or other life happens.

Or they have to cancel a meeting, too. So, it is not a policy per se. I say it really depends on the staff schedule and when they can reschedule the next meeting, so.

MARY-KATE WELLS:
Also, thank you. There was a question. -- Awesome. Tami, I will invite you to answer, but if other speakers want to chime in, I am curious, someone said, "as an advocate, are we allowed to represent when it comes to a SSI, SSI DI hearing, meaning attending the hearing. I am wondering how you handle that at Summit."

TAMI HOAR:
Yes, I can answer for Summit. We do not represent anyone. We are here to support the consumer. And we do all of that work to help them understand the process.

And to understand the appeal and to help them gather, you know, understand what paperwork and what kind of things they have together for documentation. But we are not representing anyone. If it comes to that, it is very limited here in our area.

But we do have attorneys and people specific who we can refer people to for that. We do not represent anyone. We are here to support the consumer. And we can certainly set with someone, next to someone, as kind of that confidence that we are sitting next to them, we are there for their support. But we are not there to represent them.

MARY-KATE WELLS:
Awesome, thank you. The next two questions are for Sarah. So, Sarah, I invite you to come on. Actually, we have a couple here for Sarah. First one is, "you mentioned that YLF interns did not realize they had a disability. So, how did you do outreach and get folks to know about the program?"

SARAH GOLDMAN:
I just want to circle back to follow-up on what Tami was just talking about.

MARY-KATE WELLS:
Sure. I am sorry.

SARAH GOLDMAN:
In for do, I personally had attended several Medicaid hearings and I have never one -- done one specifically for SSI or SSDI. But we do have disability rights Florida that is a PA and every state has some form of disability rights or P&A.

I can think of a chat the link to the National Disability Rights Network, I have been to a conference this week. It is a great resource, it is free. Legal resources for people with disabilities. Here in Florida, they help represent (indiscernible).

But I will go back to my (indiscernible).

MARY-KATE WELLS:
No, I appreciate that. That is a great resource. I see Amber put it in the chat.

SARAH GOLDMAN:
OK, thank you, Amber. So, in terms of the Youth Leadership Forum, we do a lot of outreach to the school districts. A lot of times, we get the answer of, "oh, well my teacher just wanted me to fill out this application." We also do interviews for each individual participant ride try to gather how much they know about their disability or if they are just kind of shutting off.

I did an individual -- interview with an individual who is coming to YLF next month and she goes, "I love helping people with disabilities. I love helping all of the other kids with disabilities at my school." And I said, "do you know much about your disability?"

So, getting them to realize what the point of YLF is and getting them to understand their disability identity or -- as opposed to, "it is something my teacher told me to fill out." We want to help them know where they are at in that disability process.

MARY-KATE WELLS:
I know I used to work at a center -- this is Mary Kate. At a center in the youth program. And it was kind of unfortunate how many students we worked with that were in the room because their teacher was like, "hey, fill out this form." Right?

And unfortunately, a lot of folks did not know or identify with having a disability. So, I think that takes a lot of skill on the IL youth advocate or the person to have to navigate those conversations.

So, yeah. It can be pretty tricky. And then Sarah there is another question. "Does the work that you are youth committee contribute, or, that your use contribute going into the SPIL or is it separate?"

SARAH GOLDMAN:
It is a great question. No, it is going right into the SPIL. They actually write their goals and activities and objectives will stop of course, we have are centers for Independent Living review it as we need 51% of our centers to sign off on the state plan. But we keep our goals for you very general.

So again, transition is a huge topic that comes up. So, we just keep our goal very broad for youth transition in the state plan. But no, they are the ones that are writing down all of the ideas that we come together and review public forum feedback and we take those issues to help right the goals, the objectives, and the activities.

MARY-KATE WELLS:
Awesome. Before I ask the next question, this is Mary Kate. I see that Jody put an evaluation link in the chat, too.

So, as we are kind of coming to an end with some of these cumin days, we do appreciate your time joining us. -- Q and As.

And ask that you complete the survey. But back to the question, Sarah. I wrote this question down, too. Because I know you are the perfect person to answer this.

So, Sandra says, "I would love to start something like while of hearing in Delaware. Is there any support to get us started with it?" And Sandra, I wonder if you could share some input on that.

SARAH GOLDMAN:
This is Sarah, yes. That is such a great question. There are resources. So, as YLF is a program and a curriculum that has come out of the California model of the Youth Leadership Forum, California was the first statewide L -- YLF to occur. So, a lot of states follow the California YLF model with the curriculum full sub there is something called the Association with Youth Leadership Forum's. Also known as AYLF.

I will throw that in the check, or if someone can throw that in there, that would be grateful stop there is a website and you are also welcome to email me. I am the vice chair of AYLF nationally full sub you're welcome to join our cause. We meet once a month. We are taking a break over the summer because we are all hosting our own YLF's over the next two or three months. But there are tons of state that are just getting started and we would be happy to give you some support and also point you in the right direction.

MARY-KATE WELLS:
Yes. This is Mary Kate. It would - I love that idea of centers kind of taking initiatives in their state to either revamp or participate in their YLF.

It is a great resource. You know, not only for youth, but really, for communities and families to kind of have that awareness. And do individual advocacy. And I am just looking at the chat. I am going to invite Mark, if you, I am going to read the question, and you will can let me know if you want to answer it or if you want answer it verbally or in the chat.

Mark, do you have any advice, or what is your opinion on what to do when a consumer might lack motivation or confidence to complete and IL skill? And you... Mute. Do you want to answer in the chat?

MARK DIXON:
Motivation and confidence.

MARY-KATE WELLS:
Yes, awesome. So I think, Mark, if you want to add any advice or tips there, feel free to add that to the chat. I wonder, Tami and Sarah, do you want to add anything about what other consumer might lack motivation or confidence.

Tami, I am curious, I mean, I feel like this relates a lot with the dignity of risk. I wonder if you could share a little.

TAMI HOAR:
Yeah, this is Tami. I think a lot of this is just continuing to talk with the consumer. So, this is building kind of relationship with the IL staff, and the consumer. Again, just really talking with them about what are their goals. Maybe they have set these goals, and it is maybe just something they are not that interested in anymore.

Maybe there is something else going on, so what is really just continuing those conversations, and just visiting, and letting the consumer know that this is, you know, their path and their journey. And if this doesn't meet what they want to do anymore, let us just keep exploring, let us keep discussing.

Is there something out they want to do? Maybe they want to join some the classes we are offering. So maybe, something has just changed, and there is something else going on that they just have not, you know, felt ready to talk about yet. Maybe that is what it is.

And keeping that line of communication open without pressuring and say well, this is what you wanted to do, you know, not taking that line with him. And like you just said, Mary Kate, that dignity of risk. Everyone has the right to choose, and that sometimes means also not following through with something that they said they wanted to do.

So, dignity of risk just means being able to make choices, and even if those choices have some consequent is, you know, some negative because what is. So, I would encourage just keeping a line of key medication open and communicating, you know, non-judge mental, and just being able to let the consumer, you know, feel like they can be open and honest about where they want the direction to go, and what path they want to go down, and if they want to try to rethink.

Any of it they said that they want to do something, maybe now something has changed or something else has sparked their interest.

MARY-KATE WELLS:
Awesome. And Mark added, sent to me, if someone is, maybe change their mind, lack of motivation or confidence may be, he said "taken IL class like I did in middle school, and talk to the consumer about obtaining training at the CIL." Mark suggests talking to a center about obtaining different skills as a self-advocate.

So, we have two more questions in the chat. Before we do that, I see folks, you know, are coming to the end, but I will plug one more time that we do really appreciate the time you put in the evaluations, and Joey is putting the link in the chat.

And I, just for time say, I wonder if we could close with this question from Sierra. And I do not know, Sarah and Tami might be able to answer this, or Mark, if you have any suggestions. The question is how can I help a consumer aged 19 to 22, independent level skills and gore, or independent living services and goals, if she is not verbally communicative? Her mom does all the talking for her.

And I know this can be a challenge at centers. Since we are consumer directed. I do not know, Sarah, do you want to start?

SARAH GOLDMAN:
Sure, this is Sarah, and I will let Tami speak specifically to what she does at her center. As a person with a disability, I think empowerment is so important in independent living, and allowing individuals that are young to find their voice is so important just regardless of disability. And so, I would encourage you to maybe find some assistive technology that would allow this community consumer to communicate whether that is an iPad or other communication devices.

A lot of times your state vocational rehab will supply those if it will help with employment or further education. I know that my state has a assistive technology alliance that meets and gives loans to families to give them that assistive technology. That would be my recommendation because I think it is so important to help the consumer find their voice. Especially at that age range. And I will let Tami speak about what she does at her center.

TAMI HOAR:
Thanks, Sarah, and I would absently ditto everything that Sarah just said. And at our center, this has come up a couple of times, it doesn't really freak when they, but absolutely everything that Sarah just said. And we emphasize that we will not communicate to a parent or a guardian without the consumer present.

The consumer must be present. And, everything Sarah just said, that is everything I was going to say, is there must be some assistive technology that could, you know, be helpful, and I would emphasize with the staff person to be very patient no matter how slow or how tedious it is, let the consumer do as much communication as they can.

And encourage the mom or the parent, I forgot who they said it was, but let the consumer do what they can to speak for themselves. Whatever assistive technology it takes, but be very patient. And no matter how long it takes, let them do as much of their own speaking as they can, and communication as they can. And again, like Sarah just said, we have a great assistive technology program here at our university where they do loan out equipment.

If the mother, or the parent is communicating for the individual, there must be some way that they can communicate, and I would just desperately say you have to encourage that, and communicate with the consumer.

MARY-KATE WELLS:
Well, I think that is a great way to end our webinar today. I want to thank all of our speakers for sharing the different perspectives, and having this conversation. We appreciate everyone's time, and please consider taking our evaluation that is in the link in the chat, or it will, and Sharon if you go next slide, there will also be a QR code.

With that, thank you everyone so much, and I hope you have a good rest of your day.

Live Captioning by Ai-Media

|  |  |  |  |  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
|

|  |  |
| --- | --- |
| logo | **NCIL-IL-NET: Individual Advocacy-(Ai-Live to Zoom (USVONC1706A - Ai-Live Premium)** |
|  |

 |

|  |
| --- |
|  |
| Page of  | Downloaded on: 05 Jun 2024 9:06 AM |
| logo | **NCIL-IL-NET: Individual Advocacy-(Ai-Live to Zoom (USVONC1706A - Ai-Live Premium)** |
|  |

|  |
| --- |
|  |
| Page of  | Downloaded on: 05 Jun 2024 9:06 AM |

 |